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SPECIAL EDUCATION: IS IDEA WORKING AS CONGRESS INTENDED?

HEARING

BEFORE THE

COMMITTEE ON GOVERNMENT REFORM

HOUSE OF REPRESENTATIVES

ONE HUNDRED SEVENTH CONGRESS

FIRST SESSION

FEBRUARY 28, 2001

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CONTENTS

Page

Hearing held on February 28, 2001 1

Statement of:

Guard, Patricia J., Acting Director, Office of Special Education Programs, U.S. Department of Education; Melinda Baird, JD, Knoxville, TN; Gary Mayerson, JD, New York, NY; Bill East, executive director, National Association of State Directors of Special Education, Inc.; and Ed Amundson, National Education Association 123

Hooley, Hon. Darlene, a Representative in Congress from the State of Oregon 38

Lamontagne, Ovide, Manchester, NH; Ginger Brown, Columbus, IN; Stephanie Fry, Indianapolis, IN; Pat Antenellis, Framington, MA; Carolyn Nunes, special education program manager, San Diego, CA; Kevin McDowell, general counsel, Department of Education, Indianapolis, IN; and Marca Bristo, chair, National Council on Disability 44

Letters, statements, etc., submitted for the record by:

Allen, Hon. Thomas H., a Representative in Congress from the State of Maine, prepared statement of 330

Amundson, Ed, National Education Association, prepared statement of 310

Antenellis, Pat, Framington, MA, prepared statement of 85

Baird, Melinda, JD, Knoxville, TN, prepared statement of 137

Bristo, Marca, chair, National Council on Disability, prepared statement of 104

Brown, Ginger, Columbus, IN, prepared statement of 65

Burton, Hon. Dan, a Representative in Congress from the State of Indiana:

Charts concerning special education 3

Prepared statement of 22

East, Bill, executive director, National Association of State Directors of Special Education, Inc., prepared statement of 301

Fry, Stephanie, Indianapolis, IN, prepared statement of 72

Guard, Patricia, J., Acting Director, Office of Special Education Programs, U.S. Department of Education, prepared statement of 127

Hooley, Hon. Darlene, a Representative in Congress from the State of Oregon, prepared statement of 40

Kucinich, Hon. Dennis J., a Representative in Congress from the State of Ohio, prepared statement of 332

Lamontagne, Ovide, Manchester, NH, prepared statement of 47

Mayerson, Gary, JD, New York, NY, prepared statement of 198

McDowell, Kevin, general counsel, Department of Education, Indianapolis, IN, prepared statement of 93

Morella, Hon. Constance A., a Representative in Congress from the State of Maryland, prepared statement of 35

Nunes, Carolyn, special education program manager, San Diego, CA, prepared statement of 56

Waxman, Hon. Henry A., a Representative in Congress from the State of California, editorial entitled, "Special Education, Discarded Vow," 31

SPECIAL EDUCATION: IS IDEA WORKING AS CONGRESS INTENDED?

WEDNESDAY, FEBRUARY 28, 2001

HOUSE OF REPRESENTATIVES,
COMMITTEE ON GOVERNMENT REFORM,
Washington, DC.

The committee met, pursuant to notice, at 1:45 p.m., in room 2154, Rayburn House Office Building, Hon. Dan Burton (chairman of the committee) presiding.

Present: Representatives Burton, Morella, Shays, Horn, Barr, Davis, Platts, Weldon, Putnam, Schrock, Waxman, Owens, Maloney, Norton, Kucinich, Tierney, and Schakowsky.

Also present: Representatives Cunningham, Pence, and Sununu.

Staff present: Kevin Binger, staff director; Daniel R. Moll, deputy staff director; S. Elizabeth Clay, Nicole Petrosino, and Jen Klute, professional staff members; Marc Chretien, senior investigative counsel; Sarah Anderson, staff assistant; Robert A. Briggs, chief clerk; Robin Butler, office manager; Michael Canty and Toni Lightle, legislative assistants; John Sare, deputy chief clerk; Corinne Zaccagnini, systems administrator; Sarah Despres, minority counsel; Ellen Rayner, minority chief clerk; and Earley Green, minority assistant clerk.

Mr. BURTON. Good afternoon. A quorum being present, the Committee on Government Reform will come to order and I ask unanimous consent that all Members' and witnesses' written and opening statements be included in the record, and, without objection, so ordered.

I ask unanimous consent that all articles, exhibits and extraneous or tabular material referred to be included in the record, and, without objection, so ordered.

During the 106th Congress we began looking at the increased rates of autism. As we did that, we repeatedly heard from families that they were facing serious challenges obtaining services from their schools. Any family that is raising a child with a developmental delay or a learning disability or a physical disability faces tremendous challenges on a daily basis.

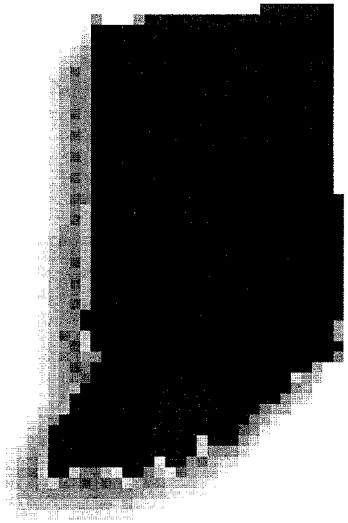
Through this investigation, we have already learned that families are physically, emotionally and financially exhausted. Why is it that when we have a Federal law that requires that every child receive a free and appropriate public education, many families are having to go to court to receive these services? And it's very costly.

The committee received thousands of e-mails, telephone calls, and letters and faxes from families, teachers, administrators and organizations about the implementation of the Individuals with

Disabilities Education Act [IDEA]. Congress has focused on the educational needs of the disabled for over 25 years. In 1975 Congress passed the Education for All Handicapped Children Act, the EHA Act, and the EHA guaranteed that eligible children and youth with disabilities would have available to them a free appropriate public education.

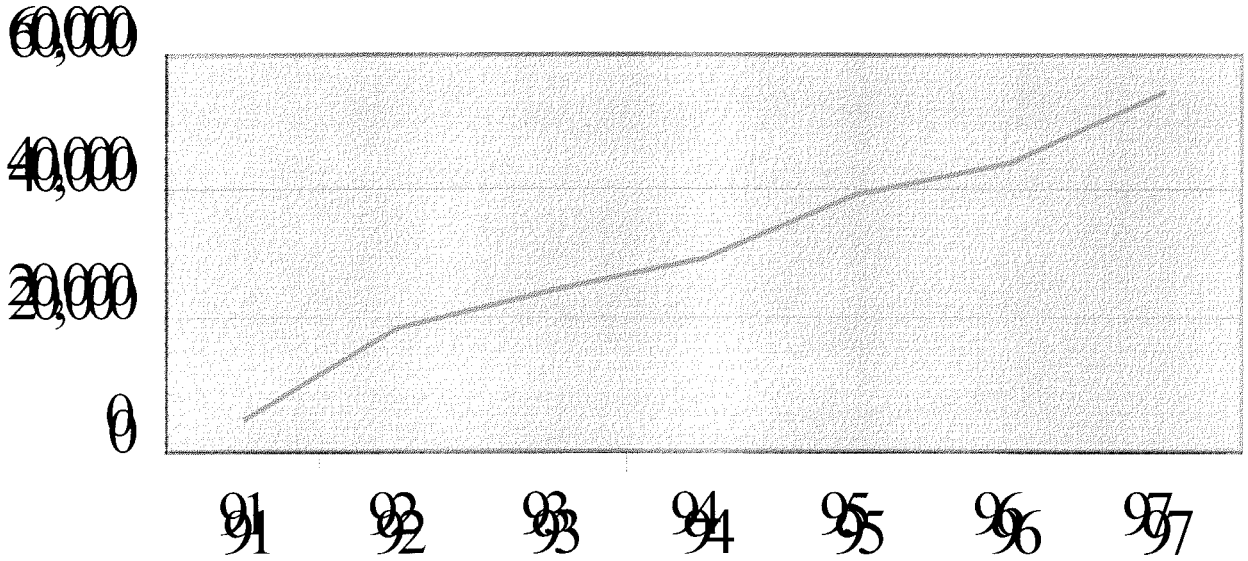
We have heard a great deal in the past hearings about the increased rates of autism, and my family's been touched by that. In 1999 there were 2,462 children ages 3 to 21 in Indiana diagnosed with autism. With the dramatic rise of autism—in fact, we have a chart that shows the increase and how it's been rising—with the dramatic rise of autism will be a dramatic rise in requests for special education services. Are schools across the country prepared to handle the needs of children with autism? It used to be 1 in 10,000 children were autistic. Now, it's 1 in 500 and in Indiana, my home State, it's 1 in 400.

[The information referred to follows:]



1999 Statistics:

There are
2,462 children
Ages 3 to 21
in Indiana
Diagnosed with
Autism.

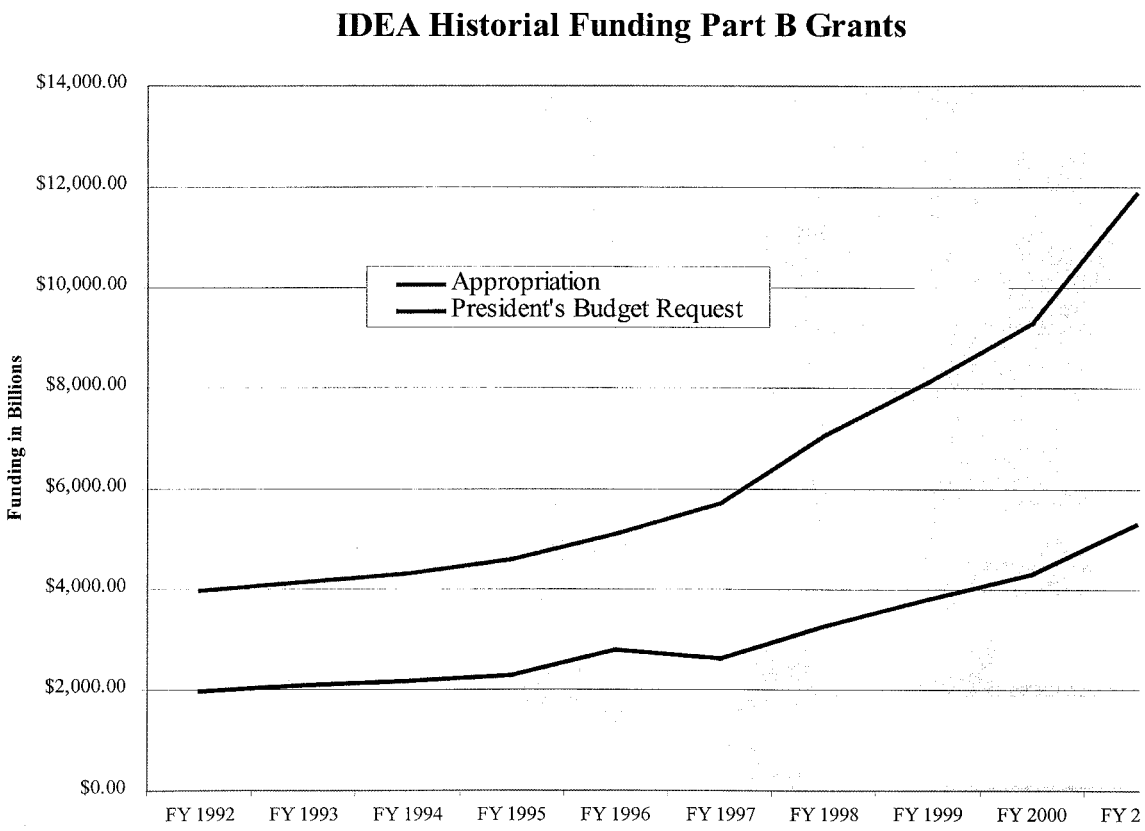

Autistic Children Ages 0-21 Years Served in Federally
Supported Programs 1991-1998
60,000
40,000
20,000
0
91
92
93
94
95
96
97

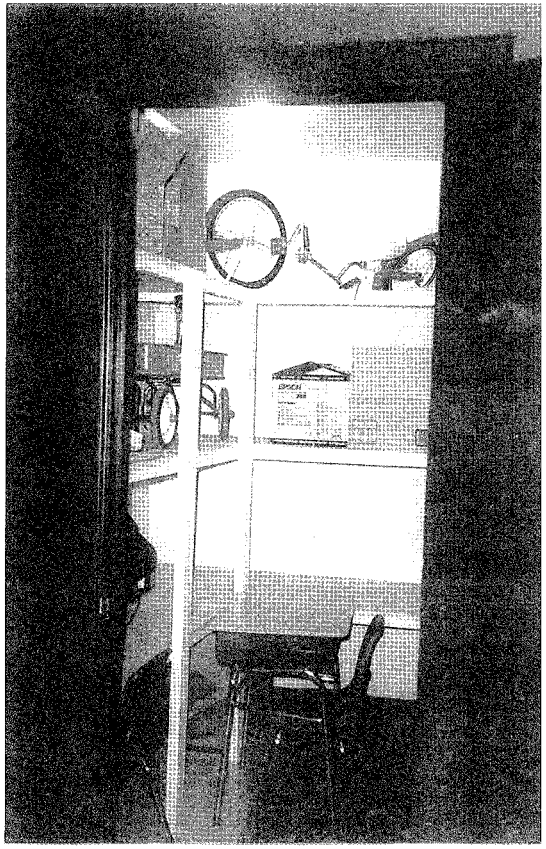
"The federal role in education is not to serve the system.

It is to serve the children."

President George W. Bush

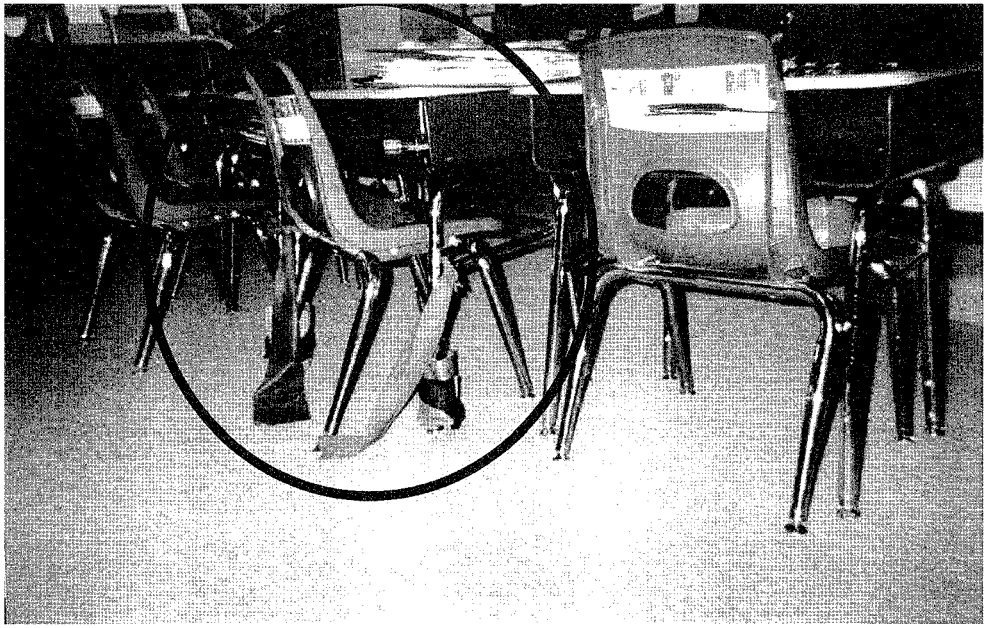
Alexandra and Christian


IDEA Historial Funding Part B Grants
Funding in Billions
$14,000.00
$12,000.00
$10,000.00
$8,000.00
$6,000.00
$4,000.00
$2,000.00
$0.00
Appropriation
President's Budget Request
FY 1992
FY 1993
FY 1994
FY 1995
FY 1996
FY 1997
FY 1998
FY 1999
FY 2000
FY 2



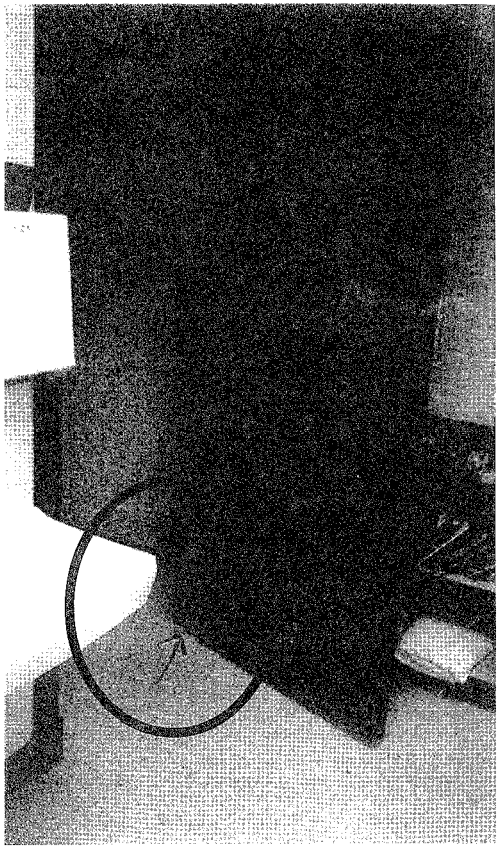
Special Education Room for Autistic Children

Is this an appropriate room?



Restraints for a 6 year old autistic boy.

Is this appropriate?



Special Education Students Bathroom

Door blocked open.

Is this appropriate?

INDIANA
SPECIAL EDUCATION
PRELIMINARY CHILD COUNT DATA
2000-2001 SCHOOL YEAR

INDIANA DEPARTMENT OF EDUCATION
CENTER FOR COMMUNITY RELATIONS
AND SPECIAL POPULATIONS

DIVISION OF SPECIAL EDUCATION
Room 229 State House
Indianapolis, Indiana 46204-2798

DR. SUELLEN REED
STATE SUPERINTENDENT OF PUBLIC INSTRUCTION

2000-2001 SPECIAL EDUCATION
PRELIMINARY CHILD COUNT DATA

TABLE OF CONTENTS

TABLE/FIGURE	PAGE NO.
P.L. 105-17, Part B of IDEA 12/01/00 Child Count	1
Percent of Students Served by Exceptionality Area by Planning District	2
Number and Percent of Students Served by Disability	4
Deaf-Blind/Autism/Traumatic Brain Injury/Other Health Impaired Child Count Comparison – 1990 through 2000	5

DOE-02
DATE LISTED:02/15/01

INDIANA DEPARTMENT OF EDUCATION
DIVISION OF SPECIAL EDUCATION
FEDERAL PART B, IDEA CHILD COUNT FOR FY-01
STATE TOTALS

COUNT DATE: DECEMBER 1, 2000

EXCPT AREA	MH	OI	VI	HI	EH-FT	EH-AO	LD	DD	CD	MIMH	MOMH	SPMH	DSI	AUT	TBI	OHI	TOTAL FY-2001	TOTAL FY-00	DIFFER-ENCE	DIFF. %
03	94	80	20	46	5	1	27	316	2123	199	65	16	1	110	9	92	3204	3016	188	6.23
04	70	122	13	56	23	4	73	169	3646	383	82	19	1	135	22	97	4915	4755	160	3.36
5A	41	65	14	41	12	2	46	66	2181	240	57	18	0	93	6	68	2950	2728	222	8.14
5B	53	64	21	36	16	16	89	0	3150	274	75	11	1	117	10	51	3984	3946	38	0.96
06	97	141	26	92	75	50	429	0	6644	737	167	33	1	253	19	167	8931	9030	-99	-1.10
07	108	132	47	105	161	131	1213	0	7726	1059	224	62	0	307	25	215	11515	11321	194	1.71
08	102	111	65	127	288	213	2835	0	7314	1242	201	57	1	308	25	305	13194	13285	-91	-0.68
09	90	137	77	121	412	347	4498	0	5628	1462	259	60	1	281	45	369	13787	13914	-127	-0.91
10	98	113	58	143	526	426	5777	0	3946	1531	227	68	0	262	33	362	13570	12940	630	4.87
11	108	116	52	134	624	495	6310	0	2209	1645	252	61	3	212	38	383	12642	11960	682	5.70
12	70	112	49	121	781	467	6507	0	1149	1634	260	62	2	191	36	382	11823	11155	668	5.99
13	75	98	50	129	876	527	6269	0	609	1661	307	62	1	167	36	325	11192	10442	750	7.18
14	57	90	44	136	826	551	6139	0	357	1456	304	70	2	136	43	324	10535	10312	223	2.16
15	59	86	50	88	824	579	5996	0	187	1479	300	64	1	136	53	298	10200	9613	587	6.11
16	58	69	49	110	682	548	5244	0	138	1292	287	61	3	118	48	222	8929	8546	383	4.48
17	64	75	38	84	450	414	4417	0	90	1105	298	70	0	92	39	174	7410	7321	89	1.22
18	44	58	29	67	203	216	2933	0	36	723	220	76	2	82	25	85	4799	4666	133	2.85
19	34	14	7	8	60	33	561	0	8	208	128	58	1	38	5	23	1186	1226	-40	-3.26
20	33	5	0	4	16	2	50	0	5	27	64	61	0	25	5	3	300	268	32	11.94
21	13	1	0	2	10	1	8	0	0	12	49	31	2	8	3	0	140	147	-7	-4.76
TOT2001	1368	1689	709	1650	6870	5023	59421	551	47146	18369	3826	1020	23	3071	525	3945	155206		4615	3.06
TOT00	1279	1671	674	1598	6535	4702	58390	0	46415	18437	3818	1094	25	2462	473	3018		150591		
DIFF	89	18	35	52	335	321	1031	551	731	-68	8	-74	-2	609	52	927	4615			
DIFF%	6.96	1.08	5.19	3.25	5.13	6.83	1.77		1.57	-0.37	0.21	-6.76	-8.00	24.74	10.99	30.72	3.06			

FEDERAL FUNDING NOT BASED ON CHILD COUNT
DOE02ST

DOE03A
DATE LISTED 02/15/01

INDIANA DEPARTMENT OF EDUCATION
DIVISION OF SPECIAL EDUCATION
PERCENT OF STUDENTS (BASED ON PUBLIC SCHOOL ENROLLMENT) AGED 3-21 SERVED
UNDER IDEA, PART B FEDERAL (UNDUPLICATED COUNT) BY PLANNING DISTRICT AND DISABILITY

DURING THE 2000-2001 SCHOOL YEAR

COUNT DATE:DECEMBER 1, 2000
PAGE: 1

PLANNING DISTRICT	MH	OI	VI	HI	EHFT	EHAO	LD	DD	CD	MIMH	MOMH	SPMH	DSI	AUT	TBI	OHI	TOTAL	SCHOOL ENROLL
ADAMS-WELLS SPECIAL SERVICES	0.195	0.097	0.058	0.185	0.331	0.107	5.937	0.000	4.358	1.033	0.097	0.029	0.019	0.244	0.019	0.273	12.985	10,258
ANDERSON COMMUNITY SPECIAL	0.092	0.171	0.053	0.118	0.736	0.512	5.143	0.013	5.963	2.542	0.486	0.223	0.020	0.263	0.026	0.210	16.570	15,226
BARTHOLOMEW SPECIAL EDUCATION	0.000	0.103	0.084	0.289	0.593	0.247	5.851	0.084	4.815	2.025	0.285	0.145	0.000	0.215	0.042	0.177	14.955	21,431
BLUE RIVER SPECIAL EDUCATION	0.544	0.155	0.122	0.100	0.422	0.311	5.993	0.022	5.682	2.186	0.189	0.011	0.000	0.233	0.089	0.422	16.480	9,011
BOONE-CLINTON-NORTHWEST	0.162	0.201	0.023	0.154	0.208	0.555	4.643	0.039	4.983	1.512	0.270	0.046	0.000	0.185	0.046	0.401	13.428	12,965
CLAY COMMUNITY SCHOOLS	0.171	0.021	0.021	0.107	0.749	0.557	7.984	0.235	6.207	1.884	0.385	0.000	0.000	0.150	0.064	0.257	18.793	4,672
COVERED BRIDGE SPECIAL	0.078	0.361	0.088	0.059	0.454	0.479	6.970	0.112	5.211	1.753	0.440	0.147	0.010	0.508	0.059	0.918	17.647	20,474
DAVIESS-MARTIN SPECIAL	0.216	0.108	0.144	0.126	0.432	0.486	8.317	0.234	6.625	1.728	0.360	0.036	0.000	0.216	0.054	0.414	19.496	5,555
DELAWARE COUNTY SPECIAL	0.183	0.183	0.078	0.178	0.684	0.411	7.576	0.022	7.465	1.584	0.183	0.044	0.000	0.283	0.111	0.472	19.461	17,990
DUBOIS-SPENCER-PERRY SPECIAL	0.000	0.250	0.083	0.167	0.368	0.007	5.906	0.083	3.370	1.223	0.285	0.090	0.000	0.271	0.035	0.299	12.438	14,391
EAST ALLEN COUNTY SCHOOLS	0.323	0.208	0.115	0.219	0.219	0.396	3.998	0.104	5.654	1.791	0.323	0.125	0.000	0.281	0.031	0.281	14.067	9,604
EAST CENTRAL SPECIAL SERVICES	0.199	0.084	0.077	0.186	0.437	0.546	9.033	0.019	4.745	1.819	0.225	0.090	0.000	0.116	0.045	0.148	17.770	15,554
EAST CHICAGO SPECIAL EDUCATION	0.000	0.028	0.056	0.085	0.748	0.000	2.835	0.268	3.738	3.710	0.776	0.381	0.000	0.141	0.042	0.183	12.992	7,089
ELKHART COMMUNITY SCHOOLS	0.165	0.094	0.071	0.133	0.840	0.306	5.430	0.031	6.262	1.946	0.589	0.110	0.000	0.212	0.102	0.290	16.582	12,743
ELKHART COUNTY SPECIAL	0.254	0.120	0.080	0.135	0.454	0.190	6.166	0.015	4.989	1.202	0.274	0.100	0.000	0.309	0.105	0.234	14.627	20,045
EVANSVILLE-VANDERBURGH-POSEY	0.185	0.120	0.051	0.138	1.186	0.457	6.867	0.051	5.725	2.335	0.475	0.087	0.004	0.189	0.018	0.674	18.559	27,583
FORT WAYNE COMMUNITY SCHOOLS	0.088	0.248	0.060	0.267	0.524	0.273	7.006	0.000	3.718	2.773	0.688	0.195	0.003	0.207	0.044	0.424	16.519	31,843
GARY COMMUNITY SCHOOLS	0.141	0.052	0.177	0.057	1.833	0.354	2.202	0.026	2.562	5.056	0.890	0.120	0.000	0.120	0.000	0.026	13.616	19,206
GIBSON-PIKE-WARRICK SPECIAL	0.154	0.111	0.062	0.129	0.382	0.326	7.213	0.031	6.357	0.986	0.302	0.031	0.006	0.191	0.043	0.314	16.637	16,235
GRANT COUNTY SPECIAL EDUCATION	0.023	0.070	0.046	0.093	0.604	0.256	4.539	0.000	5.694	1.170	0.480	0.077	0.000	0.186	0.070	0.248	13.556	12,909
CLARK COUNTY SPECIAL EDUCATION	0.294	0.119	0.063	0.112	1.576	1.002	6.500	0.042	4.973	1.639	0.364	0.098	0.000	0.280	0.028	1.450	18.539	14,278
GREATER LAFAYETTE AREA SPECIAL	0.321	0.326	0.090	0.184	0.879	0.811	5.750	0.058	5.086	1.090	0.179	0.042	0.000	0.274	0.042	0.616	15.749	18,992
GREENE-SULLIVAN SPECIAL	0.248	0.199	0.062	0.124	0.807	0.571	6.906	0.621	4.062	2.919	0.410	0.037	0.000	0.199	0.099	0.932	18.196	8,051
HAMILTON-BOONE-MADISON SPECIAL	0.087	0.207	0.035	0.182	0.525	0.327	5.739	0.041	4.533	0.751	0.215	0.141	0.003	0.509	0.052	0.433	13.779	36,751
SCHOOL CITY OF HAMMOND	0.236	0.141	0.055	0.134	0.967	0.267	5.383	0.165	5.029	1.273	0.715	0.110	0.000	0.432	0.071	0.141	15.120	12,725
HANCOCK-SOUTH MADISON JOINT	0.153	0.387	0.066	0.321	0.489	0.766	7.811	0.095	7.190	0.693	0.190	0.036	0.000	0.190	0.036	1.204	19.629	13,699
HARRISON COUNTY SPECIAL	0.248	0.000	0.050	0.033	0.893	1.935	6.485	0.050	3.755	1.704	0.414	0.000	0.000	0.248	0.033	0.364	16.212	6,045
HUNTINGTON-WHITLEY SPECIAL	0.148	0.079	0.109	0.158	0.188	0.464	5.340	0.039	3.899	1.658	0.336	0.039	0.000	0.257	0.109	0.093	12.919	10,132
INDIANAPOLIS PUBLIC SCHOOLS	0.144	0.088	0.034	0.105	1.295	0.349	5.721	0.034	3.399	5.004	0.636	0.102	0.002	0.378	0.061	0.229	17.582	41,008
JAY COUNTY	0.153	0.076	0.076	0.357	0.535	0.382	6.290	0.127	5.577	1.630	0.153	0.204	0.000	0.255	0.076	0.306	16.196	3,927
JOINT EDUCATIONAL SERVICES IN	0.296	0.126	0.044	0.132	0.536	0.340	4.337	0.082	4.306	1.699	0.359	0.050	0.000	0.158	0.063	0.139	12.658	15,863
JOHNSON COUNTY SPECIAL	0.029	0.125	0.058	0.134	0.461	0.374	6.243	0.043	3.666	1.286	0.346	0.091	0.000	0.312	0.053	0.394	13.615	20,838
KNOX COUNTY SPECIAL EDUCATION	0.000	0.185	0.067	0.067	0.504	0.588	4.169	0.034	6.858	2.622	0.504	0.185	0.000	0.050	0.050	0.235	16.120	5,949
KOKOMO AREA SPECIAL EDUCATION	0.021	0.213	0.093	0.145	0.954	0.601	5.921	0.000	5.677	2.323	0.353	0.119	0.000	0.275	0.047	0.467	17.208	19,288
MSD LAWRENCE TOWNSHIP	0.166	0.185	0.025	0.370	0.918	0.452	5.175	0.083	4.556	1.001	0.242	0.102	0.000	0.548	0.076	0.637	14.536	15,692
LOGANSPORT AREA JOINT SPECIAL	0.069	0.237	0.046	0.133	0.538	0.533	3.497	0.029	5.247	1.777	0.382	0.185	0.006	0.133	0.058	0.376	14.248	17,273

INDIANA DEPARTMENT OF EDUCATION
DIVISION OF SPECIAL EDUCATION
PERCENT OF STUDENTS (BASED ON PUBLIC SCHOOL ENROLLMENT) AGED 3-21 SERVED
UNDER IDEA, PART B FEDERAL (UNDUPLICATED COUNT) BY PLANNING DISTRICT AND DISABILITY

DURING THE 2000-2001 SCHOOL YEAR

PLANNING DISTRICT	MH	OI	VI	HI	EHFT	EHAO	LD	DD	CD	MIMH	MOMH	SPMH	DSI	AUT	TBI	OHI	TOTAL	SCHOOL ENROLL
MADISON AREA EDUCATIONAL	0.139	0.183	0.032	0.114	1.123	1.060	6.924	0.032	5.340	2.234	0.795	0.032	0.006	0.335	0.050	0.183	18.581	15,844
MSD OF MARTINSVILLE	0.092	0.074	0.129	0.221	0.240	0.793	4.888	0.000	7.655	1.734	0.406	0.000	0.000	0.240	0.037	0.295	16.805	5,421
MICHIGAN CITY AREA SCHOOLS	0.086	0.072	0.200	0.286	0.687	0.458	7.382	0.086	4.163	3.476	0.401	0.072	0.000	0.143	0.043	1.259	18.813	6,990
MISHAWAKA-PENN-HARRIS-MADISON	0.073	0.338	0.060	0.212	1.075	0.418	4.305	0.073	4.027	1.420	0.285	0.153	0.007	0.279	0.080	0.318	13.121	15,075
MONROE JOINT SPECIAL EDUCATION	0.009	0.019	0.152	0.294	0.427	0.503	5.683	0.009	5.579	1.205	0.285	0.104	0.009	0.588	0.038	0.417	15.323	10,540
NEW ALBANY-FLOYD COUNTY	0.252	0.117	0.045	0.153	0.324	1.377	7.719	0.018	5.011	1.781	0.396	0.045	0.009	0.333	0.054	0.369	18.003	11,115
NEW CASTLE AREA SPECIAL	0.180	0.064	0.106	0.626	1.231	0.796	10.194	0.117	4.954	1.453	0.180	0.202	0.011	0.149	0.106	0.530	20.897	9,427
NORTH CENTRAL INDIANA(SPECIAL	0.116	0.142	0.064	0.077	0.148	0.791	5.364	0.039	2.792	1.454	0.309	0.103	0.000	0.199	0.013	0.187	11.796	15,547
NORTHEAST INDIANA SPECIAL	0.095	0.178	0.118	0.099	0.615	0.231	6.313	0.011	3.893	1.404	0.300	0.057	0.004	0.193	0.049	0.034	13.594	26,358
NORTHWEST INDIANA SPECIAL	0.251	0.139	0.106	0.103	0.380	0.429	4.295	0.090	3.264	1.434	0.445	0.087	0.000	0.219	0.029	0.251	11.523	31,033
OLD NATIONAL TRAIL SPECIAL	0.326	0.090	0.090	0.135	0.887	0.797	8.435	0.000	6.683	1.685	0.270	0.000	0.011	0.663	0.056	0.315	20.443	8,903
ORANGE-LAWRENCE-JACKSON-MARTIN	0.283	0.307	0.105	0.129	0.436	0.606	6.469	0.073	4.797	1.397	0.331	0.032	0.000	0.299	0.065	0.162	15.490	12,382
PORTER COUNTY SPECIAL	0.004	0.168	0.066	0.156	0.457	0.410	6.208	0.016	3.776	0.993	0.219	0.141	0.000	0.297	0.043	0.915	13.870	25,580
RENSSELAER AREA COOPERATIVE	0.032	0.135	0.056	0.127	0.817	0.547	5.979	0.008	6.447	1.483	0.309	0.095	0.000	0.262	0.079	0.579	16.953	12,611
RIPLEY-OHIO-DEARBORN SPECIAL	0.190	0.072	0.072	0.164	0.256	0.893	7.536	0.072	3.998	1.700	0.341	0.020	0.000	0.243	0.053	0.630	16.240	15,234
R.I.S.E. SPECIAL SERVICES	0.122	0.177	0.028	0.157	0.809	0.236	5.481	0.008	3.560	1.823	0.652	0.181	0.000	0.801	0.051	0.220	14.305	25,453
SMITH-GREEN WEST ALLEN SPECIAL	0.195	0.110	0.025	0.076	0.433	0.085	5.508	0.009	3.451	0.450	0.263	0.136	0.000	0.331	0.076	0.374	11.526	11,765
SOUTH BEND COMMUNITY SCHOOLS	0.046	0.446	0.116	0.200	1.686	0.901	8.595	0.070	6.914	2.925	0.720	0.255	0.000	0.483	0.046	0.223	23.626	21,536
SOUTH CENTRAL AREA SPECIAL	0.022	0.248	0.076	0.216	0.367	0.886	5.683	0.022	5.802	2.485	0.486	0.086	0.000	0.324	0.065	0.281	17.048	9,256
SOUTH LAPORTE COUNTY SPECIAL	0.064	0.156	0.037	0.211	0.340	0.221	6.041	0.092	4.892	0.883	0.340	0.018	0.009	0.166	0.018	0.248	13.738	10,875
WABASH-MIAMI AREA PROGRAMS FOR	0.105	0.105	0.070	0.082	0.234	0.748	8.089	0.491	4.138	3.004	0.304	0.444	0.000	0.210	0.023	0.339	18.387	8,555
MSD WARREN TOWNSHIP	0.066	0.292	0.038	0.330	1.517	2.337	5.928	0.019	3.119	2.573	0.452	0.188	0.000	0.443	0.057	0.509	17.868	10,611
MSD WASHINGTON TOWNSHIP	0.108	0.295	0.079	0.226	0.935	0.630	4.940	0.000	4.389	1.348	0.187	0.069	0.000	0.649	0.108	0.335	14.298	10,162
RICHMOND COMMUNITY SCHOOLS	0.032	0.178	0.113	0.275	1.667	0.583	8.158	0.129	4.888	3.593	0.550	0.097	0.000	0.146	0.016	0.453	20.881	6,178
WEST CENTRAL INDIANA SPECIAL	0.202	0.140	0.085	0.147	0.248	0.574	7.102	0.054	5.319	1.644	0.264	0.023	0.000	0.194	0.054	0.202	16.252	12,897
WEST CENTRAL JOINT SERVICES	0.121	0.202	0.056	0.193	0.556	0.568	5.067	0.034	4.091	1.195	0.294	0.042	0.000	0.568	0.075	0.449	13.513	49,619
WEST LAKE COUNTY SPECIAL	0.198	0.180	0.057	0.147	0.506	0.547	6.209	0.049	6.111	0.376	0.172	0.098	0.008	0.294	0.041	0.449	15.432	12,241
FOREST HILLS SPECIAL EDUCATION	0.017	0.102	0.034	0.102	0.558	0.372	6.735	0.017	6.008	1.591	0.237	0.102	0.017	0.288	0.000	0.406	16.585	5,909
GREATER RANDOLPH INTERLOCAL	0.182	0.055	0.292	0.401	0.274	0.511	5.874	0.055	8.008	1.642	0.128	0.018	0.000	0.091	0.036	0.657	18.223	5,482
BURRIS-BALL STATE	0.000	0.125	0.000	0.376	0.000	0.376	5.270	0.000	3.388	0.125	0.251	0.000	0.000	0.251	0.000	0.627	10.790	797
** STATE TOTAL **	0.138	0.171	0.072	0.167	0.695	0.508	6.010	0.056	4.769	1.858	0.387	0.103	0.002	0.311	0.053	0.399	15.642	988,691

DOE26
DATE LISTED 02/15/01

INDIANA DEPARTMENT OF EDUCATION
DIVISION OF SPECIAL EDUCATION

COUNT DATE:
DECEMBER 1, 2000
PAGE: 1

NUMBER AND PERCENT OF STUDENTS AGED 3-21
SERVED UNDER IDEA, PART B FEDERAL (UNDUPLICATED COUNT)
BY DISABILITY

DURING THE 2000-2001 SCHOOL YEAR

STATE TOTALS

DISABILITY	NUMBER	PERCENT
MULTIPLY HANDICAP	1,368	0.881
ORTHOPEDIC IMPAIRMENT	1,689	1.088
VISUAL IMPAIRMENT	709	0.457
HEARING IMPAIRMENT	1,650	1.063
EMOTIONAL HANDICAP-FT	6,870	4.426
EMOTIONAL HANDICAP-OTHER	5,023	3.236
LEARNING DISABILITY	59,421	38.285
DEVELOPMENTAL DELAY	551	0.355
COMMUNICATION DISORDER	47,146	30.376
MILD MENTAL HANDICAP	18,369	11.835
MODERATE MENTAL HANDICAP	3,826	2.465
SEVERE MENTAL HANDICAP	1,020	0.657
DUAL SENSORY IMPAIRMENT	23	0.015
AUTISTIC	3,071	1.979
TRAUMATIC BRAIN INJURY	525	0.338
OTHER HEALTH IMPAIRED	3,945	2.542
ALL DISABILITIES	155,206	100.000

Note: Percent determined by dividing the number of children with each disability by the total number of children with disabilities served.

FEDERAL CATEGORY COUNT COMPARISON (AGES 3-21)
1990 through 1996

CATEGORY	12/01/90	12/01/91	12/01/92	12/01/93	% + or -	12/01/94	% + or -	12/01/95	% + or -	12/01/96	% + or -
Deaf-Blind	49	60	80	70	-12%	81	16%	68	-16%	55	-19%
Autism	189	340	544	578	6%	877	52%	1,110	27%	1,329	20%
Traumatic Brain Injury	NA	NA	109	205	88%	265	29%	333	26%	356	7%
Other Health Impaired	NA	NA	259	598	130%	1,024	71%	1,328	30%	1,731	30%
TOTAL	238	400	992	1,451	46%	2,247	55%	2,839	26%	3,471	22%

FEDERAL CATEGORY COUNT COMPARISON (AGES 3-21)
1997 through 2000

CATEGORY	12/01/97	% + or -	12/01/98	% + or -	12/01/99	% + or -	12/01/00	% + or -
Deaf-Blind	39	-29%	27	-31%	25	- 8%	23	-8%
Autism	1,639	16%	2,011	23%	2,462	22%	3,071	25%
Traumatic Brain Injury	393	10%	437	11%	473	8%	525	11%
Other Health Impaired	2,073	20%	2,444	18%	3,018	23%	3,945	31%
TOTAL	4,144	19%	4,919	19%	5,978	22%	7,564	27%

Autism Percent of Increase from 1990:	**1,525%**
Traumatic Brain Injury Percent of Increase from 1992:	**381%**
Other Health Impaired Percent of Increase from 1992:	**1,423%**

parker/dec1count/fedcategory

Mr. BURTON. Are teachers and administrators trained in the changes in the Federal laws regarding special education? Are families fully informed early in the process about their rights? In the State of Indiana, requests for special education services for children with autism increased by 25 percent in just 1 year. What does this mean for the local school districts?

The Indiana Resource Center for Autism is piloting a parent training program. This program helps parents of newly diagnosed children with autism spectrum disorders understand the impact of autism on their child and their family. They explain the various program options available, how to support and educate their child, how to access services across Indiana and how to identify and access appropriate and effective special education services, including their rights under the Federal law.

While we focus our discussion on the educational challenges of families with autistic children, the implementation of IDEA and the importance of schools complying with congressional intent applies to all children, all children with special education needs. We have tremendous input from parents with children with Attention Deficit Disorder, with Downs Syndrome, children who are hearing and/or vision impaired, and children with physical limitations.

President George W. Bush said with the introduction of his education blueprint, the Federal role in education is not to serve the system, it is to serve the children. And that's all of the children.

I agree with President Bush 100 percent. While there are many issues we could look at regarding special education and the implementation of IDEA, what we must keep in mind as we do this, is that it is about our children. We are talking about making sure that each child, every child, has an opportunity to excel to the best of their own abilities through a free and appropriate public education. I just noticed they put my grandkids up there, and if you want to know what my grandkids look like, there they are. The one that's smiling is my granddaughter, and the one who is not smiling is our grandson Christian, who is autistic.

The President's blueprint offers four objectives: increasing accountability for student performance, focusing on what works, reducing bureaucracy and increasing flexibility, and empowering parents.

As we heard from thousands of families across the country, we found similarities in their desires in the four objectives of the President's education blueprint. We repeatedly heard that parents did not want their children to be warehoused or placed in classes where they were not intellectually challenged. We repeatedly heard from the disability community and families about the need for accountability for schools that do not comply with the law.

We heard from families that they want their children to be in programs that are going to improve their children's lives. For some children with autism, that might be 1 hour of speech therapy 5 days a week, rather than 30 minutes 2 days a week.

For other children it may be 40 hours a week of applied behavioral analysis at an early age to improve the child's educational experience and ability to interact and communicate. For a child with physical limitations, it may mean having a full-time aide assigned to assist them in a regular classroom or access to a computer with

special communication software. Smaller classroom size in both special education and regular education classrooms was repeatedly mentioned.

We also have heard from teachers and administrators about increased paperwork burdens. We need to find the proper balance in meeting reporting requirements while taking advantage of new computer technology that can make these reporting requirements easier and less burdensome.

Families across the country do not feel that their schools are following the IDEA law. A majority of over 2,500 families we heard from had to fight for services. And that is almost criminal. The law requires that these parents get the help they need and not have to go to the legal remedies necessary to get these services.

We repeatedly heard from families that the schools do not inform them of the programs available to their children or of their rights under the law. We also learned that families spend tens of thousands of dollars out of pocket to obtain educational services for children as well as to hire lawyers to fight for their children's educational needs, and some of these people have been forced almost into bankruptcy because of that.

Today we will hear from a broad spectrum of witnesses. Unfortunately, one of our witnesses, a very good friend of mine, Ms. Sally Duncan Griffith, could not be here as planned. She had a valuable story to tell about raising a disabled child. Unfortunately her child was hospitalized this weekend, in critical care, and our prayers go out to the family.

I'm pleased that Congresswoman Darlene Hooley of Oregon is here today. She has introduced H.R. 659, a bill to achieve full funding for Individuals with Disabilities Act, Part B, by 2006.

Congress made a commitment that the Federal Government and State and local governments would share in the expense of educating children with disabilities. We made a commitment to contribute up to 40 percent of the average per-pupil expenditure of educating children with disabilities, and to date the Federal Government has never contributed more than 14.9 percent. We pledged 40 percent. This has got to change and we are going to try to help get that done.

The chart shows that Congress has repeatedly increased funding of IDEA even above what prior administrations have requested and we are talking about Republican and Democrat administrations.

I will be working with my colleagues in the Congress to ensure that we step up to the plate and fulfill our commitment to the IDEA and to the disabled children of this country. And as we do this, it's important the schools use this money for special educational children and not for other projects.

The intent of a Federal investment in special education is to fund the additional cost of providing educational services to disabled children. These funds may mean better pay for teachers and aides, more teachers and aides for the classroom, more and better training for regular and special education teachers on specific disabilities such as autism, and better educational tools. It was never congressional intent that taxpayer dollars be spent on hiring attorneys to fight parents in long and expensive court battles that will keep children from getting these services. The role of special education

directors, teachers, and administrators is to serve the children and not the system.

The new mantra at the Department of Education is that no child be left behind, and you have heard that several times recently. It is very important that no child be left behind, including any child with any kind of disability.

Our new First Lady is to become an ambassador for education. She is going to devote her energies to recruiting teachers across the country. And I applaud her in this endeavor and will be sending her a personal letter. And I'll ask my colleagues, Henry Waxman, the ranking Democrat, and others on both sides to sign that letter, making sure that she include in that recruitment special educational teachers, speech and occupational therapists that we desperately need in our school systems across the country.

We in Congress may also have to be creative in special education career development. For instance, maybe we should look at developing student loan repayment programs similar to medical school repayment programs; this loan repayment program would be for individuals who will become special education teachers or speech therapists who will teach for a 5-year period in rural or inner city schools or areas identified to be in desperate need of special education teachers and/or speech therapists.

When Congress passed legislation to require a free and appropriate public education to all children with disabilities, we never envisioned that parents would have to fight for these services. We never envisioned that schools would refuse to accept the diagnosis of a doctor and then not evaluate a child for 6 months or a year, which is a lifetime in many kids' lives, delaying all services until the school evaluation is obtained.

With an autistic child, early and aggressive intervention is universally recognized as imperative. A 6-month delay can have a detrimental effect on the child for years and maybe their lifetime. The delay may also mean that over the long-term the child will have fewer communication skills.

When Congress passed IDEA we never envisioned that schools would tell parents if we provide it for your child, then we'll have to provide it for everyone. We repeatedly heard from families that schools used this as an excuse not to provide services. If the service is an appropriate service to meet the educational needs of a disabled child, any child with the same disability in the school should be offered the same access that is appropriate.

And I'd just like to say that for those of you who don't know it, my grandson is autistic. I went with my daughter to her school. We went there because she was getting 1 hour of help a week with his speech impediment, his speech problem, and they talked to us for about an hour, and they decided that 1 hour was sufficient, even though they had correspondence from doctors on his case that said he needed at least 2 hours of speech therapy a week. And I asked them, because it became apparent during the meeting—this is in my District, incidentally—it became apparent during the meeting they had made the decision before we even got there. I said to them, why did we even come here if you've already made up your mind? Why?

Now, you know, I'm chairman of this committee and Henry's one of the leading Members of Congress on the Democrat side. If we go to a school with an autistic child or grandchild and we get this kind of response, what does that mean for the average citizen that doesn't have any influence? And that's why a lot of people feel like they don't have any place to turn. Well, we are going to try to change that and I know that people on both sides of the aisle, Democrats and Republicans, feel this way, and we are going to do everything we can to make sure that happens.

Now, I recognize my colleague Mr. Waxman for his statement.

[The prepared statement of Hon. Dan Burton follows:]

Opening Statement
of
Chairman Dan Burton
Government Reform Committee
Special Education: Is IDEA Being Implemented as Congress Intended?

February 28, 2001 -- 1:00 pm

Good Afternoon, A Quorum being present, the Committee on Government Reform will come to order. I ask unanimous consent that all Members' and witnesses' written and opening statements be included in the record. Without objection, so ordered.

I ask unanimous consent that all articles, exhibits, and extraneous, or tabular material referred to be included in the record. Without objection, so ordered.

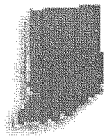
During the 106th Congress we began looking at the increased rates of autism. As we did that, we repeatedly heard from families that they were facing serious challenges obtaining services from their schools. Any family that is raising a child with a developmental delay, a learning disability, or a physical disability faces tremendous challenges on a daily basis.

Through this investigation, we have already learned that families are physically, emotionally, and financially exhausted. Why is it that, when we have Federal law that requires that every child receive a free and appropriate public education, many families are having to go to court to receive these services?

The Committee received thousands of e-mails, telephone calls, letters and faxes from families, teachers, administrators, and organizations about the implementation of the Individuals with

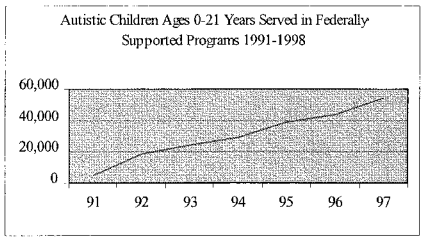
Disabilities Education Act (IDEA). Congress has focused on the educational needs of the disabled for over twenty five years. In 1975 Congress passed the Education for All Handicapped Children Act (EHA). The EHA guaranteed that eligible children and youth with disabilities would have available to them a free appropriate public education.

We have heard a great deal in past hearings about the increased rates of autism. In 1999, there were two thousand, four hundred, sixty two children ages three to twenty-one in Indiana diagnosed with Autism.



1999 Statistics:

There are 2,462 children Ages 3 to 21 in Indiana Diagnosed with Autism.



With the dramatic rise of autism will be a dramatic rise in requests for special education services. Are schools across the country prepared to handle the needs of children with autism?

Are teachers and administrators trained in the changes in the Federal laws regarding special education? Are families fully informed early in the process about their rights?

In the state of Indiana, requests for special education services for children with autism increased by twenty-five percent in just one year. What does this mean for local school districts?

The Indiana Resource Center for Autism is piloting a parent training program. This program helps parents of newly diagnosed children with autism spectrum disorders understand the impact of autism on their child and their family. They explain the various program options available, how to support and educate their child, how to access services across Indiana, and how to identify and access appropriate and effective special education services, including their rights under federal law.

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President George W. Bush with the introduction of his Education Blueprint stated:

"The federal role in education is not to serve the system. It is to serve the children."

I agree with President Bush one hundred percent. While there are many issues we could look at regarding special education and the implementation of IDEA, what we must keep in mind as we do this is that it is about our children. We are talking about making sure each child – every child – has an opportunity to excel to the best of their own abilities through a free and appropriate public education.

The President's blueprint offers four objectives:

- Increasing accountability for student performance
- Focusing on what works
- Reducing bureaucracy and increasing flexibility
- Empowering parents.

As we heard from thousands of families across the country, we found similarities in their desires and the four objectives of the President's education blueprint. We repeatedly heard that parents did not want their children to be "warehoused," or placed in classes where they were not intellectually challenged. We repeatedly heard from the disability community and families about the need for accountability for schools that do not comply with the law.

We heard from families that they want their children to be in programs that are working - to have access to programs that are going to improve their children's lives. For some children with autism, that might be one hour of speech therapy five days a week rather than thirty minutes two days a week.

For other children, it may mean forty hours a week of applied behavioral analysis at an early age to improve the child's educational experience and ability to interact and communicate. For a child with physical limitations, it may mean having a full-time aide assigned to assist them in a regular classroom, or access to a computer with special communication software.

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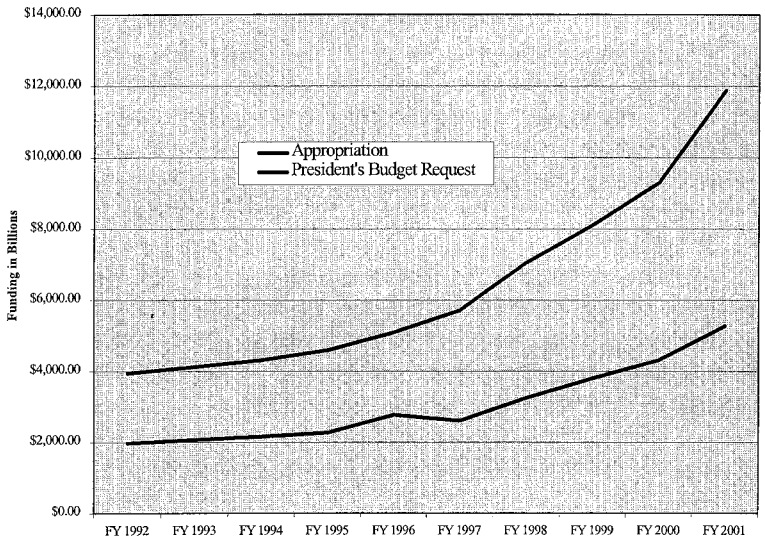
The chart shows, that Congress has repeatedly increased funding of IDEA, even above what prior Administrations requested.

IDEA Historial Funding Part B Grants



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With a child with autism, early and agressive intervention is universally recognized as imperative. A six month delay can have a detrimental effect on the child for years. The delay

may also mean that over the long-term that the child has fewer communication skills.

When Congress passed IDEA we never envisioned that schools would tell parents, "if we provide it for your child, then we will have to provide it for everyone!" We repeatedly heard from families that schools used this as an excuse not to provide services. If the service is an appropriate service to meet the educational needs of a disabled child, any child with the same disability in the school should be offered access to that appropriate service.

The record will remain open until March 15. I now recognize the ranking minority member, Mr. Waxman for his opening statement.

Mr. WAXMAN. Thank you, Mr. Chairman, for recognizing me and I want to thank you for holding this hearing. And I will join with you on that letter to the First Lady encouraging her to include special education as part of her mission.

I'm pleased that we're holding this hearing to examine the implementation of an important civil rights law that protects children with disabilities, the Individuals with Disabilities Education Act [IDEA]. This legislation was passed to ensure that children with physical, mental and emotional challenges receive a free and appropriate public education provided, to the extent possible, alongside children without disabilities, in mainstream classes, using any accommodations needed to support his or her placement.

Unfortunately, implementation of and compliance with IDEA throughout the Nation is inconsistent. The National Council on Disability, the independent Federal agency that monitors IDEA implementation, found that former Education Secretary Riley's efforts to monitor compliance and take enforcement actions were more aggressive than any of his predecessors' efforts combined; yet, despite Secretary Riley's efforts, Federal enforcement of IDEA continues to be ineffective.

What that means in practical terms is that some children who are by law entitled to educational services don't get them and must seek legal recourse. Part of the blame for this situation lies with Congress. IDEA calls for the Federal Government to provide up to 40 percent of the additional costs of educating children with disabilities. However, Congress has historically appropriated funding for only 12 to 13 percent of these costs. That's wrong. Instead of appropriating the $17 billion that would be necessary to meet our full Federal 40 percent obligation to the States, Congress for this year, fiscal year 2001, has appropriated only $6.3 billion, and that in itself was more than a 20 percent increase over the $5 billion that was provided in fiscal year 2000.

When the Federal Government does not do its share, every dollar that a State must divert from regular education to cover special education costs that Congress should have paid for is a dollar that leaves our students and our schools shortchanged. As the Los Angeles Times put it last Thursday in an editorial entitled, "Special Education, Discarded Vow," without substantial help, school districts end up raiding other instruction, pitting child against child. And I'm going to ask, Mr. Chairman, that this editorial be made part of the record.

Mr. BURTON. Without objection.

[The information referred to follows:]

B12 R THURSDAY, FEBRUARY 22, 2001

LOS ANGELES TIMES EDITORIALS

JOHN P. PUERNER, *Publisher*
JOHN S. CARROLL, *Editor*
JANET CLAYTON, *Editor of the Editorial Pages*

Special Ed: Discarded Vow

The rapid growth of special education in the Los Angeles Unified School District, part of a national trend, has some tough consequences for schools. These include a shortage of qualified special-ed teachers and a worsening of the classroom space problem in already jammed schools. Funding is inadequate to fix either.

Los Angeles Mayor Richard Riordan has said he will request additional federal dollars for special education, among other things, next month when he meets with Education Secretary Rod Paige in Washington. In truth, all he'll be asking is that Washington make good on a guarantee given 25 years ago. In the 1975 Education for All Handicapped Children Act, Congress promised to shoulder 40% of additional costs of educating disabled children in public schools by 1982. Without substantial help, school districts end up raiding other instruction, pitting child against child.

In the current federal budget, the government contributes about $6 billion for the 6 million children identified as disabled, only 12% of the actual cost. States pay the rest, a huge unfunded federal mandate that keeps getting bigger.

The soaring costs reflect a 30% increase in the number of children identified as having special needs during the past decade. That growth includes a spike in students diagnosed with attention-deficit hyperactivity. It also includes significant increases in children with more severe or multiple disabilities that require more expensive care. These children are entitled to an appropriate public education, but the huge and fast-paced increase raises an urgent question: How many of the students in special-ed classes are there because they misbehave or cannot read?

A 1999 Times analysis found that tens of thousands of students in California's special education classes had been placed there not because of a serious handicap but because they were never taught to read properly. Across the nation, children who are similarly and wrongly labeled "learning-disabled" retain a stigma throughout their public school careers. Rampant misclassification based on reading problems can be reduced or prevented altogether with systematic, intensive, research-proven instruction as early as kindergarten.

Reading First, a $5-billion initiative proposed this week by President Bush, would triple the amount the federal government spends on reading instruction. The plan, part of the reauthorization of the law that funds Title I programs, would finance teacher training, frequent diagnostic testing of children and the purchase of proven reading programs. That is part of a long-term answer, but in fairness to the states and their students, Washington needs to also triple its share of funding for special education.

Mr. WAXMAN. In the last Congress, former Education and Workforce Chairman Goodling introduced legislation that would have authorized full funding for IDEA by 2010. This legislation was supported by every member of the Government Reform Committee on both sides of the aisle. Mr. Goodling's bill passed the House but stalled in the Senate. There are several bills pending in the House again this year, including one introduced by our first witness, Representative Hooley, and I hope that we can all agree to meet our obligation to the States and to the children who need this funding and follow Representative Hooley's leadership.

Another issue that I want to raise is a little-known loophole in that 1997 amendment to the IDEA that permits local school districts to shift education funding to noneducational purposes. As a result, local school districts this year could shift $270 million that would otherwise have been spent on special education into their general treasuries. This number will only continue to rise the more we commit at the Federal level to IDEA.

I commend Mr. Tierney and Mr. LaTourette, both members of this committee, for their bipartisan introduction of H.R. 714 which would close this loophole and require that all funds allocated for IDEA be spent on educational expenses. Other members of this committee, including Mrs. Morella and Mr. Lantos, Mr. Kucinich and Mrs. Mink, have joined me in cosponsoring this important bill, and I hope this legislation helps ensure that all the money designated for education is spent appropriately.

I do not want to convey the impression that IDEA has been a failure. It has not. Before 1975 when the first version of the law was enacted, many children with disabilities were not educated at all. The original Education for All Handicapped Children Act brought about 1 million disabled kids into the education system for the first time and provided services for millions more who were attending school without the support they needed to overcome the challenges of their disabilities.

In the years since, the educational rights of children have been expanded and today approximately 6 million children with disabilities receive services under IDEA. Today we're going to look at ways those children are helped by the law and how we can do a better job of providing the educational and related services they need.

I want to thank all of the witnesses for coming today. I look forward to their testimony. I want to indicate to the witnesses and others here that, unfortunately, different committees scheduled their hearings at the exact same time, so I'm going to be bouncing back and forth, but we will have the record, and that record will be very helpful for all of our colleagues to be educated further on this issue.

Mr. Chairman, I thank you for your leadership and we look forward to taking this record and trying to correct the problem to make sure this law, which was a good one, is implemented the way it should be. Thank you.

Mr. BURTON. Thank you Mr. Waxman.

Further discussion? Mr. Barr.

Mr. BARR. Thank you, Mr. Chairman.

The only thing I'd like to mention is as we conduct our oversight today and throughout this session under your leadership, Mr. Chairman, regarding IDEA, while the primary focus will be funding and to take steps to ensure that the program is meeting the needs of the American people as addressed already by Congress, there are some perhaps what might be considered tangential but very important issues that I hope we address.

One is to address the issue of violence in our schools and to ensure, as we tried to address in the last Congress, that some of the perhaps unintended consequences of IDEA do not hamper local schools from protecting students. If a student who falls under the provisions of IDEA poses a danger to the other students or to teachers, for example, by bringing a weapon to school, we don't want to see the danger perpetuated by IDEA, tying the hands of the local school to take disciplinary steps to protect the other students.

That's something, as the chairman is aware, we addressed in the last Congress. It remains somewhat unresolved, and I would hope that would be part of our oversight because, of course, throughout all of these efforts, Mr. Chairman, first and foremost must be the protection of our students and our teachers. So I do hope that remains and will be part of our oversight efforts regarding IDEA.

Thank you, Mr. Chairman.

Mr. BURTON. Thank you Mr. Barr. Mr. Tierney.

Mr. TIERNEY. Thank you, Mr. Chairman, and thank you for having this hearing today on a very important subject. I thank all of our witnesses whose written testimony has already been helpful to many of us, and I'm sure the record of this hearing will continue to be helpful.

Let me just recount a little bit of the history on this. The Federal role in education has always been a limited one and for some period of time didn't exist. I think most people realize that. The obligation to educate our children rests 100 percent with the States, and I think that's something we shouldn't forget. The absolute fundamental obligation to educate our children, all children, is with each and every one of the States in this country.

Unfortunately, we found out before the 1960's that obviously States are not meeting that obligation. They were not educating and identifying many, many, many children with special needs. As a result, a series of acts were enacted by the Federal Government, giving States the option, if they chose to get Federal help, to meet certain standards, thresholds, with which they had to comply; virtually, State opted to accept the Federal assistance and to take the help that was available.

Now, in the early authorizations, it was authorized that the Federal Government would contribute up to 40 percent of moneys expended on IDEA. That was certainly a noble goal but unfortunately something that the Congress at that time apparently knew it wasn't going to be able to meet, because since the very first appropriations the amount was far less than that 40 percent.

I commend my colleague, Ms. Hooley, for putting the bill before us—she's going to speak to it today—to raise that amount, and I think it is appropriate to try to do that. I just think we should not lose focus that this is the Federal Government hopefully coming in

to be helpful, hopefully setting some standards, minimum thresholds, and hopefully encouraging States to live up to their commitment and their obligation to educate children.

The last part of that is I thank Mr. Waxman for making comment on the bill that I filed with Mr. LaTourette and which others on this committee, Mrs. Morella, Mr. Lantos, Mr. Kucinich and Mrs. Mink, have cosponsored also. The way the law is currently constructed, we could continue to give a higher percentage of Federal money and some of that may well go right out the window. If our intention is in fact to make sure that we increase the percentage of Federal money that's given through IDEA, then we're going to have to close that loophole. We're going to have to make sure that once we hit the $4.1 billion mark that States aren't able to draw out 20 percent of that amount and put it somewhere else. Right now, we would have no way of telling where they're going to put that, and it amounts to some $270 million so far.

At the very least, we ought to obligate the States to keep that $270 million in the field of education, and if we're entirely successful, hopefully they'll put as much as is needed into special education so this program works the way it's intended for everybody.

So we look forward to working with the chairman and the rest of this committee, as well as the Education Committee on which I and some others also serve, to get this job done. And we thank everybody for making their testimony available us to here today. Thank you, Mr. Chairman.

Mr. BURTON. I think that's a very good bill, and I wish you would add me to your bill with Mr. LaTourette.

Mrs. MORELLA. Thank you. Mr. Chairman in the interest of time, my excellent statement that I have before me urging that IDEA be raised to the Federal commitment of 40 percent I will ask be included in the record, and I am concerned about a backlash toward those students with disabilities if we don't fulfill our commitment. Thank you, sir.

[The prepared statement of Hon. Constance A. Morella follows:]

Mr. Chairman, I appreciate your efforts to hold this hearing on the Individuals with Disabilities Education Act. I look forward to hearing the testimony of the witnesses.

Before I begin my statement let me say that in this country we do not view education as a privilege, it is a fundamental right of all Americans.

Let me also add, that it is my opinion that IDEA is one of the most important civil rights laws ever written.

Over twenty-five years ago, Congress enacted and President Gerald Ford signed the Education for All Handicapped Children Act.

The basic premise of this federal law, now known as the Individuals with Disabilities Education Act (IDEA), is that all children with disabilities have a federally protected civil right to have available to them a free appropriate public education that meets their education and related services needs in the least restrictive environment.

The statutory right articulated in IDEA is grounded in the Constitution's guarantee of equal protection under law and the constitutional power of Congress to authorize and place conditions on participation in federal spending programs.

Mr. Chairman, in 1970, before enactment of the federal protections in IDEA, schools in America educated only one in five students with disabilities. More than1 million students were excluded from public schools, and another 3.5 million did not receive appropriate services. Many states had laws excluding certain students, including those who were blind, deaf, or labeled "emotionally disturbed" or "mentally retarded."

Almost 200,000 school-age children with mental retardation or emotional disabilities were institutionalized. The likelihood of exclusion was greater for children with disabilities living in low-income, ethnic and racial minority, or rural communities.

What is most troubling is that a government study published last year by the National Council on Disability finds that 25 years after enactment of IDEA, not one single state is in compliance.

States cannot afford to be in compliance.

IDEA established the federal commitment to provide funding at 40% of the average per pupil expenditure to assist with the costs of educating students with disabilities. Today IDEA is funded at about 14. 9 % of the average per pupil expenditure -- much higher than the 7% of 5 years ago, but this, as we all know in this room today, is not good enough.

We must continue to increase funding to reach the 40% of the average pupil expenditure funding level mandated in law.

Without these federal IDEA funds, local school districts must cover the unpaid federal share.

I can tell you that the schools in my district are struggling to carry out IDEA, and my concern is that without the 40% percent federal support, we will see a backlash against those students with disabilities.

Congress must fulfill its commitment to assist States and localities with educating children with disabilities. Congress must ensure that the Federal government lives up to the promises it made to the students, parents, and schools over two decades ago.

Congress needs to fully fund IDEA and maintain its commitment to existing federal education programs. We should ensure that children with disabilities receive a free and appropriate public education and at the same time ensure that all children have the best education possible.

Mr. Chairman, the Individuals with Disabilities Education Act (IDEA) is a landmark civil rights law that was intended to open the doors to education and success for more than six million American children each year.

In this time of record prosperity, with more opportunities for success than ever before, we must ensure that all of our children have the education that will allow them to go to college, get good jobs, and play active roles in their communities. America's ongoing commitment to this principle, embodied in the IDEA, is both an economic and moral imperative for our future.

I look forward to hearing the testimony of the witnesses, and thank you Mr. Chairman for holding this important hearing.

Mr. BURTON. Thank you, Chairwoman Morella. It shall be done. Did you have a comment, Ms. Schakowsky?

Ms. SCHAKOWSKY. Just briefly, Mr. Chairman, and thank you for holding this hearing. I want to thank Representative Hooley. I look forward to her testimony and give a very special welcome to Marca Bristo who is chair of the National Council on Disability, from Chicago, my hometown, and a very good friend and really one of the Nation's leading advocates for persons with disabilities. Thank you.

Mr. BURTON. Thank you, Ms. Schakowsky. Further discussion, Mr. Horn.

Mr. HORN. Just briefly, I want to commend you, Mr. Chairman for getting this important topic. There are thousands of people and parents that will be welcoming this airing of the issue.

Over a year ago, Charles Bass, colleague from New Hampshire, had told us that we should assume that 40 percent, because we've never got it up to the full level, it ought to be there because it is squeezing other students out of the system to get enough money to help the students that we are talking about.

Mr. BURTON. Mr. Shays.

Mr. SHAYS. Thank you, Mr. Chairman. Not an eloquent written statement, just a heartfelt one. Thank you for holding these hearings. I thank my colleagues for being here and thank our witnesses for their willingness to wait and our panelists for participating; and also to say that I, too, want to join others in saying that every year we should work toward full funding of IDEA. Thank you, Mr. Chairman.

Mr. BURTON. Thank you, Mr. Shays. Mrs. Davis. Mr. Putnam.

Very well. We now will recognize the gentlelady Mrs. Hooley, and I would like to start off by saying I appreciate you introducing your bill and I wish you would add me to it. I think we should have strong bipartisan support for it, and anything I can do to be of help I will do. Can you turn on your mic and pull it closer to you, Ms. Hooley.

STATEMENT OF HON. DARLENE HOOLEY, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF OREGON

Ms. HOOLEY. Thank you, Mr. Chairman. I appreciate your comments and I would like to associate myself with those as well as Ranking Member Waxman, and thank you for allowing me this opportunity to testify. And I'm going to be very brief because you have the really important people sitting behind me that you want to hear from.

And this is an issue as has already been introduced as talking about children with special needs. Again, this bill was introduced almost 26 years ago, and it was estimated at that time that the cost of educating a special needs child would be about twice what other students cost, and that we said we would pay 40 percent of that excess cost, and you are all aware we haven't done that. This year was the best year we've ever done, to bring it up to 14.9 percent.

But let me give you an example of a typical student with disabilities from my district. We'll call this student Susie. She's an autistic child, like your grandson. The cost of a special education teacher for Susie is about $64,000. An instructional aide costs a little over

$29,000. Susie requires 3 hours of physical therapy per month. The cost is a little over $1,100 per year. An autism specialist consultant comes in to work with Susie 9 hours per month, which costs $3,647. Other costs include $627 for 2 hours per month with a registered nurse, $500 for special supplies and equipment, and $14,800 for transportation services. When you add all of that up, Susie for 1 year costs $109,377.

Now, other children in the school without special needs are $5,675. We thought when we enacted this—we didn't think it would be that high, but it is. And if you looked at one school district where there are 98 children that have disabilities, if they all required the same amount of time and effort that Susie requires, their bill would be over $10 million a year. Now, they don't all do that, but that's just to give you some numbers.

Special education can be expensive, but I don't think anyone will argue that these children deserve the services they're receiving, and likely more. And as you talked about, Mr. Chairman, a lot of these children don't get the services they need.

By not paying our share of the costs, the Federal Government is putting States and local communities between a rock and a hard place. When the State of Oregon and the Salem-Keizer School District have to make up that money we aren't providing, they're taking that money for someone else or they're not providing the services.

I have introduced legislation, with many of you sitting up there, that would really try to address this 40 percent issue, and it is time we talk about it, we pass resolutions and then we don't put our money where our mouths are, and this would take the next 5 years and say we are going to increase the funding by $3 billion a year to get to the 40 percent by 2006. I think that is a reasonable plan, you know, and it is really based on somebody's wonderful idea when we increased funding for the National Institutes of Health, but we said we're going to double it in 5 years. I think we need to get IDEA's funding up to 40 percent in the next 5 years, and I think with all of your help we can do that. I think it's time we kept the promises we made to our children.

Thank you. Happy to answer any questions you have.

[The prepared statement of Hon. Darlene Hooley follows:]

IDEA Testimony
Congresswoman Darlene Hooley
House Committee on Government Reform
February 28, 2001

Thank you Mr. Chairman, for allowing me the opportunity to testify before this committee today. I am here today to speak briefly about an issue that is extremely important to us all. I'm here to speak about a group of people who have no enemies, whose needs bring about no opposition. I'm here to speak about children with disabilities.

As you all know, Congress began this discussion 25 years ago. When Congress passed the predecessor language to IDEA in 1975, it was agreed that states and local education agencies should be required to provide a free appropriate education to every eligible child with a disability. At that point, it was estimated that educating children with disabilities cost twice what it costs to educate other children. Because of these additional costs, Congress authorized the federal government to pay up to 40 percent of each state's "excess cost" of educating children with disabilities.

I think we are all aware of our success rate thus far. This year, we appropriated $6.3 billion to be divided among the states. Unfortunately, this only constitutes 14.9 percent of the total costs.

Let me give you an example using a typical student with disabilities from Salem, Oregon in the heart of my district. We will call this student "Anne." Anne is an autistic child. The cost of a special education teacher for Anne is $63,982. An instructional aide to assist the teacher costs $29,460. Anne requires 3 hours of physical therapy per month. The cost of this service is $1183 per year. An autism specialist consultant comes in to work with Anne 9 hours per month, which costs $3647. Other costs include: $627 for 2 hours per month with a registered nurse, $500 for special supplies and equipment, and $14,800 for transportation services. When you add all of this up you will see that to educate Anne for one year and provide her the services she needs, the total cost is $109,377.

Last year, the Salem-Keizer School District educated a total of 98 children with disabilities. If each of these children required the same services Anne did, then Salem-Keizer School District had a bill of $10.7 billion for the education of children with disabilities last year.

I don't think anyone will dispute the fact that special education is expensive. I also don't think anyone will argue that these children don't deserve every service they are receiving and most likely more.

By not paying our share of these costs, the federal government is putting states and local communities between a big rock and a hard place. When the state of Oregon and the Salem-Keizer School District have to make up for the money we aren't providing, they are taking that money from somewhere else. As a result, every child in this country is helping to pay our debt.

I have recently introduced legislation with our colleague from Connecticut, Congresswoman Nancy Johnson, that would address this issue.

In a sense, our bill, H.R. 659 would authorize funding to bring the federal government's share of educating children with disabilities up to the 40 percent mark by 2006. This is an increase of approximately $ 3 billion every year. That is a very large investment but we must remember, if we don't pay our share of the cost, our share of the cost doesn't just go away. Someone else is covering it for us.

It is time we kept the promise we made 26 years ago and invest in the education of EVERY CHILD.

Thank you. I will be happy to answer any questions you may have.

Mr. BURTON. Well thank you, Ms. Hooley. I think you've covered it very well and we certainly will support your legislation.

Ms. HOOLEY. Thank you.

Mr. BURTON. The costs that you talked about, let me just ask one or two questions, and make a comment.

Ms. HOOLEY. Sure.

Mr. BURTON. The costs that you're talking about for children with various physical disabilities and handicaps such as autism.

Ms. HOOLEY. Right.

Mr. BURTON. They're not all that expensive.

Ms. HOOLEY. No they're not all that expensive.

Mr. BURTON. The child you mentioned had some physical handicaps as well as being autistic?

Ms. HOOLEY. Right.

Mr. BURTON. So I wouldn't want my colleagues to think that every child is going to cost $100,000 a year because they have disabilities. Many of them—and I'll take my grandson as an example—he only requires 1 extra hour a week of speech therapy. And so a lot of the children are like that. Some have the majority of problems, greater or less, and so I don't know what the average cost would be. But I think our colleagues, when they start thinking about the budget we're facing and the budget the President prepared last night, the first thing they think is, oh, my gosh, we are going to blow the budget out the window if we start doing some of these things.

The fact of the matter is, if you averaged it all out, it would be something that's manageable, workable, as long as we meet our commitment.

Ms. HOOLEY. It is something that is manageable for all of us, and again, this was an example of a very high-end child. You're right, there are some that are twice. There are some that are one-third more, some like your grandson that are a little bit more. So the range is huge but it is—what I tried to do is illustrate that you do have this wide range, and for school districts also to provide the services—and we want them to provide the services and we want them to be willing to provide the services, but we also need to do our share. And that's really the only point I'm making, is it's time that we step up to the plate and do our share.

Mr. BURTON. Ms. Schakowsky, do you have any questions? Any questions Dr. Weldon?

Mr. WELDON. Thank you, Mr. Chairman. One of the things I'm interested in is medical costs associated with dealing with these children. The intent of the law was to make sure that they get a proper education. But often there are medical issues that get tied up in the proper education and I think that's one of the issues we are struggling with. You mentioned physical therapy on the child that you cited. You don't have any more details on that at all——

Ms. HOOLEY. I don't.

Mr. WELDON [continuing]. That you could provide me? Maybe in the future you could.

Ms. HOOLEY. I would be happy to get more details and provide those for you.

Mr. WELDON. It's a fine line sometimes: When is it medical and when is it educational? And you can't educate them unless their

medical needs are being taken care of. But when you start looking at these very expensive kids, a lot of times the health issues are becoming a major factor.

I appreciate your leadership on this, and I do want to thank you so much for your testimony, and I'll be looking at your bill as well. And I have signed letters to the effect of increasing the funding to the full 40 percent level in the past, and I hope that I'll be able to sign on to your bill as well this year. Thank you so much.

Ms. HOOLEY. Thank you. I just want to make one response to your comment. And you're right; it is sometimes a fine line. But when you talk about physical therapy, sometimes that is how to hold a pencil or pen in your hand so that you can actually do the work. Thanks.

Mr. BURTON. Any more questions from any Members? Any other questions? Mr. Horn.

Mr. HORN. I'd simply like to short-circuit the system, and please add me to your bill.

Ms. HOOLEY. Thank you.

Mr. BURTON. Any further comments or questions?

Ms. HOOLEY. Any other people that would like to be added, you can just raise your hand. Thank you.

Mr. BURTON. OK. Well, thank you very much Congresswoman.

Ms. HOOLEY. Thank you so much.

Mr. BURTON. Appreciate it. We'll now have our next panel come forward, and if I don't pronounce your names properly, forgive me.

Mr. Ovide Lamontagne; Ginger Brown of Columbus, IN; Stephanie Fry of Indianapolis; Pat Antenellis from Massachusetts; Carolyn Nunes, special education program manager from San Diego; Kevin McDowell, general counsel, from the Department of Education in Indianapolis; and Marca Bristo, chair of the National Council on Disability. And we will have some of these very fine individuals introduced by Members of Congress who have been here with us today.

And first of all, let me ask you all to be sworn, those of you—would you stand and raise your right hands?

[Witnesses sworn.]

Mr. BURTON. I'll now recognize the great Congressman from the great State of New Hampshire, Mr. Sununu, for an introduction.

Mr. SUNUNU. Thank you, Mr. Chairman. I'm grateful to see the number of members that have come to the hearing today and certainly pleased that you are engaged in this extremely important discussion about education first and foremost. And we heard in the President's address last night, and of course in the comments of the committee members today, how important that issue is and, in particular, your focus on IDEA and in special education.

This is a critical issue, not just here in the Nation's Capital, but back at home. Anyone that's visited with parents and teachers, school board members and administrators have heard many of the concerns that have been echoed here today raised. This is a significant unfunded Federal mandate. Despite the fact that as a member of the Budget Committee, I am pleased that we have doubled funding over the last 4 years, we know there's much more work to do, and moreover it's not just a matter of resources. This is a complex problem. It is a complex Federal regulation. It has issues regarding

administration and planning, adjudication, resolution, the issues of health care as well that were just raised by Congresswoman Hooley and Congressman Weldon and others. We need to make sure that this program works, that it works effectively, that it delivers a benefit and addresses the needs of students.

And I'm very pleased to be here today to introduce a resident of my district, a teacher, former member of the Board of Education in New Hampshire, a former chair of the Board of Education in New Hampshire, Ovide Lamontagne.

Ovide has a professional experience dealing with education in general, and special needs education in particular, in his capacity on the board of education. He's also worked, of course, as a lawyer and as a counsel for the State Senate in New Hampshire and had to wrestle with these issues in a professional sense, but he also is able to provide a personal perspective as a parent as well. And I think we're fortunate to be able to draw as legislators on a panel like this that is represented by not necessarily elected officials, but by parents, administrators, teachers, with that personal experience administering special needs education, working with the unfunded mandate, dealing with some of the cost constraints back home, to bring their perspective here and to ultimately help us to make this important program work better for the parents and the teachers back home.

It's my distinct pleasure to introduce Mr. Ovide Lamontagne.

Mr. BURTON. Welcome, Mr. Lamontagne. I have got that name correct now. I'm going to work on my French. And, Representative Sununu, welcome back. You were a very valued member of this committee for some time and we miss your smiling face and your great intellect as well. Mr. Lamontagne.

STATEMENTS OF OVIDE LAMONTAGNE, MANCHESTER, NH; GINGER BROWN, COLUMBUS, IN; STEPHANIE FRY, INDIANAPOLIS, IN; PAT ANTENELLIS, FRAMINGTON, MA; CAROLYN NUNES, SPECIAL EDUCATION PROGRAM MANAGER, SAN DIEGO, CA; KEVIN McDOWELL, GENERAL COUNSEL, DEPARTMENT OF EDUCATION, INDIANAPOLIS, IN; AND MARCA BRISTO, CHAIR, NATIONAL COUNCIL ON DISABILITY

Mr. LAMONTAGNE. Thank you, Mr. Chairman.

Mr. BURTON. Incidentally, before you start, because we have so many panelists, if you could try to keep your remarks as close to 5 minutes as possible, we'd appreciate it.

Mr. LAMONTAGNE. Will do. Thank you very much, Mr. Chairman, members of the committee, committee staff, guests and fellow witnesses. First of all, thank you, Congressman Sununu, for that kind introduction. I had the pleasure of being on the campaign trail at the same time that Congressman Sununu was as an initial candidate, and we are indeed pleased and fortunate to have Congressman Sununu representing not only the State of New Hampshire but also the national interests here in Congress.

I have prepared remarks which I have submitted to the committee, and I would like to stray from those remarks with your permission, Mr. Chairman, to address a couple of points.

First of all, I do have experience as a former chairman of the State Board of Education of New Hampshire, working 3½ years as

a volunteer, 20-hour-a-week job, basically as a volunteer, as most people do who work in the State boards, and I can tell you, Mr. Chairman, that not a day went by in my service when I did not receive a call from at least one parent every day, one parent at least calling me, pleading with me to try to do something to help them in their situation with their children.

And your particular experience, Mr. Chairman, relating that even you as the chairman of the committee attending a school district IEP planning meeting, feeling that if it that's difficult for your family to achieve the services you feel is important, how much more difficult must it be for our working families, those families who have children in need of services to obtain those services.

I must say that in my view the appropriate role for the Federal Government and the States is somewhat like Representative Tierney alluded to, which is that primarily the role of educating children should remain with the States. But in 1975, Mr. Chairman and members of the committee, this Congress acting then assumed for the Nation a priority, a duty that the Nation would require and encourage the States to educate every child with or without special needs—in this case with special needs—and in exchange for that imposition of duty, this Congress provided a mechanism which included funding to meet that national duty.

President Bush in his State of the Union Address was quite correct in challenging us as a Nation to leave no child behind. In 1975, as a matter of public policy, this Congress tried to articulate that for our most vulnerable of children, those with special needs.

The 40 percent target was never met as part of the quid pro quo, if you will, for States to elect to participate in IDEA. And it is important, I think, to understand this is an elective system. The standard that the duty to provide an adequate education, a free appropriate education to all children is not elective. The program itself is elective.

And in 1995 I commissioned a task force in New Hampshire to evaluate special education, and the first question I asked the task force of citizens, educators, board members, was to answer the question, should New Hampshire continue to participate in IDEA. We decided after evaluating it that, yes, we should, for all the right reasons. And we're asking the Congress and I'm asking the Congress on behalf of the State of New Hampshire and on behalf of all State leaders in education to meet the obligation of fully funding IDEA.

Now, I must also address a point which I think is a misconception about IDEA. IDEA is not a reimbursement program for services. Forty percent is not keyed to the amount of money that is spent by a State in providing educational services. Forty percent is a formula that's derived by counting the number of children who are identified with special needs times the average per-student expenditure of the State times 40 percent. It is a block grant in that sense, but it is not a reimbursement formula.

And the first point that I ask the Congress to consider here is to change the funding mechanism of IDEA so that we empower people to access those services. We empower, incentivize the system to access the services on a reimbursement basis, not on a State grant basis alone.

Second, we need to empower parents and put the power of the decision about where those moneys are expended in the hands of parents. If we can do it through—by amending the IDEA to include some voucher provisions, to the extent that services are available in the community outside of the regular employees of the school district, that will empower parents, and allow parents to opt-out of an IEP if there is not meaningful assessment and not meaningful results for that IEP.

And last, in order to avoid continuing to divert moneys into the legal proceedings and legal process, I urge Congress to require, as an intermediate step, ombudsmen to mediate, if you will; mediators to meet with parents and school districts to resolve disputes before the due process provisions and proceedings can begin, before lawyers get involved and before those funds are diverted.

The Congress has a great opportunity now to meet its obligations. I'd ask this Congress to look at both fully funding and making meaningful reforms to IDEA for our millions of children. Thank you, Mr. Chairman.

[The prepared statement of Mr. Lamontagne follows:]

Ovide M. Lamontagne
172 Young Street
Manchester, New Hampshire 03103

Testimony Before the Committee on Government Reform
House Of Representatives
Congress of the United States

February 28, 2001

Mr. Chairman, Members of the Committee, thank you and the Committee staff for providing me an opportunity to speak to you about Special Education at the elementary and secondary educational level and the federal government's role in this increasingly important area of education under the Individuals with Disabilities Education Act (IDEA), Public Law 105-17.

I have spent the better part of my adult life working in education as a teacher, the chairman of New Hampshire's Catholic school system, the chairman of New Hampshire's State Board of Education, a founder of the national Education Leaders' Council, and an educational surrogate for a severely challenged special needs foster child for 10 years. Among the public policy issues which I undertook to evaluate as Chairman of the New Hampshire State Board was special education with the appointment of a Task Force which met extensively during the 1995 and 1996.

In my experience, no other area of education evokes more passion, consumes more resources, or causes more consternation than the education of children with special needs. Given the federal "entitlement" created with the passage of IDEA over 25 years ago -- the enactment of

which caused the States to adopt and to implement a comprehensive, expensive and bureaucratic system for delivering special education services in detrimental reliance upon the shared funding by Congress of its prescriptions -- Congress now has an opportunity to give new meaning to the adage: "No child should be left behind." This can be achieved by streamlining IDEA and by fully funding the federal commitment to support special education.

First, with all of the focus on budget surpluses, tax cuts and debt reduction, the Congress has the opportunity to evaluate the programs it has implemented and the unfunded mandates it has imposed upon the States. In crafting the next federal budget, the Congress should take stock of its partnership with the States and its People and honor its commitment to fund those portions of federal programs whose prescriptions – even if they are technically elective – pass substantial costs on to local and state political subdivisions amounting to over 20% of total elementary and secondary education expenses. In this regard, "fully funding" IDEA – defined at 20 USCA 1411 (a) (2) (1999) as 40% of the average per-pupil expenditure in public elementary and secondary schools in the United States times the number of students in the respective State who are receiving special education and related services – must be a top priority of this Congress. Whether or not this funding formula is the correct one, according to the non-profit National Campaign to Fully Fund IDEA, founded in NH, FY '2000 funding was $4,924,672,000 -- a paltry 13% level of funding and a far cry from the 40% commitment or $15,568,000 at the FY '00 40% funding level. So the first step in meeting its obligations to the States and to their children, this Congress should make one of its top priorities fully funding IDEA.

But money alone will not achieve what President Bush and the controlling majority of this Congress have set as one of the nation's top priorities for this legislative session: passing meaningful education reform which empowers parents and enhances their role in the public education system through school choice and innovation; raises academic achievement and character development for all students; and minimizes the diversion of economic resources away from the classroom while maximizing the targeting of these resources directly to students in the classroom. The passage of IDEA with its subsequent amendments created both federal substantive and procedural rights. All States elected to participate in the program and with the federal government created reasonable expectations in the citizenry that benefits would be provided to all children who presented themselves at the schoolhouse door so long as the federal prescriptions were followed. Make no mistake about it, at the State and local levels, IDEA's substantive and procedural requirements are as often used as a club than as a safety net for our most deserving citizens.

Therefore, the second step for this Congress is to pass IDEA reform legislation which shifts the focus from a top down, mandate-driven program to a child/parent focused, risk-sharing program. No amount of bureaucracy, due process, or professional credentialing will improve the efficacy of our existing delivery system or enhance the performance of our students. No fad, one-size-fits-all strategy, or theory -- even if properly implemented -- will insure that the objective of "leaving no child behind" is achieved. Flexibility in administering special education services at the local level with a generous reimbursement by the federal government of funds actually expended to provide these services is what is needed to bring our special education delivery system to the next level.

In order to achieve the foregoing, IDEA reform should include the following themes:

(1) **Change the funding formula into a reimbursement formula and adopt financial incentives to reward LEAs when children are no longer in need of services**. The funding mechanism cited above encourages "coding" or identifying students in need of services. By negative implication it penalizes school districts which succeed in assisting students to the point that they are no longer in need of services. Because the funding formula is directly related to the number of students receiving such services, to the extent the services are no longer needed for a particular child, financial support is withdrawn. The formula should be revised so that it provides funding as reimbursement for the cost of services actually provided and enhancements for children who are no longer in need of services.

(2) **Place federal funds under the control of parents or guardians through vouchers.** By changing the federal funding mechanism from a straight revenue sharing model to a reimbursement system, the Congress has the opportunity to place parents in control of directing how those funds will be expended (in consultation with school officials) through a voucher program. Parents should be free to retain the services of qualified professionals and should not be limited to those directly employed by or under contract with the school district.

(3) **Require accurate and meaningful assessment of student achievement and performance.** Whatever individualized educational program ("IEP") is developed for a particular child, the success of the program must be susceptible to reliable and meaningful evaluation by professionals and it must be understandable by parents and other caregivers. Parents should have the ability to "opt out" of an IEP if, upon reviewing the assessment data, they conclude that the program is not successful. The burden of developing a new plan should shift to the professionals who must satisfy the parents that the revised IEP has some reasonable likelihood of success.

(4) **Require school districts to retain the services of an ombudsman to facilitate the resolution of disputes between parents and school districts prior to the commencement of formal due process proceedings.** The identification and evaluation of children with special needs and the development and implementation of IEPs are extraordinarily time intensive activities for both school professionals and parents. When compounded by the burdensome due process proceedings for resolving disputes between districts and parents, the special educational system can be overwhelming for most participants. By providing for the services of an independent ombudsman whose charge is to bring resolution to contentious issues, the conflict resolution system can be streamlined and made more effective for providers, parents and children alike.

Thank you again for providing me with an opportunity to address the issue of special education. I trust that this Congress will, for the first time, meet the federal obligation to fully fund IDEA in a manner which will leave no child behind.

Mr. BURTON. Thank you Mr. Lamontagne. I will have some questions for you, as my colleagues will in just a few moments. We'll now recognize the Congressman from the great State of California, Mr. Cunningham, for an introduction, and thank you for being with us today. This gentleman was an ace in Vietnam, one of the great pilots that we ever had during the Vietnam War. He's a legend among the pilots in the U.S. Navy. He taught at the top gun school. In fact, he even showed Tom Cruise how to act like a pilot in that movie Top Gun, and so we'll now recognize the gentleman from California.

Mr. CUNNINGHAM. Thank you, Mr. Chairman, but now I'm just an old fat guy.

Mr. Chairman, I'm very honored to be able to introduce Carolyn Nunes to the committee and to you. The San Diego City School Superintendent is a man named Alan Bersin. He was a Clinton appointee. I'm Republican, but he's got my full support.

I was the subcommittee chairman that rewrote IDEA. I'm now on the Appropriations Committee so I have got my heart into this area. And the reason that I'm honored to introduce Carolyn Nunes is that Alan Bersin has met with the parent groups many, many times and has had an outreach program, realizing that many of the children have been underserved within the IDEA program. That's why he put Carolyn Nunes in charge of the administration of the IDEA program for special needs of San Diego City School District, one of the largest city school districts in California.

I know what's in her heart. She's been a teacher for 22 years, and now an administrator. She went into the profession to help children with special needs. That's where she wanted to teach, to make sure that no child, as Mr. Lamontagne said, that no child is left behind. But I think it's important to realize and understand from the parent groups, from the teachers in many areas, what are the limiting factors on the schools that prevent the services that Carolyn and the superintendent want to get to give to the children and to the parent groups.

That's why I'm very honored to introduce Carolyn Nunes. I know what's in her heart because she's my sister-in-law. She's the sister of my wife, Dr. Nancy Cunningham, who is the director for Education of Encinitas Union School District. My whole life is filled with educators and I have two built in lobbyists and I'm very honored to introduce Carolyn Nunes. Carolyn.

Mr. BURTON. Welcome. You have to push the button on the mic.

Ms. NUNES. Thank you, Chairman Burton, and committee members, and thank you, Congressman Cunningham.

For the past 22 years I have served in San Diego City School District in the field of special education as a special day class teacher and currently as an administrator for the low incidence programs and related services for students from birth to 22. In addition, I coordinate the input for the collection of data on special education students. I appreciate the opportunity to address the committee today regarding the implementation of IDEA and the challenges in special education.

The San Diego Unified School District currently serves over 142,000 students in 184 schools. Of those students, almost 16,000 have active IEPs and receive special education services. Ninety-two

percent of our current budget provides direct instruction for the support of students receiving special education services. The following addresses some of our current issues, as well as our recommendations for possible solutions.

Nationally we have witnessed an alarming increase in the number of students identified with autism. Families are bombarded with the latest in the new forms of treatment for autism. All who view and read this information in the media make assumptions that such services are research-based and conform to best practice.

There are a variety of instructional strategies and methodologies that are available. As educators we realize that using only one instructional strategy for all students is not appropriate.

Today, a multiple of agencies are funding services for students with special needs. These agencies, although funded by Federal dollars and driven by Federal legislation, are under different rules in different systems. Although these agencies have a common purpose, to provide services for students, these systems become a barrier. At times, although with good intentions, Federal laws frequently promote the system of disconnect.

More emphasis must be placed in the area of research in educational approaches which will promote student achievement based upon the student's ability and level of independence. School districts are currently finding the need to retrain teachers in strategies and techniques used for students with autism.

We would recommend the development of special grants for the purpose of ongoing professional development for the training of certificated and classified staff in the field of autism. Although Congress placed limitations on the recovery of attorney's fees in the 1997 IDEA reauthorization, little has been done to reduce the significant rules such fees continue to play in the decisions that school districts, and even parents, make regarding appropriate educational programs for students with disabilities.

Early independent review, without all the formal requirements of a due process proceeding, may temper each side's expectations and lead to a quicker and fairer resolution. I suggest mandating school districts to participate in alternate dispute resolution in all due process proceedings and reducing reimbursement for attorney's fees proportionately for parents when they fail to participate.

I believe that special education has resulted in a system driven more by the need to comply with numerous requirements of both Federal and State laws and regulations than in genuine educational needs of students with disabilities. The California Department of Education has developed a process of sanctioning school districts who do not meet the zero tolerance level of compliance with the time lines for review of annual IEPs and 3-year reviews, and the system does not allow for reporting extenuating circumstances for missed time lines.

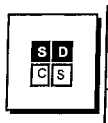
While our district has made great strides in electronic capture of information regarding the status of students receiving special education, 100 percent of compliance is difficult to achieve. At times, IEP teams are faced with breaking one regulation in order to meet another. Requests for data collection and reports by various agencies at the national, State and local level impose a strain on the district's ability to provide information in a timely manner.

Data collection at the State level should allow for reporting extenuating circumstances that prevent time lines from being met. Definitions regarding placement settings, disability categories, and designated and related services should be consistent across agencies. Data repositories should be developed so that they can be accessed by any interested agency from a central location.

Thresholds of compliance should reflect on the percentages of students reported. Compliance should be driven by quality and student outcomes as opposed to checklist compliance.

On behalf of the San Diego City School District, we appreciate the opportunity to comment on these issues. We also hope that our comments are helpful to the committee as they continue to investigate the IDEA. Thank you.

[The prepared statement of Ms. Nunes follows:]



SAN DIEGO CITY SCHOOLS

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SUMMARY of Written Testimony for
February 28, 2001 1:00 p.m.
Carolyn Nunes, Special Education Program Manager
San Diego Unified School District

Description of San Diego Unified School District
- 184 schools
- 142,300 students
- 15,592 students receiving special education services

Recommendations of how Federal Government needs to improve special education implementation of IDEA:

Autism
- Unique characteristic of autism is the range of ability level
- The rate of increase of students diagnosed
- Multiple agencies are providing funding
- Frequently the most sought after services are those not substantiated by research

Funding
- At this time districts are required to retrain teachers in the strategies and techniques needed use with students with autism
- Recommendation: the development of special grants for the purpose of professional development for training in the field of Autism

Reporting Process
- Request for reports
- 0% of Overdue IEP and 3 Year Reviews

Legal Fees
- On those occasions when IEP teams are unable to agree it is unfortunate but legal fees become a factor as teams work to make decisions regarding services to be offered
- Congress should encourage a process of Alternative Dispute Resolution

Independent Assessments
- Setting specific steps for independent assessments

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The Honorable Dan Burton
Chairman
Committee on Government Reform
Washington, D.C.
February 28, 2001

Revised 2/27/01

I feel I am very qualified to address issues regarding the implementation of the Individuals with Disabilities Act (IDEA). I hold three teaching credentials, including two in the field of special education, a Masters degree in Special Education and an Administrative Credential. For the past 22 years I have served the San Diego Unified School District in the field of special education. My experience ranges from ten years as a special education classroom teacher, eight years as a diagnostic resource teacher for the Special Education Early Childhood program and the past three years as a special education administrator. My responsibilities as an administrator include the low incidence programs, speech and language, psychological services, as well as programs which serve students from birth to 22. In addition, I coordinate the input and collection of data on special education students. Working in a large urban district has given me a broad perspective on many special education issues.

I also have the perspective as a student who received special education services from San Diego Unified School District. While attending high school, I was enrolled in the Home/Hospital program on and off over a three year period, due to the fact that the school system at that time had virtually no ability to accommodate wheelchairs throughout the campus of the school I attended.

It brings me great joy to see how far we have come for all of our students.

I appreciate the opportunity to address the committee today regarding the implementation of the IDEA and the challenges in special education.

As educators we have witnessed a wide variety of benefits from each passage of legislation providing language addressing the needs of our special populations. These include: a free and appropriate education for all students; early intervention services through Part C; the workability program which addresses the needs of our students as they prepare to exit the public school system; as well as campuses that are equipped to accommodate all students.

While we have witnessed the advances we have made together, we continue to face challenges. Some of these challenges are reoccurring, and others are generated by new issues we have encountered since the 1997 Reauthorization of IDEA.

The San Diego Unified School District currently serves 142,300 students at 184 school sites. Of those students, 15,592 have active Individualized Education Plans (IEP) and receive special education services. A review of historical data indicates that approximately 10% of the district's student population receives special education services each year. Ninety-two percent of the current budget provides direct instruction and support to students receiving special education services.

The table below indicates San Diego's total budget for special education and provides a historical perspective:

Item	Fiscal Year projection 2001	Projected Students 17,000+ over year	Fiscal Year 2000	Students 12/1/00 15,658	Fiscal Year 1999	Students 12/1/99 14,652
1) Total Budget including special ed transportation	$152,810,800		$131,565,200		$115,399,400	
2) Encroachment	$37,285,800		$30,157,700		$20,582,770	

Item #1) Total Budget—This is a 32% increase in the cost of special education since fiscal year '99
Item #2) Encroachment—This is an 81% increase in encroachment on the general fund by special education since fiscal year '99

The following addresses some of our current issues as well as our recommendations for possible solutions.

Autism

Challenges:
Nationally, we have witnessed an alarming increase of the number of students identified with autism. Families are bombarded with the latest in the new forms of treatments for autism. In addition, services are advertised on the internet and discussed in magazine articles on a daily basis. All who view and read this information in the media make assumptions that all such services are researched-based and conform to best practice. Unfortunately, this is not always the case.

Students with a diagnosis of autism display a range of ability levels. There are a variety of instructional strategies and methodologies that are available. As educators, we realize that using only one instructional strategy for all students is not appropriate. However, parents frequently request a particular form of instruction through a private agency at district expense, even though the district may have an appropriate program for the child.

The district's goal is to provide quality services to all students and this is a standard to which we should be held. However, once accomplished, we must factor in the ability level of the individual child and make appropriate modifications to the student's program based on need.

As professionals we fear we are creating a population of dependence rather than productive individuals who will be as independent as possible.

Today, multiple agencies are providing funding for services for students with special needs. These agencies, although funded by federal dollars and driven by federal legislation, are under different rules and different systems. Although these agencies have a common purpose to provide services for students, these systems become a barrier. At times, although with good intentions, federal laws will frequently promote this system disconnect.

Recommendations:
More emphasis must be placed in the area of research in the educational approaches which will promote student achievement based upon the student's ability level and independence. Hearing officers called to mediate disagreements must be informed of educational research and best practice.

School districts are currently finding the need to re-train teachers in the strategies and techniques used with students with autism. Teacher training programs are not addressing these teaching skills to the degree that newly credentialed teachers are able to practice these instructional strategies in a classroom setting. Special education teachers holding existing credentials have not been exposed to instructional strategies developed since their days in teacher training programs. In San Diego, we are now in communication with local universities to discuss standards of competencies special education teachers should demonstrate upon the completion of a teaching program. We would recommend the development of special grants for the purpose of ongoing professional development for the training of certificated and classified staff in the field of autism.

Item	Fiscal Year projection 2001	Projected Students 17,000+ over year	Fiscal Year 2000	Students 12/1/00 15,658	Fiscal Year 1999	Students 12/1/99 14,652
1) NPS/ NPA Contracted Includes: Vision therapy Music Therapy Autism NPA	$16,488,900		$15,772,300		$12,050,900	
2) Paraeducators 1:1 assistants Formula assistants	$22,256,800		$19,247,500		$17,296,200	

Item #1) NonPublic School (NPS)/NonPublic Agency (NPA)
Item #2) $5 million increase in two years primarily due to the services of assistants newly written into IEPs
Item #2) formula assistants are those assigned to each special day classroom

Attorney Fees/Alternative Dispute Resolution

Although Congress placed limitations on the recovery of attorney fees in the 1997 IDEA reauthorization, little has been done to reduce the significant role such fees continue to play in the decisions that school districts, and even parents, make regarding appropriate educational programs for children with disabilities. I believe that disputes often are prolonged when both the school district and the parents have unrealistic expectations of their respective legal claims and positions. In these cases, an early independent review, without all the formal requirements

of a due process proceeding, may temper each side's expectations and lead to a quicker and fairer resolution. I recognize the attempt that Congress has made to encourage alternative dispute resolution for disagreements between parents and school districts. However, school districts were not sufficiently encouraged by the IDEA provisions to develop alternative dispute resolution processes due to the Act's failure to provide programmatic or economic incentives to do so. I suggest mandating school districts to participate in alternative dispute resolution in all due process proceedings, and reducing reimbursement or attorney fees proportionately for parents when they fail to participate.

Independent Educational Evaluations

For large school districts such as mine, significant amounts of program monies are spent on independent educational evaluations. These evaluations are conducted at the request of parents when they disagree with the result of a school district evaluation. Under the IDEA and its regulations, an independent educational evaluation is paid for at school district expense when parents state that they disagree with the school district. The school district must then initiate due process proceedings and its associated costs to avoid paying for an independent educational evaluation. In some cases, these evaluations may cost as little as a few hundred dollars. As a result, school districts have little economic incentive to request due process in challenge an independent educational evaluation when such an action would prove costlier than paying for the evaluation.

Item	Fiscal Year projection 2001	Projected Students 17,000+ over year	Fiscal Year 2000	Students 12/1/00 15,658	Fiscal Year 1999	Students 12/1/99 14,652
Litigation-due process/reimbursement (primarily attorneys fee, independent assessment)	$548,700		$470,300		$284,100	

Compliance

Challenges:
I believe that special education has resulted in a system driven more by the need to comply with the numerous requirements of both federal and state laws and regulations, than by the genuine educational needs of children with disabilities.

The California Department of Education (CDE), in response to the corrective actions imposed by the United States Department of Education's Office of Special Education Programs, has developed a process of sanctioning school districts who do not meet a "zero tolerance" level of compliance with the timelines for review of annual IEPs or three year reevaluations. In large urban school districts with highly mobile populations of students, this is an unreasonable level of compliance. Over one hundred special education students per week enroll or dis-enroll in our district's schools. In addition, students move frequently within the district and are assigned new case managers at their new schools. While our district has made great strides in the electronic capture of information regarding the status of students receiving special education, 100% compliance is difficult to achieve. The California Special Education Management

Information System (CASEMIS) does not allow for the reporting of extenuating circumstances as to why a timeline is missed, e.g., parent was unable to meet with the IEP team before the timeline had expired, parent refuses to sign an IEP, consent for assessment has not been received for three year evaluations, extensive student absence precludes appropriate assessment. At times the IEP team is faced with the decision to postpone the IEP meeting to ensure parent participation, or to hold the meeting without the parent in attendance, breaking one regulation in order to meet the other.

Requests for data collection and reports by various agencies at the national, state and local level impose a strain on the district's ability to provide information in a timely manner. In response to corrective actions or site visitations by personnel from OSEP, Office for Civil Rights (OCR), CDE, etc. the district has been required to provide a wide variety of data and information regarding policies and procedures, budgets and services, compliance with federal and state laws, and information about students, programs and outcomes. The timeline for the provision of this information may be as short as one week. The information requested must be consolidated, analyzed and produced using existing staff. New data requested may be in addition to previously required reporting elements, or be in a slightly different form. This requires changes to existing database structures, data collection methods, and report generation.

Recommendations:
Data collection at the state level should allow for the reporting of extenuating circumstances that prevent timelines from being met. Sufficient lead-time to implement any changes to the data collection process should be extended to ensure that systemic changes can be developed and institutionalized.

Definitions regarding placement settings, disability categories and designated and related services should be consistent across agencies. Data repositories should be developed that can be accessed by any interested agency from a central location. Assurances must be made that the information reported is consistent, timely and accurate.

Thresholds of compliance should reflect the percentages of students reported. The California Department of Education imposes sanctions on districts not meeting timelines with 100% accuracy. Although this is the standard we strive to achieve, it is difficult, if not impossible, to meet. Compliance should be driven by program quality and student outcomes as opposed to "checklist" compliance

On behalf of the San Diego Unified School District, we appreciate the opportunity to comment on these issues. We also hope that our comments are helpful as the committee continues to investigate and review the implementation of IDEA.

Carolyn N. Nunes, M.Ed.
Program Manager
Center for Student Support and Special Education
Special Education Programs Division
San Diego Unified School District

Mr. BURTON. Thank you, Ms. Nunes, and we'll have some questions for you as well.

We now, I think, have Congressman Pence from Indiana, one of our new Members, and a very good friend of mine. He's actually only 21 years old. That gray hair is just to make him look older, but Congressman Pence has an introduction. Welcome.

Mr. PENCE. Thank you, Mr. Chairman. It's an honor to be with you today and it's an honor to take a moment to introduce a distinguished fellow Hoosier from my hometown of Columbus, IN, Ginger Brown. Ginger is the proud mother of two, but she is, Mr. Chairman, the courageous mother of young Bobby Brown, age 5. And as we will hear today, Ginger fought an extraordinary fight over the last year and a half to bring the strictures of the IDEA to bear on the local school system in Columbus, IN, particularly championing the Applied Behavior Analysis Approach.

I'm honored to introduce Ginger to this committee today, and I'm honored to call her a constituent. She seems to me to be a wonderful example of citizenship and, more importantly, parenthood. So I give you Bobby's mom, Ginger Brown.

Mr. BURTON. Ms. Brown. Congressman Pence, thank you very much.

Ms. BROWN. Thank you, Chairman Dan Burton, for inviting me here to speak on behalf of my son, Bobby Brown. I would like to just go over the last year of his school, which would be from August 1999 to the year 2000. When Bobby began the school year he was unable to do anything independently. He was not able to put his coat on. He was not able to brush his teeth. He sat around and he banged his head on the floor. He did hand flapping, stereotypical behavior of children with autism.

I looked forward to putting him into an early childhood program, hoping I would see lots of success or at least forward motion in Bobby's advancements. As the year progressed, I only received notes from his teachers that Bobby was not making the gains. Bobby was unable to even understand the smallest of steps in order to be taught the larger steps. The teacher suggested that I seek out an independent behaviorist and have my son evaluated and try to implement a program.

I sought out a behaviorist in Applied Behavior Analysis from New Jersey who designed a program for my son. I asked her to implement the program both in the home and in the school to help Bobby to be able to tolerate being in the school and being able to sit at circle time and music time and participate with his peers.

When the program was designed, the teachers felt like it was not adequate and did not want to pursue it in the school. I decided to go ahead and pursue the program on my own. The school year was coming to an end, and I approached the director at the time, and explained to her what I was seeking was a one-to-one program of Applied Behavior Analysis with my son. I went ahead and hired a team of girls to work with my son. It was a 40-hour a week program. Remember, my son was not independent in any way. He was unable to use the restroom.

Within 3 months he was able to be potty trained. He was able to sit for 1 hour at a table and work. He was able to relate to his sister. He was able to relate to me and to his father.

Bobby continued his progress and the school year was nearing to start for the year 2000 and 2001. When the year began, I went to the school and asked the school if they would be willing to help me continue the program. I had data sheets, I had video footage and I had graphs. I took the behaviorist from New Jersey in with me and explained to them exactly what Applied Behavior Analysis was, the importance of one-to-one teaching for a child like Bobby.

What the school actually told me was that unfortunately a mistake had been made in the computers in the State of Indiana and that too much money had been given to their district. They now were held accountable to repay $1 million and would not be able to educate my son. I also asked them if they could help me fill out an application to send in to the State, and they said they would do that.

We filled out the application. We sent it in to the Department of Education of Indiana. I got the letter back and it made perfect logical sense to me when I read it, and I called and talked to a director who informed the reason why the application was turned down is it didn't match the IEP. There was nothing in the IEP that reinforced the needs of what Bobby was getting, that I was giving to him.

When I went back to the school and explained this to them, they said that they understood Bobby was making progress. The teacher supported that he had made incredible gains since last year. He had made gains in areas that they had no way of teaching him, but still they were not going to help me out financially. They said that it was entirely too expensive for them to take on.

I actually spent five meetings with the school district in IEP meetings, a total of 20 hours, trying to resolve the issue. Still, I was paying for Bobby's program. I was paying to send a trained aide in ABA into the school. I was paying for his in-home program, and I was still getting no assistance. They did finally say that they would call the Indiana Resource Center and ask for someone to come in and give a 2-day overview of what ABA was. ABA cannot be learned in 2 days. It cannot be taught to someone in just a matter of 2 days to take over and do the data sheets, fill out the graphs and report back to the head person in charge of the ABA program.

Actually, what the Indiana Resource Center suggested to them was that they continue with the people that I had in place, that it was beneficial to Bobby. Still, the school denied this. I was left no option but to go ahead and continue the due process.

During this time period, the directors actually switched; the one resigned, and we had a new director come into the community. The new director was a little bit more open to this, but we still went ahead with due process. But now I can say that my son has received a free, appropriate public education, but unfortunately it has cost a lot more both to the district and to myself because of having to go due process.

When people ask me what I would like to see, I would like to see the schools be open-minded when parents go in and they have data sheets that show last year for 9 months my son made zero progress, but in 3 months I potty trained him. That's a hard task to do with a child with autism, but it was successful for my son.

Applied Behavior Analysis is the way of the future of education with some children. I would like to see the districts have an open mind.

Thank you.

[The prepared statement of Ms. Brown follows:]

Testimony of
Ginger Brown
To Government Reform Committee
Hearing on "Special Education – Is IDEA Working as Congress Intended?"
Wednesday, February 28, 2001

Thank you, Chairman Dan Burton, and Ranking Minority Member Henry Waxman, and other members of the committee for inviting me here to speak on behalf of my autistic son who receives education in southern Indiana

To begin, my son was placed in an early childhood program. He continues to go Monday through Thursday for two hours and fifty-five minutes each day, during which time he receives speech therapy, two times a week for one half hour each time, on a one-to-one basis. When I was first introduced to the public school system, I was under the impression that the school was there to help educate my son, and that we would be working as a team. I thought both the teachers and the parents would work together to help my son receive the skills that he would need just to be able to sit in a classroom all day long, to learn and pay attention, and to not be a distraction for other students. Soon after my son entered the public school early childhood program, I received little notes form the teachers that my son was "not grasping" what they were talking about or "(he) does not have the ability to sit at circle time" or "(he) does not have the ability to join in at music time". He was "unable" to remove his own coat, to brush his teeth, to wash his hands, or to go to the restroom independently. He was "unable" to sit on a square at circle time and listen to the story that was going to be read. These all became issues throughout the entire school year. Whenever I received progress reports that had been sent home, all the progress reports would tell me that progress was being made; however, my son was still unable to do the smallest of tasks that were being asked of him.

It was during this time period that it was suggested to me by the school's teachers that I should probably seek out an independent evaluation from a behaviorist and try to come up with a program for my son. I obtained a behaviorist and asked them to come in and evaluate my son to help out both in the classroom and in the home. In doing so, I accepted the responsibility of getting my son educated so that he could attend a public school.

During the whole time period of trying to obtain an education for my son, I would ask what was being taught to my son, how was my son doing in the classroom, and how was what he was being taught going to affect him later on in his life at school and in adulthood. I was continually told that the school was unable to teach him the smaller steps that he needed in order for him to understand the larger steps. I saw the need for my son to have one-on-one teaching. In the classroom, my son was allowed to walk the perimeter of the room and do stereotypical behavior that interfered with his ability to be compliant and to sit and to learn. He had self-injurious behavior. He was a danger to himself and to other students.

The behaviorist that I continued with at the school's suggestion came up with a plan that would help educate my son and help teach my son compliance. However, the school did not like the program, and insisted that I do away with the program. Of course, I wanted to keep the channels with the school open as much as possible, as I figured my son would be attending school for many years to come.

I set out on my own and found a behaviorist from New Jersey that I brought in to work with my son. We designed a program and went ahead and went forward with that program. The end of the school year was coming, and I notified the special education director of my plans – that we would be doing a one-to-one program with my son all summer – and asked if they would be willing to assist in filling out an application to send to the state asking for support of this program and to help with the financial cost of the program. (Because I had been doing the program on my own since February, I had taken the responsibility of the cost on my own without asking for any assistance. I first wanted to see if the program was even going to work and did not feel that I had reason to ask for any financial help at that time. Once I was able to see that the program was working and that it was a good program, and that my son was capable of learning and his compliance was much better – according to the reports that the teachers were giving me – I felt then it was the responsibility of the school to help out.)

Because it was the end of the school year, and school had just let out, I was told that the directors would be working outside of their contract and no assistance could be given to me unless out of their good nature they filled out an application and/or paperwork. I asked the director if she would at least be willing to make a phone call to companies who specialize in Applied Behavior Analysis teaching, which offers one-to-one teaching. At the time, the assistant director did make one phone call; however, he never followed-up with me. I called the company he had called, and they said that the assistant director had called, but that the director had felt that the school was capable of providing an education for my son and did not see the benefit of outside assistance.

As the summer progressed, I went ahead and hired a team on my own, paying for them out of my own pocket, and continued to watch my son progress much better than he had during the school year. His compliance was much better. He was able to sit at the table for at least an hour to work. He was no longer biting or throwing himself on the floor, banging his head against the floor or against the wall, and he had successfully been potty trained.

I had held a summer workshop with the behaviorist to help educate anyone who would be working with my son during the next school year. When the school year began, I asked for an IEP meeting/case conference to meet with everyone -- my son's teachers and the director. It was during the first case conference meeting that the teachers agreed that my son had come a long way since the previous year. Although he still displayed many self-injurious behaviors and still had problems with compliance, he had improved much from the prior year. The teachers agreed that they knew nothing about Applied Behavior Analysis, and they did not know how to teach Applied Behavior Analysis. They also agreed that anything and everything that they did know about it had been learned through me through the summer workshop that I had held. They also agreed that my son was benefiting from having a full-time, trained ABA aide with him. They also agreed that having my son in a full day of school would not be beneficial to him, but did feel that having a program before school in the home was very beneficial for him. The school felt he needed to have some firm footing, firm foundation, before he could handle being in a classroom all day.

No one, during any of these meetings, ever told me that the school could pay for an in-home program, or so many hours before or after the school day. I was just simply told that they did not think putting him in a classroom for a full day would be beneficial to him. I asked if the school could help out financially by paying for the aide while we were waiting to fill out an application to send to the State Department of Education. I was told that they did not have the money, that what I was asking was extremely expensive, and that there was no way that the school district could be held accountable for something like that. I was told that it was just more than they could handle and that the only way that I could hope for it to be paid for was through the State Department of Education.

Because the teachers did support the fact that my son had made many gains, the assistant special education director agreed to fill out an application to be sent to the Department of Education. In a couple of weeks, I received a reply. The letter basically stated that the application was being turned down due to the fact the State Department of Education did not see where the IEP supported the application.

I called the Department of Education and asked what the letter had meant, and they explained that the school could be paying for an aide and could be paying for an in-home program. The in-home program could be considered an extended school day. Just because it was being done in the home did not mean that the school was not responsible, that they were quite capable of paying for it. I went back to the school and asked them, once again, if they were willing to help out and, once again, they said they did not have the money and that it was not something they would pay for. Yes, they heard the benefits, and, yes, they understood what the teachers were saying – that my son was benefiting from this – and, no, they were not trained in it, but they still would not pay for it.

I was sending a full-time, trained ABA aide to school with my son, and thus, I had data sheets to prove how my son was learning in-home versus in the classroom. For example, in the classroom, they were doing things like taking cotton balls and gluing them together versus in the home, we were trying to teach him how to hold a pencil correctly and how to place the pencil on the paper and draw from one dot to

another dot. He was also learning to match colors and to identify letters, preparing him for kindergarten, or even first grade. These skills were not being taught to him in the classroom.

The State Department of Education said that it was the district's responsibility to offer an education to my son. I, once again, went back to the school and asked what they were willing to do financially to help educate my son. The school basically said they would contact the Indiana Resource Center on Autism, and have someone come in and give a two-day overview of Applied Behavior Analysis. Also, they would be willing to hire someone to be trained as an aide for my son – someone who knew nothing about Applied Behavior Analysis, who knew nothing about keeping data sheets, who knew nothing about the behaviorisms of autism, but who would be exposed to a two-day verbal overview of Applied Behavior Analysis. Of note, is that people who are trained in ABA usually complete a one-year residency before working alone with a child who has autism.

I asked if I could have permission to call the individual that they were speaking about at the Indiana Resource Center on Autism, and they said that would be fine. When I called the Indiana Resource Center and spoke with the individual, I explained to them what kind of program my son had and what it was that I was looking for. I also asked what the school had asked out of them. The Indiana Resource Center said that all they could offer to the school and my son was a verbal overview of ABA, and that their suggestion to the school was to go ahead and obtain the people that were already working with my son.

I called the school and explained what I had been told by the Indiana Resource Center, and, once again, the school replied that their responsibility and what they could offer would be very limited

I decided to go ahead and go due process, and basically I requested to be reimbursed for the money that I had spent on the education that the school agreed was beneficial to my son. I had data sheets, video footage, and graphs that showed the improvements in my son from the time I had started the program. I had proof that his compliance had become better, his self-injurious behavior had decreased, his ability to sit was better, and his verbal aggressions and screaming were decreased. I felt like this was the only option that was left, because the school certainly did not have anyone lined up to come in and educate my child. Nobody wanted to come in and teach the school, because everyone they contacted kept telling them that this was not something they could learn in just a couple of days, a couple of weeks or even a month. It took more than that.

So, in due process, I asked for an in-home program before school, a full-time trained aide, and Applied Behavior Analysis at school. Also, I asked for a transitioning program back into the home. I asked for all of the things that I had been paying for out of my pocket, as everyone agreed that this was working, and is still working, for my son. Applied Behavior Analysis is not a forever program. Most children can transition out of it after a year. Some children require up to three years, but the bottom line is that one year of Applied Behavior Analysis, one-to-one direct teaching, can cost around thirty thousand dollars. Children who do not receive this might be placed into an institution, which could cost, perhaps, millions of dollars.

People often ask what's the problem, what's going on with the schools, why aren't parents happy, or why are parents fighting with the school systems. I do not necessarily see this as the parent fighting the school or the school fighting the parents, but rather it is a lack of understanding. It is a lack of understanding of what autism is and the fact that when special education teachers attend college, there are no courses on autism. Because the field of autism is such a wide spectrum and there are many different ways and different methods of teaching a child with autism, it is very difficult for the teachers to keep up with the releases of what is going on in the world of autism.

When parents first find out their child has autism, they begin doing research on their own. Parents stay up late at night. They spend their days working to find out what is best for their child. They do not want to watch their child drift away and become withdrawn and revert back into himself. So, they go to the school system and make suggestions on how to teach the child. When they have data and videos and graphs that show the progress of the child, they would like for the school to listen with an open mind.

When the parents come in and ask for assistance, they are asking someone to listen and to offer help in seeking an appropriate education for their child.

The argument could be made that any child would benefit with one-to-one teaching, but we are not talking about "any child" today. We are talking about a child with a special need. We are talking about a child with a disability known as autism. We are talking about a method of teaching that has been proven through research and statistics. This is a way of teaching children, and this is a way of changing their future. This is a way of education.

Thank you,
Ginger Brown

Mr. BURTON. Real briefly, can you tell us how much you personally had to expend to get those benefits?

Ms. BROWN. I personally spent $30,000 out of my pocket to do the ABA program for my son, and then I spent an additional $17,000 in attorney's fees.

Mr. BURTON. So it cost you almost $50,000.

Ms. BROWN. Yes, sir.

Mr. BURTON. I will now go to Ms. Fry. Ms. Fry, I'll introduce you. Since we don't have some good-looking young Congressman, you have to settle for one of these old fogies up here. So, Ms. Fry, you're recognized.

Ms. FRY. Thank you for inviting me here to testify. My name is Stephanie Fry.

Mr. BURTON. Excuse me, Ms. Fry, you're one of my constituents, I understand.

Ms. FRY. I believe so.

Mr. BURTON. Well, can I shine your shoes or anything?

Ms. FRY. We'll think about it. I have three children, three boys, all born on Fridays in October. All of my children have autism. I brought pictures so everybody can see. They don't look any different from anybody else. They may act different. I don't expect any special red carpet treatment for them. All I want from a school is an education for my children.

My oldest son was diagnosed in June 1991 with autism. The doctor told me, here's your diagnosis, come back and see us in 3 months. What am I supposed to do now? So I called the parent support group and I found a preschool in our community that did early childhood intervention and they took him on during this summer.

Mr. BURTON. Would you pull the mic a little closer so we can hear you better?

Ms. FRY. He went to school for about a month and then was off a month for summer break. During the month he was off, he regressed quite significantly. He still was not speaking more than 20 words. He was not toilet trained. He could not play appropriately. He had stem behavior. There were many, many issues.

The administrators at the preschool told me when he went back that fall that once he turned 3 years old they could no longer take him, but the new law had been passed that school districts were required to take a child at age 3 and teach them. So I called the local school district and I spoke to the director of special ed and she said that they had to do a psychological testing on him before he could attend their school. There was no possible way that he could go before the testing was done. And I said, well, I have a doctor's diagnosis that says my child has autism. And she said, well, he may not be autistic enough. And I'm still wondering what "autistic enough" is.

He did go to school on his third birthday, having known no one there, did not know the teacher, did not know the students, had never been there, and for an autistic child it is a very difficult transition. I sent him to school and waited as patiently as I could for him to arrive on the big bus, just like all the other kids. And when I went to get him off the bus, he had a fat lip, a very large fat lip. And I said, what happened? And all the bus driver could tell me was he fell. I had not been called by the administrators. I had not

been called by the teacher. I just got the surprise of taking him off the bus, and this was our first experience with public school. I later found out that he had been following the teacher because he knew that she was in charge, and she turned and he ran into a table, but I was just very, very concerned at that point.

He did learn. He learned very, very well. He learned to comply with them, he learned to sit in circle time. He liked to listen to the songs. He did everything he was supposed to do. He was in a classroom with a teacher, two aides and eight students. We moved to Warren Township, school district in Indianapolis, in 1993. He started the preschool there. That year he was due to go to kindergarten. When the time came to place him, he had been in preschool about 2 years, and I was concerned that moving him to a regular classroom, even though he had made so many gains, it would not be enough. I was told least restrictive environment, this is what you get. So I said OK, and we put him in.

They told me they had to ask the kindergarten teacher if she would accept an autistic child in her classroom before they could place him. She agreed and so he was there. She had no training in autism. The resource teacher that he had, the part-time special ed teacher did have training but was not in the classroom at all times.

He did very very well in kindergarten with 18 students, 1 teacher, a part-time aide and a part-time resource teacher. He learned, and again he was moved on to first grade. This was a whole new transition because this was a whole day of school instead of half a day. He had more academic things asked of him, more patience issues asked of him. He became frustrated, sensory overload, and had many crying episodes. The teachers did not know what to do with him, and they tried peer tutors, which is regular students helping to keep him on task. He did not deal well with that. What he did was, he would sit under his desk and cry. So they would send him to the office. He spent more time in the office than he did in his classroom.

I did not know what to do. I expected the school district to do what was best for my child, and they didn't. He moved on to second grade because he did learn. That year our school district started year-round classes. He moved to another school, new teachers, new special ed teachers. He did fairly well, but again the frustration issues were there. He had trouble complying with what they were asking him to do, but he learned. He still learned, despite all this. And that's one thing I'd like to say. He—through it all, the kids are able to do so much, even though we don't know the things that are in there.

He was promoted to third grade. At the annual case review going into third grade, the resource teacher asked me to cut his hours back and said that he didn't need as much help as he was getting, which was 25 to 50 percent. So we're down under 25 percent of the time of a full school day that he would get help. I said OK. She said if there was any trouble it could be easily changed. That was the worst year that we had. The third grade is when they start adapting to new curriculums, extra harder work, things like that, and he could not maintain with what the other students were doing. He had acted out. They put him in a resource classroom,

which is when they put all the students with learning disabilities or other disabilities in the same room, only to get a blanket service so they can qualify all their services for each person at the same time.

I don't feel this is right. I have been told over the years that teacher training is not necessary. Over that whole time we have never had a teacher that's been trained in autism, a regular education teacher, and he has always been in a regular education classroom.

The teachers called me to ask what I had done to cause him to be upset. They called me often to ask me things that were very, very rude. I was also told—I asked for an aide because I thought that would help—if we give you an aide we'll have to give everyone an aide. We don't need to train the teachers because we won't see another autistic child in our regular classroom for another 10 to 15 years. There were a lot of things I was told that were very, very wrong, but I didn't know that the parents had rights.

I didn't know that I did not have to sign an IEP that I didn't agree with. And my son was in fourth grade before I found that out. The school district did not tell me what was available. All they'd said was, this is what we can give you, we cannot give you any more due to funding.

I have two other children with autism. My youngest is in a moderate to severely handicapped classroom. He is moderately autistic. He has made great strides in the last year but is still very far behind.

My middle son is Autism/Asperger Syndrome. He is in regular classroom with no support. He does extremely well. Academically he is at or above his peers. He does not need any resource help or anything else. Last year in kindergarten his teacher was very argumentative. She would call me often and ask me to come in and calm him down. He would not comply with what she asked and he understands verbal language very, very well. She would stand next to him and call me, and I could hear him in the background crying because he knew she wanted me to take him out of there.

Mr. BURTON. Ms. Fry, can we get on with your children when we get to questions? I have a number of questions I'd like to ask you. This was the Warren Township School System?

Ms. FRY. Yes.

Mr. BURTON. And they're still in the Warren Township School System?

Ms. FRY. Yes.

Mr. BURTON. OK. Can I ask you some questions after we get through some of the other witnesses?

Ms. FRY. OK.

Mr. BURTON. Be with you in just a few moments.

[The prepared statement of Ms. Fry follows:]

Testimony of
Stephanie Fry
To Government Reform Committee
Hearing on "Special Education – Is IDEA Working as Congress Intended?
Wednesday, February 28, 2001

My name is Stephanie Fry. I have three sons, all born on Fridays in October and all have Autism. Parents of autistic children are a breed unto themselves. We are forced to explain autism, our children, and our entire lives to doctors, teachers, lawyers and even people on the street. We do not ask for pity. We want for our children what every other parent wants: for them to grow up healthy and happy, then get a job and move out of the house.

In June of 1991, my oldest son, Mike, was diagnosed with autism. I was ecstatic! Not because there was something different about him, but because it had a name. I could finally tell the people in the grocery store, shopping mall, gas station that my child was NOT a brat, my child has autism. He does not need a good spanking. That will not make him talk. I won't withhold food from him until he asks for it. That time may never come. There were many nights of little sleep; screaming, crying tantrums that lasted for hours; and worst of all the self injurious behaviors he inflicted upon himself: headbanging, freefalling onto the floor, the grass, the sidewalk, whatever was there. Again and again and again. I finally had a diagnosis and now I could get him some help.

I had been reading books from the library on different disabilities in search of what could be happening to my son. Autism was it. I was sure. The doctor confirmed my thoughts but did not tell me what to do next. "Here is your diagnosis, come back and see us in three months." I called the local support group for autism. The contact person was very helpful. I found a preschool in my community. After a meeting with the administrator, Mike went to school. It was a rough transition for both of us. I was a single mother who had been with my son almost every minute of every day since he was born. Now, for 6 hours a day, 5 days a week, someone else was caring for him, teaching him, nurturing him. I didn't have to pay for this care. First Steps-Early Childhood Intervention did.

Mike went to preschool for a month and adapted very well. He didn't talk much more, but his behavior changed. He was able to sit for longer periods of time, doing puzzles and playing with toys, though not in the usual ways. He had things he carried around with him, a plastic hammer, rubber tubing from a bicycle handle, blocks, things he HAD to have or a meltdown was sure to occur. Mike had a month off in August (for summer break) , then went back when school starting in September.

The administrators told me that because there was a new law passed, the school district would take over his education starting at age 3. I had 6 weeks. I called the school district's special education office. After telling the secretary what I needed, she connected me to the director of special education. I will preface myself with the facts: I have a doctor's diagnosis of autism, my son will indeed be 3 very soon, he had adapted very well to the changes in routine of the preschool and there was a new law. I explained my situation to the director, she told me they would need to do a psychological testing of

Mike BEFORE he could attend their school. She said it would take 6 to 8 weeks before they could fit him in. When I said that he had a doctor's diagnosis, she said, "well he may not be autistic ENOUGH." To this day I still wonder what "autistic enough" is.

I went to the administrators of the preschool upset at the thought that my child would have to sit out of school for 6 to 8 weeks or more, before they could evaluate him to see if he qualified. The preschool said the new law prevented them from keeping Mike there beyond his 3rd birthday. I called the director of special education again, and said my child HAD to have services on his 3rd birthday, due to the new law. I couldn't wait and have the possibility of regression (losing skills he had learned). Mike did go to the district's preschool program, on his 3rd birthday. A long bus picked him up and took him to a school where he knew no one, and they didn't know him. When his bus came back, after lunch, I eagerly anticipated his return. I went out to meet him and was shocked to find this was not the same child I sent to school. He had a huge fat lip and the only thing the bus driver could tell me was, "he fell". Thanks for the news flash. I had not received any calls from the school or administrators that day. I found out later that he had been following the teacher and when she turned he walked into a table. This was NOT a good beginning to our public school experience.

The rest of his preschool experience was fairly uneventful. His psychological testing was done while he was in school and an administrator came to my home to complete the rest. He had different teachers and different aides. He adapted well to it all and he LEARNED. He was using more language, began to point and had less tantrums. He enjoyed being around other children, though he still had impaired social skills.

I met my husband in the fall of 1992 and we married in 1993. We moved to Indianapolis, Warren Township School District. He went into their preschool with no problems. The classroom was one teacher and two aides to eight special needs children. The teachers there were willing to get help when they didn't know what to do. The teacher, speech pathologist, my husband and myself went to Indiana Resource Center for Autism for an evaluation, to get recommendations on what to do and how to place him for Kindergarten. I was concerned that after having only been with special education students, he wouldn't be able to adjust to a regular classroom. He was talking, toilet trained and much closer to age appropriate level than he had ever been. At his Annual Case Review (ACR), it was decided to place him in kindergarten with resource support.

I was told at the ACR that they would ASK the teacher if she had a problem placing an autistic child in her class. Least Restrictive Environment (LRE) mandated that he be placed there. I didn't know any different so I was thankful he was accepted. The kindergarten teacher had no training in autism. The resource teacher was trained but was not in the classroom at all times. Mike adapted, learned and did surprisingly well in a class of 18 students, one teacher, a teacher's aide and part-time resource teacher. The students were accepting of him. He was promoted to first grade.

Mike's first grade teacher had no training in autism. She accepted him and did what she could to help. There were more bad days than good. Mike did learn but this was another adaptation. Full day school instead of half day. The kids were asked to be peer tutors and they wanted to help him. He couldn't adjust to having that many "bosses" so he would hide under his desk and cry, "They're bugging me!" He was sent to the office often when he couldn't cope and would start to cry. I had no idea what to do

and no one there offered any suggestions other than punishment. Some days he spent more time in the office than he did in the classroom. His frustration level increased, but through all of it, he still learned. He was promoted to second grade.

That year our district began a year round schedule, nine weeks of school, followed by 3 weeks "recess", two weeks of which could be used for remediation. The traditional year was offered but we chose year round to help prevent regression. Mike started second grade in July 1996 at a new school, new teacher, new part-time resource support. Again, the teacher had no training in autism. Second grade was a lot like first grade. Mike was frustrated, sensory overloaded, and had many crying episodes. New noncompliance issues emerged. He swore and cursed, kicked desks and had general screaming tantrums. I again didn't know what to do, expecting the school to know best. Many days the teacher called me and I would go over and spend time with him during recess, completing the work from that morning. Even though we went through a great deal of noncompliance, Mike learned. He could read, write and do math problems. He was promoted to third grade.

At Mike's ACR for third grade, the resource teacher suggested that we give him less resource support than he was getting. Since he did learn and was academically close to where he should be, why did he need the support? I was also told that if it didn't work out we could easily change it. This was the beginning of the worst year in Mike's academic career.

The new resource teacher had done her college thesis on autism. I THOUGHT this was a good thing. Now I look back and realize she was around 40. It had to have been at least 15 years since she'd done this thesis. I should have known. She anticipated, I think, a child who could not function normally, and probably did not understand why he was in a mainstream classroom. The classroom teacher was not trained in autism. I want to say, now, that I do not blame the classroom teachers. I fault administration for knowing it was required and for NOT enforcing the law. The teachers did the best they could. They had classes of students, usually around 18, many of which had issues. Mike was placed in Resource classrooms. These classes include students of many differing abilities and issues: some learning disabled, some could not read, others not understand math. The resource teacher was in this classroom part of the day to teach a subject and assist the classroom teacher. I personally think this is wrong. It is another way for the school system to save some money by giving all the special needs children their "time" all at once. Biggest bang for your buck! But who loses out? The primary reason of school is to educate. When we fail at that, we fail more than the system. We fail the children.

Mike had many issues that year. He cried, had tantrums, cursed, and was very non-compliant. I was trying anything I could think of. Mike had seen a psychiatrist since he was 6 or 7 and she prescribed his medication. I cannot remember what he was taking but I know two things were Prozac and Risperdal. The doctor had told me it was to control his hyperactivity, constant pacing and talking to himself. It hadn't worked very well but she said to wait and give it a chance. She also told me the average dose was 6 to 16 milligrams a day. Mike took 5 mg a day, one in the morning and 4 at night. I was concerned about medication but I thought if it helped him cope, then it was worth it. The doctor said, "If he was diabetic, you would give him insulin." No difference. I had gone shopping and found a prescription medication reference guide. I looked up Risperdal.

The first thing that struck me was "anti-psychotic agent". I had NO idea what this medicine was or what it was doing to my child. Safety and efficacy for children had not been established. Doses greater than 6 mg were not recommended for persons 18 to 60 years of age. My son was 9 years old. I was irate. Not only were there school issues, medical issues became the forefront. I began slowly backing Mike off the medication. I knew that to move up the doses we had to give him ½ mg more than before and wait 3-5 days before we increased any more. I did the same in taking him off the medication. I also put a call into a new doctor and made an appointment. At this point, the resource teacher began calling daily to report that Mike was having problems. She asked more than once what I had done to CAUSE this. I was offended and upset. I told them all that I was doing, whether it was changing his medication, or if had not slept well the night before, to keep the lines of communication open. I was often accused of not being a "team player". This, to me, meant I did not conform to what they wanted therefore I was not cooperating. I wanted to do whatever would help Mike. That was and still is my primary goal.

Mike's fall conference was horrible. His report card now had asterisks by most of his grades. *Modified curriculum. I was shocked. He was doing almost all the same work the other kids were, the modifications were for time. If the rest of the class had 25 math problems to do, Mike did 15. He did the same work, though less of it. I had no notice of this, no warning. The resource teacher also suggested that Mike be placed in the Moderate/Severely Handicapped Classroom. I asked if we could add more resource time for him. I was told that she just didn't have time for him, her schedule was too full, and she didn't think it would help anyway. After being in regular mainstream classrooms since kindergarten, he was being punished. Punished for being autistic.

The teacher in the Handicapped classroom had a background in autism. She KNEW how to deal with autistic children. This was the first time she had been notified that Mike was even in the building. I don't understand WHY she had not been consulted to help when problems occurred. I was told it was a matter of confidentiality, they couldn't discuss him with a teacher that wasn't on his case record. I was flabbergasted. They are there to do what is best for the child. Wouldn't it be in his best interest to get help from someone who has training in autism?

We had a mid-year conference that the director of special education for the township attended. I disputed their rationale that Mike didn't have the academic skills to stay in a mainstream classroom. They agreed to have him tested by a psychologist outside the school system. At this conference, we discussed Mike's behaviors: kicking, screaming, hitting his desk. The director said, "If he has those issues then he should be placed in the EH class (Emotionally Handicapped)." This class is for children who have been abused and neglected and act out irrationally without regard to who they hurt. There was NO way I was going to allow my child to be placed in an environment where he was more likely to mimic problem behaviors than cause them. It was decided that a 1:1 aide would be beneficial for Mike, though I was told that this wasn't an assurance that he'd always had one. "After all, if we give your son an aide, we'd have to give everyone who wants one, an aide."

Mike went through the psychological testing in the early spring. We continued to work on his behavior. I called an advocate from IN*Source who was available to come to the conference. The psychologist who did the testing of Mike also

attended. The main issues I wanted were teacher training (regular education teacher) and an aide. Mike was not capable of taking himself out of a situation when he reached the overload point. Sensory issues were looming large. The bus was a constant problem due to extreme noise, the jumble of many little squirming bodies in a tight space. He rode a regular bus with his peers. I wanted him to ride a special bus, not to attach stigma to him or make the other children more aware that he was different, but to help Mike. These children were aware that Mike was different. They didn't need to be told. They knew.

Many people attended Mike's ACR: the classroom teacher, the resource teacher, the advocate, the psychologist, the special education teacher from the Mod/Sev class, the director of special education for the township, speech pathologist, and myself. The testing had concluded almost the same results as the school's testing had. I disagreed with the results saying that a child with a communication disorder such as autism would have trouble with standardized testing that is language based. I was told IQ tests were accurate and that they had been used for hundreds of years with success. The advocate, the psychologist and myself all suggested teacher training. I had been told by the classroom teachers over the years that IF they had had the opportunity for training BEFORE Mike became their student, they felt their performance would have been improved and some of the problems minimized or removed entirely. The director of special education told me there was NO possible way we could have teacher training. "It was beyond the teacher's scheduled contract hours." "Why train a mainstream classroom teacher about autism when they won't SEE another autistic child for 10 to 15 years?" The advocate did nothing to sway their opinions and I had no idea that I did not have to sign an IEP that I disagreed with. I felt I was lucky to get an aide for Mike. It was the usual: fight but settle for less than what is recommended. Mike would be listed in the Mod/Sev classroom but spend most of his day mainstreamed. I asked for a small bus for him but was told if I was going to push for him to be mainstreamed then he'd have to be like the other kids and ride the regular bus. The only other thing I requested was that Mike be placed in a classroom that was NOT resource. If he had trouble, it would be him and not the other students that came first. I had won a battle but lost the war.

I had no idea at this time that the law stated the teachers had to be trained in autism. The special education teacher had training and I was told that if the other teachers needed help, they could go to her. If I were to go on the internet and download information on heart surgery, then read all I could find. Does that qualify me to be a heart surgeon? I see this as no different. Just because someone has given you a book or a bundle of papers to read, does NOT mean you're trained to do something. This is MY son. This is his education. It is very important to me. I feel he was slighted and missed out on help early in his education that would have been beneficial. You would not build a house on quicksand. My son's educational career has been built on something similar.

When we went to orientation for 4th grade, my son didn't have a classroom teacher. I was told because he was listed in the Mod/Sev class that he didn't need one. I had to go to the principal who was new to the school that year and ASK for him to be placed. I also had to tell them to put him in a classroom that was not resource. I felt they should have already known this and taken the necessary steps to make sure the IEP (individualized education plan) would be implemented appropriately. The classroom teacher was not trained in autism, but Mike did have an aide who worked under the supervision of the special education teacher. I was told that the ONLY way for Mike to

have a 1:1 aide was for him to be listed with the special education teacher as his 'teacher of record'. Mike was also allowed to ride a smaller bus because he was listed as a special education classroom student. I had been told at his conference that was not possible but due to an error in the transportation department, he was assigned a small bus.

Fourth grade went very well. Mike excelled in spelling and math, his two best subjects. The concepts became more abstract. Questions regarding why were difficult for him and still are. He understands the more concrete aspects of life. At the beginning of the year, I asked that the children be informed of Mike's diagnosis. This was not to draw him out and make him a martyr. This was to help the children understand why he behaved the way he did and why he had an aide to help. We did this while Mike's aide took him for a walk. The children were very understanding. That is the best thing that has come from this whole ordeal. I was always concerned about how Mike would be treated by his peers. From the first day of kindergarten the children are the ones who exceeded my expectations of help. The other children were told if they had any issues with Mike to talk to their regular teacher, Mike's aide, the special education teacher or myself, as I was in the classroom often. This was also the time that we explained to Mike was autism was. I explained that his brain functioned differently and that it did not mean he was dumb or could not learn just that he learned differently that most of the other children. Shortly after this, Mike was doing homework and said to me, "Mom, I can't do this because I'm autistic." I told him that "can't" was not acceptable and that he was able to do the work and I expected him to. He completed the assignment with minimal help and was proud. I wanted him to understand autism is not an excuse to get out doing things that he didn't want to do. It is just part of who he is.

We became connected to the Internet in early March. I found other parents online who understood what we were going through. Many of them had gone through similar situations and worse. This opened my eyes. Autism is not a US issue, it's a worldwide issue. Many other people had experienced the same things my family had. The difference is there are laws here designed to protect our children and to give them the opportunity for a "free and appropriate public education in the least restrictive environment".

I called our state department of special education and explained our problem with teacher training. I was told this is a "gray area" but that the law states that teacher training is required. I went to the ACR prepared to fight. Two things I wanted to know "why did he have to be listed in the Mod/Sev class to have an aide?" and "why did they NOT provide teacher training?" With my friends and the state department of special education behind me, I got the teacher training, though no explanation of why he had to be listed that way. The only thing I was told was that "due to funding" he could not receive an aide unless he came from that classroom. Again the almighty dollar rules. We had two IEP meetings because the teacher was not prepared for my stubbornness on these issues. The director of special education for the township had to be called in again to agree to my demands. He gave me the teacher training.

Mike started 5th grade with a teacher trained in autism. She had previous experience with another student with autism. She told me several times that she often forgot to call on Mike for answers because she forgot he was verbal. Mike did very well in 5th grade. He didn't have the same aide every day. They used several different aides from the Mod/Sev classroom so that he wouldn't get too attached to them and too

dependent on them. He was placed in a resource classroom again, they said due to the volume of students. I didn't argue because 4th grade had gone so well. I wasn't concerned, yet. His classroom teacher did not put up with any monkey business. She told him that if he acted out or caused a disruption, he would be removed from her class the same as any other child. This worked very well for Mike, as he didn't want to be separated from his peers. We had a new special education teacher in the building who didn't have a background in autism but was willing to learn. Overall it was a good year. The teachers and other students learned from him and Mike excelled academically. It was a positive situation.

This was a good thing because I had another child in the school system. My son, Josh, was going into kindergarten at the same time Mike entered 5th grade. I had concerns about Josh starting when he was around 2 years old. I didn't immediately address these concerns because he was not Mike's full biological brother, they had different fathers. I assumed that autism was not likely to strike our family again. I was wrong. I was pregnant with my third child when I became increasingly aware that Josh's speech was not appropriate to his age level. His behaviors were quirky and he had very poor social skills especially with children his own age. We were preparing to have him evaluated when he finally did start to talk. I put off the evaluation thinking the doctor was right and that Josh was just a late starter. Looking back I wish I hadn't. When he was 4, my concerns became greater. I called the special education office and scheduled an evaluation for him. Their findings were that although he was very intelligent, he was communication delayed, with some motor skill delays. This qualified him for services. I was told at this time that he did not meet enough criteria to be considered autistic.

Josh started preschool that spring, right after spring break. He did very well with the other children, and academically excelled. They worked on his speech and his sensory motor issues. He completed that year and went back for a second year, this one a full year. Since his birthday is in October he didn't qualify for kindergarten.

Josh's preschool teacher was the same teacher Mike had when he came to the district. To me this was a plus, she knew us and she knew autism. At the fall conference, I asked her if she thought Josh was autistic. I had watched him carefully since the evaluation and saw many things that pointed to autism. She was surprised that I would ask. I guess she assumed I already knew. She THOUGHT that autism was his primary reason for being there. I asked the district's office of special education for another evaluation to make autism his primary disability. I was told that the school psychologist was pregnant and having a rough time with that. She was unable to retest him at this time. I was also told there was no need to retest him since he had been tested only 6 months prior. I didn't force the issue, though I should have. There are many times you don't rock the boat just to maintain some semblance of sanity.

At Josh's ACR that spring, in preparation for kindergarten, I again asked for another evaluation and was told it was not necessary. I told them that would be fine because I would have an outside evaluation done. I asked for teacher training since that was a big stumbling block. They said they would give it. That it would be the same as Mike's, over the course of the school year. WHOA! Wait a minute! The teacher needed to know what to do BEFORE not make it retroactive. I realized then that even though I thought I won, I had not. I had to call the district's director of special education and DEMAND teacher training before school started. They complied but only because

shortly after Mike's ACR, the gentleman I talked to at the state department of special education had taken it upon himself to call the director of special education to see how our IEP went. He gets a gold star in my book. The training was a one-day seminar, 3-4 hours, with several different speakers. They spoke about how sensory issues such as the buzzing of fluorescent lights could overwhelm a child. It was very informative and both my husband and myself attended.

I met Josh's kindergarten teacher at the training seminar. I wanted her to be aware of where he needed the most help. He is bull-headed and stubborn (he gets it from his dad) but he can do the tasks required of him in kindergarten. He would swear, cry and have a general temper tantrum. I told her that being firm with him worked very well. I often wonder if she thought he had horns and a tail. The kindergarten class that year consisted of 27 children in the morning and 27 children in the afternoon. I was upset and asked that another class be arranged but was told it wasn't necessary, due to children moving out of the district. They finished the school year with at least 25 children in each class. The teacher had one aide and Josh had part-time resource help. This was his "least restrictive environment". Nowhere near the most productive environment for him or any of the other kids in his class.

This teacher called me many times to tell me Josh would not cooperate. She said she didn't know what to do. This is a seasoned teacher with over 20 years experience. I gave all the suggestions I could think of and again told her to call me if she needed me. I think THAT was my mistake. She called me a minimum of once a week and sent home notes periodically. Josh's resource teacher was only in the class for ½ an hour of his2½ hour day. The aide I had requested would have been very handy.

I remember vividly a phone call I received from her that spring. My father and his wife had come to help us fix our kitchen. The teacher called and said, "I know that Grandpa is here in town. Josh is very excited about that. He will not do what I ask. You need to come here and calm him down or take him home." This was shortly before spring break. Josh was in the background crying hysterically. Every time she called me, she did so in front of him. He is totally verbal and understood everything she said. This to me is a form of punishment and if she thought it would help, it backfired. Josh loved school and he wanted to be there. I went to the school that day. I took him to the special education room and even though she was not his teacher, she tried to help me. I did everything I could think of. Josh kept asking to go back to his classroom. I finally gave up. I walked him back down to get his coat and his backpack. Josh screamed and cried through the entire building. While I signed him out in the office, someone asked me if I was ok. I said, "No, how could I be?" I took him and left. On the way home I cried. Where do you draw the line?

Josh's resource teacher called me the next day to ask about his ACR. I asked about the situation and found out that she had not been called in to help with him at all. First line of defense had not been implemented. I'd had time to cool down and think. I told the resource teacher to make the classroom teacher aware. If she demanded I remove my child from her classroom again, I would sue. I spent the rest of the year biding my time until he would move on to 1st grade.

I had Josh evaluated by Mike's behavioral pediatrician. He diagnosed Autism/Asperger Syndrome. At his ACR, I told them he had been officially diagnosed

and they needed to change the paperwork. The change was made with little fanfare but great satisfaction, on my part. He was promoted to 1st grade with resource support.

Josh went to first grade with minimal trouble. He has done so well that the teacher asked me if I thought the resource help was necessary. Josh is now listed with resource help only on a consultant basis until needed. Academically he's above his peers. Socially he's learned a great deal, made friends and still likes school. His teacher is a velvet hammer: tough on the inside but soft on the outside. She is an excellent teacher for him.

Mike is now in 6th grade in Middle School. He has adapted very well. He still has a 1:1 aide. He still has modifications in his academic work. He changes classes, takes gym, has a locker and is basically like the other kids. He has had more behavior issues this year and more trouble with peers. Socially Mike is still very immature. If someone does something he doesn't approve of, he will tell them. The little Jiminy Cricket conscience voice is silent. He has become more aggressive with age and the onset of puberty. He was in a pushing match in the locker room after gym one day. He lost. I found out then that other boys had been teasing him for months but he hadn't told anyone. I am still not sure why. Academically he is on the Honor roll with A's and B's.

Last but not least, my youngest son, Matt, was 18 months old when I went for Mike's orientation of third grade. He was hopping and flapping his arms through the cafeteria. Someone said, "I see you have another one." Until that point it never occurred to me that he was autistic, though he is the most "textbook" of them all. He has very little speech, mostly echolalia. He flaps his arms and hands, hops, bounces, and wiggles his fingers in front of his face. He has poor eye contact. He has little or no social skills and is not toilet trained. I did not have him evaluated at that time, though I should have. There were many reasons but mainly because I was already so stressed out dealing with his brothers, I didn't have the energy for another battle.

I scheduled an evaluation for him through the school district in the fall of 1998. This is seven years after Mike started in public school. They told me that we could test him as early as August, but he wouldn't be able to receive services from them until his 3rd birthday. Many changes had taken place in that time. I waited for another reason. My mother was diagnosed with terminal cancer on July 2, 1998. She died two days after Matt started preschool. The reason I include this is not for pity. It is to show that my thought processes weren't clear. When I filled out Matt's paperwork for preschool, I had the wrong birth date on a lot of forms because I couldn't remember which one was which. They could have sent me on a slow boat to China and I probably wouldn't have known the difference.

Matt has had different issues from his brothers. He is not high functioning. He is moderately autistic, evaluated by the behavioral pediatrician in January, 2001. He is a compliant child. He is very happy and playful most of the time. Matt shows many autistic behaviors. His sensory issues loom large. His hearing is extremely oversensitive while his sense of touch (tactile) is less sensitive than normal. I continue to push for him the same way I do with his brothers. I only want what is best.

The only disagreement I have with the school is their classification of him. He is listed as Moderately Autistic, Moderately Mentally handicapped because he cannot follow their language based tests. I disagree that he is mentally handicapped because autism is a communication disorder. The only reason I see for them adding that to his

paperwork is funding. The school district gets more money for a child that is multiply handicapped than a child with only one handicap. They're out for every last dollar.

I feel that school districts do not comply with IDEA for one main reason: MONEY. They don't tell parents about the services their children could and SHOULD receive because it costs money for personnel, classrooms and supplies. The teachers are under-staffed, over-worked and the CHILDREN are the ones who suffer. The special education students already have the short end of the stick. This just pushes them off with splinters. Funding seems to be the root of all situations, no matter how large or small.

Accountability is another issue. It appears that the districts have no one to be accountable to. They receive money for children with disabilities from state and federal government. I would like to know WHERE the money for them is spent. My son, Josh, is not using any more resources than an undiagnosed or a neuro-typical child. Where is the money the school receives for marking him as autistic going? If the kids that are currently in the system aren't getting the services they NEED, the bigger projects should wait. Over crowding is an issue. Why must the special education students lose services or get poor quality of services so the school district can build a new gymnasium/natatorium 'for the community'?

Why do the parents have to fight so hard and go through stress in addition to the usual stress of having a child who is handicapped? I have had to tell total strangers more about my family, income and life than I care to. If I question why they need this information, they get defensive. When I question why the Social Security Administration uses the gross and not the net income to figure the amount my children can receive, I am told we are not NEEDY enough.

My husband and I have been told to divorce in order to receive more services from the state. We have been told to NOT work. We are supposed to stay home and do nothing. I am not willing to do this. If it means I continue to fight, then that is my choice.

I am not asking for handouts, a free ride or anything of the sort. It was MY choice to have children, though I did not choose to have children with disabilities. I love them just the same. These children can become productive members of society with encouragement, patience and assistance. If we help them when they're young, we can build on a strong foundation.

My children cannot get private insurance. They are automatically denied due to autism. Group insurance policies only cover partial services with a low spending cap, opt out of covering autism altogether due to "clauses", or raise the premiums so high that working parents cannot afford them. My children all take medication to control behavior. Without medication, my children cannot perform to their potential and in some cases, could be suspended or expelled for inappropriate behavior. I don't want it to come down to that.

Help us make education a service that we give to our communities without the barriers that currently exist.

Mr. BURTON. Ms. Antenellis.

Ms. ANTENELLIS. Yes.

Mr. BURTON. Would you like to address the committee?

Ms. ANTENELLIS. Sure.

Ms. ANTENELLIS. First of all, because I couldn't bring him for our sanity, I brought you a picture of my son Connor. My story is probably very similar to other stories——

Mr. BURTON. How old is Connor?

Ms. ANTENELLIS. Connor is 6 now. But I'd like to thank you and the committee members for inviting me here to testify. I believe that my experience as a mother of an autistic child, and now as a provider of services for autistic children, will give you information that will help you make some changes. The main reason I have come to Washington is a simple one: to encourage the special education system to provide access to Applied Behavior Analysis for young children diagnosed with autism.

My story is one of a legal battle with the educational system that turned out to be the ultimate success. Depending upon whom you talk to in my town, I'm either a tireless advocate for my son or the mother from hell.

My son Connor's story is very typical. He had a very normal early childhood, and at 16 to 18 months lost all his skills. He lost his eye contact, he lost his language. He started to abuse himself and gouge his eyes. At that time I was told there was a 75 percent chance he would never speak and an 85 percent chance he would be retarded, but I was determined that Connor was not going to be one of those odds.

I pressured the Department of Health in our Early Intervention System to provide us with an ABA program, which they did do. In 9 months Connor made over 15 months' gain. When he started ABA he had a 7-month speech and a 10-month cognitive level and he was 27 months old. So he was 15 months behind in all levels. At the end of 9 months he had gained a minimum of 15 months in almost all areas and was able to be back in our world. If I called his name, he said "What?" He came to me, he was able to understand things that I asked of him, when a year before the house could burn down and he wouldn't get out, but he could hear a Cheerio drop at 50 paces.

I began the transition to the school system about 6 months prior to his third birthday. It was my understanding that the school system would provide Connor with a program that would help him achieve his maximum feasible benefit, and that was Massachusetts standards at the time. I was mistaken. The school system felt it had to offer only what they deemed was an appropriate placement. It did not take into account the recommendations from the medical professionals from Children's Hospital nor the progress that he had made under his current program. They felt they knew better than anyone else what Connor needed.

They did offer an integrated classroom program but it lacked the learning tools that had been so successful for Connor. He was entitled to an education that would ensure he would reach his maximum potential. That meant he needed his school program supplemented with an ABA program. Then began a 3½ month battle with the school system.

As a credit to the school system, it did continue his ABA program while we negotiated services. On a personal level, it was the worst 3 months of my life. I lived in fear that they would take away the services Connor so badly needed. Without these services, Connor would regress and never make the strides he had the potential to make. I truly felt as if I was in a fight for my son's life and his future. It seemed to me as if my son had a form of cancer and ABA was the chemotherapy that would cure it. What right did the school system have to deny him the services that had proven so successful? Of course, it all boiled down to cost and not the best interest of my son.

I tried to negotiate with the school system on my own but got nowhere with them. I couldn't afford to hire a lawyer but in the end, to get the services needed, I got legal representation. The battle was finally settled in mediation, one step short of a formal hearing. The school agreed to provide 12 hours of ABA, down from the 20 he was receiving. I accepted it because I knew I couldn't afford more. In total, I paid over $5,000 in legal bills. This was my own money, spent to obtain the services that my child should have had from the beginning. In addition, I supplemented out of pocket for an additional 2 years, the ABA services that the school system did not provide.

When the dust finally cleared, Connor had a good program. I felt that I had done the best within my powers and financial limitations to provide what he needed. The program stayed in place for 2 years, and Connor made gains which can only now be considered phenomenal. It is clear from the evidence that the education provided works.

Today, Connor is a success story. He turned 6 last month. He has defied all odds, and today he reads at a 10-year old level, has an above age level vocabulary, has no self-abuse behaviors, and has his first best friend. Remarkable for a child who had a 75 percent chance of never speaking and an 85 percent chance of being retarded.

Does he still have issues? Yes, but we're working on them. Will he ever be cured of autism? No, but he will be able to function as an active and productive member of society, probably making more money than I will.

I credit much of Connor's success to the hard work he has done and the constant vigilance that I keep on his program. I go to the school once a month. I watch his classroom, I watch his teachers. The minute they are out of line I'm on them. They don't have an option not to answer to me.

But I also see in the system the other children in his classes don't get that. No other child in the school system diagnosed with autism, some as severe or worse than Connor, they don't get the services. And when they ask me how I got them, I said I fought for them. They have no idea how to even begin. I have never seen a child go to a school system and be offered ABA. I actually had a special education director once tell me, we provide services for early intervention now through the State of Massachusetts, and he wrote to me and said, what will my money buy me? Not what's in the best interest of the child or how can your services help me, but what will it buy me.

And I think the long run of IDEA is that we either pay for these children now or we pay for them for the rest of our lives. If these children can't make the gains when they're young and they're early—and as you know, autism is not an easy disability—we will pay for them when we're long gone, and society will pay much more than the 40 percent that you talk about now. And the only sort of disheartening thing that I heard today is that 40 percent hopefully by the year 2010. Well, by 2010, Connor will be almost graduating from high school. I really hope that it will be within your power to fund that sooner so the children that are there and in the system now can get what they really need.

Thank you.

[The prepared statement of Ms. Antenellis follows:]

Testimony to
Government Reform Committee
For hearing on
Special Education – Is IDEA Working as Congress Intended?

Wednesday, February 28, 2001

CONNOR'S STORY

Representative Burton, Members of the Committee, thank you for your invitation to testify here today. I believe that my experience with the special education system both as a mother of an autistic child and a provider of services for autistic children will give you valuable information for your committee. The reason that I have come here to Washington is a simple one. I want all children diagnosed with autism spectrum disorder to have access to an educational program that has **Applied Behavior Analysis (ABA)** as a core component. My story is one of a legal battle with the educational system that turned out to be the "ultimate" success story. Depending on whom you talk to I am known as a tireless advocate for my son or the "mother from hell".

I am sure that my son Connor's story is typical to other stories that you have heard. He had a normal early childhood and lost all of his skills including eye contact, communication, language and ability to relate to his world at about 16 – 18 months. At that time the prognosis offered was not a happy one. I was told that there was a 75% chance that he wouldn't talk and an 85% chance that he was mentally retarded. I was determined that Connor would not become one of those statistics. I embarked on a journey to learn what would be best for my son. After research and much pressure to our Early Intervention Program, my son began an intensive program of **Applied Behavior Analysis (ABA)** at 27 months of age. At this time he was functioning at a 7 months speech level and 10-12 month cognitive level, a minimum of at least a 15-month delay in all areas. He scored in the severe level on the CARS rating scale.

The method of Applied Behavior Analysis we used is a learning approach where skills are broken down into small steps and taught until the child masters each skill. They then learn to maintain the skill and generalize it over different environments with a variety of people. Skill acquisitions are positively re-enforced and errorless teaching is used. It is both time and labor intensive, but my experience has shown it to be the one method that has had the most success for Connor. Although ABA has been shown to be very effective for use with autistic children, it is costly. It has been my experience that it is the cost of these services, not the service itself, that school systems is opposed to. The needs of the child, not the cost of the service should be the overriding factor in decisions.

Connor received 20 hours per week of **ABA** therapy for 9 months until he turned three in January of 1998. Within that time period he developed language, was able to communicate, began to play, learned some basic self-care skills and was able to understand and relate to the world around him. He gained well over 15 months of skill

acquisition in many areas in this time period. Although still far from a typical child, he was no longer in his own private world to which we had no access, but a participant in our world on a daily basis.

I began the school transition process about 6 months prior to his third birthday. It was my understanding that the school system would provide an education that would allow Connor a program with the standard of "Maximum Feasible Benefit" (Massachusetts standard at the time). I was mistaken. The school system felt that it only had to offer what it deemed was an appropriate education. It did not take into account the medical recommendations of some of the leading medical personnel in the field, nor the progress that he had made under his current program. The school felt they knew better than the experts and refused to continue ABA services through which Connor had thrived. They did offer a good integrated classroom program but it lacked the learning tools that had been so successful for Connor. Connor was entitled to an education that would insure that he reach his maximum potential. That meant he needed to have the school program supplemented with an **ABA** program.

Then began a 3-½ month battle with the school system. As credit to the school system, it did continue his **ABA** program while we negotiated additional services. On a personal level, it was the worst three months of my life. I lived in fear that they would take away the services that Connor so badly needed. Without these services Connor would regress and never make the strides that he had the potential to make. I truly felt as if I was in a fight for my child's life and his future. It seemed to me as if my son had a form of cancer and ABA was the chemotherapy that would cure it. What right did the school system have to deny him the services that had proven so successful? Of course, it all boiled down to cost and not the best interest of the child.

I tried to negotiate with the school system on my own, but got no where with them. I couldn't afford to hire a lawyer, but in the end, to get the services that Connor needed I secured legal representation. The battle was finally settled in mediation, one step short of a formal state hearing. The school agreed to provide 12 hours of ABA (down from the 20 he was receiving). I accepted the IEP because I could not afford to keep up with the ever rising legal bills. In total, I paid over $5,000.00 in legal bills. This was my money spent to obtain the services that my child was entitled to by law. In addition I supplemented out of pocket the additional hours of **ABA** that he needed over the next year.

When the dust cleared, Connor had a good program. I felt that I had done the best within my power and financial limitations to provide the services he so desperately needed. This program stayed in place for 2 ½ years and Connor made gains that could only be considered phenomenal. It is clear evidence that special education when provided in the best interest of the child, does exactly what it should do. It gives children an education that will help them succeed and achieve, not just maintain.

Today, Connor's life is a success story. He turned six in January. He has defied all the odds and succeeded. His success happened because he was provided with the appropriate education. Today, Connor reads at a 10 year old level, has an above age level

vocabulary, has no self-abusive behaviors, and has his first best friend. Remarkable for a child who had a 75% chance of never speaking and an 85% of being retarded. Does he still have issues? Yes, but we are working on those. Will he ever be cured of autism? No, but he will be able to function as an active productive member of society, probably making more money that I will.

I credit much of Connor's success to the hard work he has done and the constant vigilance that I keep on his educational program and services. Much of the credit goes to the professionals who have tirelessly helped him along his journey back from the dark side. But I truly believe the main reason for my son's success is that he had access to an intensive ABA program at an early age. Research indicates that tremendous gains can be made for young children when they are provided with ABA early and in an intensive manner. I only hope that my testifying before you today will help other families receive ABA services for their children.

Since I believe so strongly in the educational services that Connor received, I have moved in that direction on a professional level. I am currently the program director of a company that provides ABA services for early intervention programs and school systems. In every instance I see young children making huge gains when provided with these intensive services. In the state of Massachusetts these services are provided at no charge to families until the age of three. After the age of three it then becomes the responsibility of the schools to provide services. It is like a train wreck waiting to happen. Prior to age three all the services are in place, the children are thriving, and at age three it is all taken away. In all of my experiences, never has a school system offered ABA as part of a program for an autistic child without firm pressure from the parents or legal intervention. I truly believe that it is the cost of such a program, rather than the program itself that prohibits it acceptance as an educational methodology. I recently received a letter from a special education director who asked, "what exactly is my money going to buy me". So much for the best interest of the child, it is all about money. In the short term, not offering a program that has shown to be successful, but costly will save money. In the long run, our society as a whole will bear the burden of supporting these children as they age. They will not be productive members contributing to the greater good, but rather by bystanders draining it. Is it not better to spend the money now and provide the resources that special education was designed to, then to support people for the rest of their lives?

Taking into consideration the ever rising number of children diagnosed with autism spectrum disorder, it is incumbent upon our education system to provide these children with an education that will help reach their full potential, and not require parents to fight for it every step of the way. I thank you for your time, and on behalf of parents all over the country, please find a solution so that children with autism may receive ABA as part of a special education program to meet their needs.

Respectfully submitted,

Patricia J. Antonellis
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Mr. BURTON. Before we go to our next witness, let me just say that I agree with you, and we ought to move as fast as we possibly can, and you may rest assured that we will. And I personally apologize to every parent that has a child with a disability, because I was ignorant of the facts until it happened to me. That's one of the big problems that we face: Do we have to wait until we're hit in the face with a shovel before we realize the need? And I plead guilty to that, but we are going to do our best to rectify that. And I know Ms. Schakowsky and others feel that way as well, because you're absolutely right, if these kids who are autistic and who are disabled now, for whatever cause, if they're not helped while they can be helped, they will be a huge burden on society later on and we will pay a great deal more than we'll have to if we don't deal with it right now.

Mr. McDowell.

Mr. MCDOWELL. Thank you, Mr. Chairman. And I also appreciate being sworn in today rather than being sworn at, which seems to be the experience of State agency personnel.

My name is Kevin McDowell. In 1972 I was drafted into the Army.

Mr. BURTON. You're from the great State of Indiana.

Mr. MCDOWELL. Great State of Indiana and also the Sixth Congressional District.

Mr. BURTON. Yes, and I think I talked to one of your compatriots at the agency today, if I'm not mistaken.

Mr. MCDOWELL. Pardon me, sir?

Mr. BURTON. I think I talked to one of the people at the Department of Education today. That's where you work; is that correct?

Mr. MCDOWELL. Yes I work for Dr. Suellen Reed. I'm the general counsel for the Department of Education.

Mr. BURTON. Yes.

Mr. MCDOWELL. In 1972 I was drafted into the Army, that being the only lottery that I've ever won, but as I left the Army, I found myself in Fort Gordon, GA, which is near Augusta, which is the mecca for all golf. But for those who are literary-minded, that is also near Wrens, GA, the birthplace of Erskine Caldwell who wrote Tobacco Road and God's Little Acre. And there's a stretch of road that runs for 20 miles from Augusta to Aiken that's called Horse Creek Folly; has a road, but most of the roads are unimproved and the people poverty stricken. And my first teaching job was with delinquent children, extreme poverty, under a Title I program that was in place at the time.

From there I have had the opportunity to come back to Indiana to teach both in institutions with students who had emotional disturbances—at that time autism was not a separate category, it was included with emotional disturbances—both in institutions and in the public schools and in the private schools.

And from that time for the last 15 years—I was in private practice as an insurance defense lawyer—and the last 15 years my responsibilities have been with the Department of Education and its 28 divisions and offices, not the least of which is Special Education.

As I indicated in my written testimony, during those years I have observed a number of different things, not the least of which is that parents of students with disabilities tend to go through the

same stages that Dr. Elizabeth Kuebler-Ross described as those who come to grips with a terminal illness. And I hate for that to sound so ghoulish or Draconian, but you will find that is the case. And that was my observation then and it was my observation in 1985 when I found out that my own daughter had autism. It was a surprise, and thus became an odyssey that brought to bear many of the experiences I had already had dealing with families of children with significant disabilities well before that had ever occurred.

That is mostly an irony. It's not the reason for what I do, because I would have done what I'm doing today anyhow. But there are a number of different things that have occurred over time, and certainly Public Law 94–142 which Mr. Chairman mentioned at the beginning, and its progeny, including the reauthorization in 1997, have been major laws that have provided services that would never have occurred at all, and it's not because there are people out there who are not well intentioned. They are. But sometimes some things do need to be done in order to benefit the whole.

However, that does not mean that the law itself does not have areas that require some tinkering, for want of a better term. And, Mr. Chairman, the list you gave me was a number of different areas that you wished for me to address and I will, very quickly. I will not elaborate upon the written testimony I gave you, but it does serve as the basis for some of the comments I do have today, including addressing your concern about the empirical data that needs to be collected, which I also notice that Patty Guard will be later testifying about what efforts there are in this regard.

To go through the list of questions that were posed to me, you want to know if schools are following Federal laws and providing a free and appropriate public education. There are some things that I will bring to your attention now. I'm not going to list every single thing that I see in my office that prevents this from working as it should, because to do so would require me to put all of my "begs in one ask-it." And I think maybe it might be a better situation that later on as you move into more specific areas, my office would be more than happy to provide you an abundant amount of information regarding all these different issues, including the legal analyses in transit we identify that's on our Web site, which is also a part of the written testimony that I gave you, some things that are occurring that are preventing parents from working together with schools, things you would not imagine.

For example, a number of schools enter into collective bargaining agreements that restrict the meeting of IEP teams to contract hours. That means that if a parent wants to have an IEP team meeting, whatever it may be called from State to State, they can only meet during contract hours, not before and not after. Makes no difference if you're a single parent that has a job and if you miss one more time you're going to lose your job. These IEP meetings occur right now, and I'm sure that some of the parents can tell you they have had those experiences. Some of the administrators have likewise had those. We don't know those occur until they come to us.

Other provisions in the collective bargaining agreements restrict who can make decisions about grade placement. Well, that's an IEP team decision. That raises an issue. Some give it solely to the stu-

dent's teacher. And you also have the other problems that have occurred in those areas and that we heard one today about the kindergarten teacher. The kindergarten teacher has to agree to take a student? You know, that does—unfortunately, that sounded like an Indiana case, and we actually have had some situations where when we found them out we have corrected them.

That is not how it works. You don't ask someone whether or not you take a student into your classroom in that stint; but on the other hand, that teacher needs to have specific training, not just in autism, because autism's not a very good descriptor. You have to have training in how autism is manifested in that student. That is not a good descriptive. In fact using the term "autism" is not. And that's why in our rules implementing them under disorder, to cover them all, so that schools and parents will make decisions based upon the need for educational services, because there are some conditions that adversely impact educational performance; because if we just use the term "autism," the student with Asperger syndrome down here is not under autism as that's defined in the DSM-IV. It's not. And so you get this problem; school officials say, well, it's not autism because it's not in the DSM–IV, therefore, they don't need services. Not right.

And we've told schools before that when we talk about educational performance, and I give 35 to 40 different presentations in Indiana alone every year to all these various groups, there's a number of things I stress to them. Educational or academic performance is not the only concern.

In Western culture we certainly prize academic performance, but we prize social adeptness more than we do academic performance. And that may sound strange. I've been teaching for 27 years, and those who have taught and those who have observed know that if you're socially adept, a multitude of sins and transgressions will be forgiven. But if you have ineptness, that sets you apart, no matter how gifted you are in other areas. So it's not just academics. That's not the sole determiner.

As far as legal costs involved in resolving disputes and who pays those fees, I think you heard from Mrs. Brown today. What she described was our extraordinary funding system that we created in Indiana where we will wrap services around a student so they don't have to go to residential facilities; but the school has to demonstrate to the State that there is educational justification for that service. That educational justification is in the student's individualized education program, the IEP. They didn't put it in Mrs. Brown's IEP. And what happens, we wrote our rules in such a way as to say, Schools, if you don't put it in your IEP, you may be responsible for the cost of that service. You need to justify it.

That's born out of a class action lawsuit that schools initiated against us—unfortunately, litigation is one of the things that I have to do—so we made sure that we put that in there so that we don't have people who are trying to pass services along that they don't agree with. But rather than discussing that with the parents, they try to pass it along to the State and then make the State look like a bad guy, which is pretty much what happened in Mrs. Brown's case.

She can certainly give you her own rendition of it.

As far as attorneys' fees, the attorneys' fees provision in IDEA is not really encouraging a lot of attorneys to go into this area. As a result, parents do not have available to them competent counsel who can help them.

I realize a lot of people say, maybe we should keep the attorneys out. I'll tell you right now, as an attorney who represents a State agency—and we get involved in these hearings a lot—I would much rather have the school and the parent being represented by counsel who understands the law. But unfortunately the way the funding has been set up over the years, protector advocacy, LSO and a lot of the other services like that cannot handle these cases anymore. As a result, they really are not available to parents, competent counsel. If you have competent counsel, these things typically don't go to hearings.

Mr. BURTON. Mr. McDowell, I don't know how many questions the staff has sent to you.

Mr. MCDOWELL. They sent me two pages full of questions.

Mr. BURTON. Did they? Were they answered in your statement?

Mr. MCDOWELL. Not all of them, because I needed to know what data was sent to you from our Division of Special Education. For that—we coordinated that together. I realize that I've gone over time.

Mr. BURTON. That's OK. Could we do this? Could we go to Ms. Bristo? And the questions that you think are relevant and we need to talk about—and we will be asking you questions in just a few moments—maybe we could get back to that.

Mr. MCDOWELL. Sure. Yes, sir.

[The prepared statement of Mr. McDowell follows:]

TESTIMONY BEFORE THE

HOUSE COMMITTEE ON GOVERNMENT REFORM

FEBRUARY 28, 2001

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VITA

Kevin C. McDowell is the General Counsel for the Indiana Department of Education. As such he is the Director of Legal Services for the Indiana State Superintendent of Public Instruction, the Indiana Department of Education, the Indiana State Board of Education, and the Indiana Board of Special Education Appeals. He also edits Recent Decisions and **Quarterly Report**, two publications of the Legal Section. He graduated from Butler University in 1972 (B.S., Journalism/Mass Communications). He received his M.S. in Education from Butler University in 1977 with an endorsement for teaching students with emotional disturbances. He received his J.D. from Indiana University (Indianapolis) in 1981. He served in the U.S. Army from 1972 through 1974, receiving the Army Commendation Medal. Mr. McDowell also has worked as a journalist and photographer; authored a number of television scripts; written numerous articles on issues affecting education and religion; taught English (American, British, and World Literature), mathematics, and journalism; coached cross country and track at both the secondary and collegiate levels; and represented clients as insurance defense counsel. He has contributed to textbooks on English usage and, most recently, to a textbook regarding assistive technology and technology devices. He recently received achievement awards from the Indiana Association of School Psychologists; IN*Source, a parent-training organization; and a "Bell Ringer" citation from Dr. Suellen Reed, the State Superintendent of Public Instruction for contributions to education in Indiana. He has also been recognized as a Paul Harris Fellow and has been designated a Kentucky Colonel.

He is the Chair of the National Council of State Education Attorneys (NCOSEA), an affiliate of the National Association of State Boards of Education (NASBE). He is also a member of the Indiana State Bar Association.

He is married to Susan L. (Roesch) McDowell, an Autism Consultant. They have two children: Liesl (17 years old) and Gavin (15 years old).

I greatly appreciate the opportunity afforded to present testimony today regarding the delivery of services to our students with disabilities. I am encouraged that not only this Committee has expressed a positive attitude and encouraged a constructive approach to improving services but that House members are forming a bi-partisan Coalition for Autism Research and Education (CARE) Caucus to promote discussion, knowledge, investigation and funding of issues affecting persons with autism. The contact letter from the Committee indicated a desire not only for statistical data but for a more personal perspective on how such services can be enhanced.

You Can Never Really Know Someone Else...

Charles de Gaulle was something of a mystery to most Americans. His image here is not particularly a positive one. He is sometimes characterized as buffoonish and boorish, especially after his unfortunate remarks in Quebec regarding self-determination. This is the historical personage.

But as any person is, de Gaulle was much more. His daughter Anne, born in 1928, was severely retarded from birth, and required constant care. Her language never developed fully; she could neither clothe nor feed herself. General de Gaulle–always aloof in public–spent every available hour entertaining his daughter, playing and teaching her games, working with her. At night he would hold her hand till she fell asleep. In 1948, Anne died of a lung ailment. At her grave site, de Gaulle turned to his wife and said, "Now at last our child is just like all children."

The Experience of Being A Parent of a Child with a Disability

The Committee asked for some insight as to what special problems parents of children with autism face. I have been involved in education for nearly twenty-seven (27) years, teaching students with special needs and students adjudicated delinquents, as well as more traditional students. I have had the opportunity to teach students who were institutionalized as well as students in public and nonpublic schools. Over the years, I have observed some commonalities.

Dr. Elizabeth Kubler-Ross is noted for her description of the five stages that a person experiences when coming to an understanding of a terminal illness, if such an understanding occurs. Oddly, these same five stages seem to apply to the parents of a child with a disability, especially a disability such as autism that for so long has been greatly misunderstood. As the patient with a terminal illness, parents will move through these stages at different paces.

Denial. This is often accompanied by a degree of shock. Most people have little understanding of autism. Popular portrayals leave many people believing that persons with autism range from severely withdrawn, possibly self-injurious individuals engaged

in meaningless repetitious activity to those who display savant abilities, such as rapid calculation and the ability to play a musical instrument. These portrayals serve to deny the essential humanness of persons with autism. Early identification of autism is difficult. Parents usually note that certain developmental milestones are not being met. However, this may be masked by the child's displaying of other abilities, possibly precocious ones. At some point, it becomes apparent that something is "not right." Thus begins the journey that no parent forgets: the pediatrician who has little familiarity with autism and little, if any training but attempts to caution the parent that institutionalization may very well be in the child's future; the referrals to neurologists, neurosurgeons, and psychologist; the "evoked potential" tests, the discussion of shunts, the CAT scans, the battery of psychological tests; and finally, the painful diagnosis. There is no painless or perfect way to reveal such a diagnosis to a parent. The initial reaction is inevitably denial. There must be a mistake.

Anger. This may last for many years and carry over into the school environment. A child with autism is not a typically developing child. Parents often have to endure uncomfortable situations in teaching their child with autism the social necessities for such things as eating in a restaurant, attending a movie, participating in church or temple services, and many of the other functions a family wants to—and needs to—do. There is a tendency to withdraw from social functions, friends, and family, which is usually accompanied by a tendency to become overprotective. Many marriages do not survive this strain, which then tends to exacerbate the withdrawal and the overprotectiveness. The tendency to overly protect one's child can result in unfortunate situations within the school context. Anger can be directed at those who are perceived as possibly threatening the child or the child's welfare. Anger is often directed at an "unjust" God and one's self.

Negotiation. This phase is sometimes characterized by a yearning for something that is not and never will be. It is the beginning of a reflective period. This is a "quid pro quo" time. There may be intense sadness, fear for the present and especially the future ("What will happen to my child when I am gone?"), guilt, and yearning. It is also the beginning of a searching process.

Resignation. This can be a painful time. Acceptance of the diagnosis of autism is often associated by the grieving parents as somehow failing their child. This is a period of some disorganization, but it is also the period when the parents realize that it is time to get on with living, although enthusiasm is somewhat lacking. There is a need to evaluate the family situation, begin to make difficult decisions (such as whether the parents should have more children), and begin to learn different ways to manage life as a family.

Acceptance. For those parents who reach this level, the autism becomes less a reality and their child becomes more "real" in every sense. There will still be some sadness, and fears for the future never leave; but the parents learn that this is a child that not only can

be loved but can be loving. This is a child of amazing abilities. This is a child who does not complicate the truths and realities of life with rationalizations. This is a child that they would not trade for all the world.

Imagine our surprise when my wife and I were informed in 1985 that our daughter had autism.

Recommendation: No one misunderstands autism more than insurance companies, who treat autism as a mental illness. Diagnosis and treatment of autism is routinely excluded under the typical insurance policy. This forces medical service providers to resort to less-than-forthright practices, such as masking the diagnosis and treatment as one for a condition that is covered, usually mental retardation. This only adds to the stress the family is experiencing. However, the alternative is to assume inordinate expenses for evaluations, hospitalizations, and prescription medications. Evaluation, diagnosis, and treatment of autism should not be category excluded for coverage under insurance policies.

The School As A Community

In any given school building, there should be a "community." This community should interact with the various communities where the students and school personnel reside. Although "school climate" is affected to a great extent by building-level and district leadership, the achievement of the essential educational function—or the failure to achieve same—is more often the result of other factors, such as lack of school readiness, extreme mobility of the student population, unstable or inadequate familial relationships, and a number of other factors that, although real, more often are used as excuses rather than reasons. A chief inhibiting factor is the current result from four decades of reorganization and the attendant "economies of scale."

In any given school building, there will be a continuum of abilities. For the sake of illustration, such a continuum would have at one end students with significant cognitive involvement (for the sake of illustration, this will be designated as "S/P" for severe and profound impairment). At the other end of the continuum would be students who demonstrate high academic achievement (for the sake of illustration, this will be designated as "G/T" for gifted and talented).

ABILITY CONTINUUM

S/P _____ **G/T**

An effective school community will have recognized several realities. One is that Western culture values academic achievement. But it values social adeptness to an equal if not greater extent. A multitude of sins and transgressions will be forgiven the socially

adept individual. The same cannot be said of one who is perceived to be socially inept, no matter his level of academic achievement. Another reality is that education, to be effective, should not only place emphasis on a student's benefit from being a member of a school community but the student's responsibility to contribute to the school community. This dichotomy can be illustrated thusly:

BENEFIT
CONTRIBUTION

The experience has been that in most schools, the more disabled one is considered, the more emphasis is placed on "benefit" with "contribution" presumed somehow. As one moves the other direction along the ability continuum, the more emphasis is placed on "contribution" with "benefit" presumed. In either direction, the dichotomy becomes imbalanced and the students lose. The students who are considered approaching or at the S/P end of the continuum can contribute to the school community. It takes conscious decision-making to ensure that this occurs, but it can occur. For students approaching the G/T end of the continuum, more emphasis must be placed on their realizing benefit from the school community. Teaching is a conscious effort.

However, the "economies of scale" over the past four decades have resulted in far too many elementary, middle, and high schools that are too large to ensure that each student benefits and contributes to the school community. There is a "point of diminishing return" not only in economic theory but in educational practice. If school personnel are not able to know who their students are, how can they ensure each student has the opportunity to benefit and contribute?

Recommendation: There is more than sufficient data that indicate the maximum student enrollment for elementary, middle, and high schools. If federal funds are to be allocated for school building construction, these funds should require that student populations be within an acceptable range that will enable teachers and other school personnel to ensure, to the extent possible and appropriate, that each student benefits from and contributes to the school community...and that each student have the opportunity to be known. For government and other policy makers, greater effort must be made to identify and rectify those elements of laws that serve to inhibit the necessary working relationship, especially for students with disabilities.

Resources and Resourcefulness

The story is likely apocryphal, but it is still instructive. A principal at a middle school found herself having to address the latest aggravation that middle school students are so adept at devising. Middle school girls had learned that it creates quite an impression to put on lipstick and then leave lipstick prints on the mirror. The principal tried everything to bring this practice to a halt. There were homeroom announcements. There were

posted warnings. There were observations of the girls' restrooms with increased surveillance by faculty. This was all to no avail. Finally, the principal invited to her office several girls that were considered as leaders in the school. Of course, all protested their innocence and their lack of knowledge regarding the perpetrators of these transgressions. The principal assured them that she was not accusing them of any untoward activity. She merely wanted to have them witness a demonstration. Accordingly, she had the girls accompany her, along with the custodian, to a nearby restroom where, of course, there were fresh lipstick prints. The principal asked the girls if they were aware how difficult it was to wash lipstick off the mirrors. They all remained silent. The principal then looked to the custodian and asked him to please clean the mirror. He dipped his mop in a nearby toilet and proceeded to wash down the mirror. From that day forward, there were no more lipstick prints.

This is a somewhat graphic depiction of another truth in education: We are more often limited by our lack of resourcefulness than our lack of resources. I have found this to be the case in special education, especially with respect to students whose disabilities are defined more in medical terms than educational need (i.e., autistic, other health impaired, and traumatic brain injured). Teacher licensure in these areas is questionable: Students within these exceptionality areas are more diverse than any of the specific educational diagnoses. Their abilities are spread across the continuum. The better educational programs for students with such needs are influenced to a great extent by the resourcefulness of the participants, both teachers and parents. Sometimes solutions can be discovered from the experiences of the participants, or by the culmination of experiences within a school community. As a recent example, several students with autism were enrolled in a nutrition class. The lesson plan called for the use of the microwave oven. The microwave oven does not give off the typical sensory warnings a more conventional oven will. As a consequence, the students did not realize that the food to be retrieved from the microwave will be too hot to handle. The teacher's solution was to use an egg timer. When the microwave ended its process, the door could be opened and the egg timer employed. After its usual three minutes, the food was usually able to be handled.

Another student with autism had, as a part of his individualized education program (IEP), various job experiences. Although he could read time, he did not really understand the concept. He did not know when to take a break. The solution was to provide him a watch that not only provided a read-out of the time but had alarm settings that would indicate when it was time to take a break and when it was time to go back to work.

Another student did not know what to do should his transportation not arrive on time because he did not understand "on time." Left to his own devices, he would stand there, waiting for a bus that would never come. His watch was set so that, after the passage of a decent interval, had the bus not arrived, he should come back indoors.

There are numerous examples, many involving solutions that were borne from the singular and collective experiences of teachers and parents. Resourcefulness.

University preparation of teachers has not adequately prepared teachers to be in a position where they are comfortable addressing the educational needs of students with special needs, especially a student tagged with the "autism" label. In my discussions with teachers, I often stress that there is nothing magical about special education. Many of the fears teachers express are borne from their lack of preparation at the collegiate level where disability concerns, if addressed at all, are mentioned in passing except for those teachers seeking licensure in this area.
Teacher, parents, and other allied professionals need more opportunities for the professional development of the teaching cadre. No broad category of students would benefit more than students with autism or within the autism spectrum. Teaching licensure, where it exists, is inadequate because this population is so diverse. A student with autism will benefit more from the combination of specific knowledge of the student and the student's learning style coupled with the resourcefulness that is present at the school, both in general and special education. (This is also true of students with traumatic brain injuries or identified as "other health impaired.")

The three suggestions above did not come from special education teachers. The suggestions came from the nutrition teacher, a job coach, and an instructional aide.

Recommendation: There is a significant need for professional development with respect to students with autism, traumatic brain injuries, and "other health impairments." University training has proven inadequate in preparing general education teachers for their shared responsibilities for students with disabilities. This has served to exacerbate attitudes of fear and apprehension especially regarding students with autism. Autism needs to be demystified. Because parents are indispensable partners in this process, professional development should recognize this resource and include parents in this process. In addition, federal funds allocated for professional development should encourage or require cross-discipline involvement. A "teacher" is a "teacher." Resourcefulness is dependent upon our sharing of experiences and shared experiences.

Oh, The Language That We Use...

F. W. Nietzsche observed that "Every word is a preconceived judgment." These judgments can be subtle, subconscious and, on occasion, divisive. Consider the federal language in IDEA that refers to "regular education" and "regular education teacher." Nietzsche wasn't the first person to note the judgmental aspect of selected words. Others have considered the semantic obverse imparted by certain words and the concepts they impart.

When considering "regular education," one must ask: What is its obverse? Its actual obverse is "irregular," a negative concept. But we state the semantic obverse as "special education." "Special" then becomes synonymous with "irregular," and thereby becomes a negative concept, something to be avoided, something less than the whole. This creates a largely artificial division between that which is "regular" and that which is "special." No state has a licensing pattern that confers "regular education" upon any prospective teacher; but because of the federal language from P.L. 94-142 to today, this term and its attending concept have created a division, a polarization among the teaching ranks. It serves to disenfranchise students with disabilities who require "irregular" education. It becomes, in some schools, an "Us" versus "Them." A "regular" teacher should be one that drinks prune juice and nothing more. A "teacher" is a "teacher." It would be far better for the federal law to eliminate the use of the descriptor "regular education" in favor of "general education."

Miscellany...

When Congress reauthorized IDEA in 1997, there were a number of improvements, including the provision for mediation and the establishment of "manifestation determinations" as an evaluative process rather than a due process. However, Congress should remove that portion of 20 USC §1415(e)(2)(B) that allows the establishment of procedures whereby a parent who chooses not to accept mediation would be required by a local school district to meet with a "disinterested party" who could extol the virtues of mediation. If mediation is a voluntary process, then why should a parent who declines this opportunity be essentially punished for their perceived lack of insight? Having such a provision is calculated to ensure that school personnel and parents could not warm up to each other if they were cremated together. This is an extremely divisive and counter-productive provision.

I greatly appreciate your allowing me to share a few thoughts with you today. As you can imagine, there are many areas where improvements can be made. At this writing, it is just as important to identify those areas that set us apart, that divide us from one another.

Mr. BURTON. Ms. Bristo.

Ms. BRISTO. Good afternoon, Chairman Burton and the distinguished members of the committee. Thank you very much for inviting NCD, the National Council on Disability, to participate in this important hearing.

As you know, the National Council on Disability is charged to provide policy guidance and research support to Congress and the White House about Federal statutes and programs pertaining to people with disabilities. Before 1975, the educational needs of more than 8 million students with disabilities were not being met.

Since 1975, when IDEA was passed, the doors have been opened to untold numbers of students with special education needs in America. However, over the years, parents have told us, and we have found, that the promise of IDEA is not being fulfilled, and too often parents and families bear an undue burden of enforcing IDEA. We were delighted last night to hear President Bush reaffirm his commitments to the New Freedom Initiative and to "leave no child behind." Taken together, they represent a new opportunity to improve the implementation of this important civil rights legislation.

We agree with our President that increased funding and enhanced accountability by our public schools are two critical elements to ensuring that no child will be left behind, including the 6 million students served through IDEA.

It saddens us to tell you that NCD's research embodied in our report, "Back to School on Civil Rights," which I will leave for the record, indicates that all 50 States were out of compliance to varying degrees with the main provisions of IDEA. It is also troubling to report to you that there were no serious consequences for continued and persistent noncompliance with IDEA.

All too often the burden of enforcement rests on the shoulders of parents. NCD believes that preventing discrimination and ensuring educational equality of opportunity is an appropriate role of our Federal Government. It is time to put that responsibility back to the Federal Government in upholding the constitutional guarantees afforded to millions of children with disabilities.

A complete copy of our report has been entered into the record. I would just like to summarize a few key findings and a few key recommendations.

Ninety percent of the States had failed to ensure compliance in the category of general supervision where States are expected to hold local school districts accountable; 80 percent of States failed to ensure compliance with the law's free appropriate public education requirements; and 72 percent of the States failed to ensure compliance with the placement in the least restrictive requirements of IDEA.

NCD made a variety of recommendations in our report. I'm only going to point on a few priorities here today.

First, the Departments of Education and Justice should develop national compliance standards with enforcement triggers and mechanisms and with involvement of stakeholders.

Second, Congress should authorize and fund the Department of Justice to independently investigate and litigate IDEA cases.

Third, increases in IDEA funding should include portions to build enforcement complaint handling and technical assistance to ensure top to bottom accountability.

Congress crafted a statute in 1975 that, if faithfully implemented, will consistently produce quality outcomes for students with disabilities. We firmly believe that if IEPs are based on the unique needs of students, if instruction is individually designed, if IEPs are faithfully implemented, if the least restrictive environment requirements are followed, and if there is failure to comply with IDEA that there will be real consequences, students will achieve quality outcomes while enjoying maximum independence in interactions with their nondisabled peers.

Compliance with these IDEA requirements is a sufficient condition for quality outcomes. Funding and accountability are interconnected parts of the solution.

Improvement in the implementation of IDEA will take the concerted efforts of parents, advocates, State and local governments and leaders such as those conducting this important congressional hearing.

I want to express our deep appreciation of the important work we are engaged in here today. And to the chairman, to welcome you on board for the important journey of opening opportunities for people with disabilities. Thank you.

[The prepared statement of Ms. Bristo follows:]

TESTIMONY OF MARCA BRISTO

CHAIRPERSON
NATIONAL COUNCIL ON DISABILITY
before the
U.S. House of Representatives
Committee on Government Reform
Individuals with Disabilities Education Act Hearing
Washington, DC, February 28, 2001

Good afternoon. Chairman Burton, Congressman Waxman and distinguished members of the committee, thank you very much for inviting me to participate in this hearing. I am Marca Bristo, the Chairperson of the National Council on Disability (NCD). As you know, NCD is charged by Congress with monitoring federal statutes and programs pertaining to people with disabilities, and assessing their effectiveness in meeting their needs. On behalf of the Council, we appreciate the opportunity to share with Congress our findings on one of the most important pieces of civil rights legislation in history, the Individuals with Disabilities Education Act (IDEA). We are pleased to note that President George W. Bush has recognized the importance of the role that a strong and effective IDEA plays in ensuring that no child gets left behind: the President has provided his immediate and firm support of the IDEA in his *New Freedom Initiative* and other education proposals.

NCD is an independent federal agency representing *all* people with disabilities, regardless of severity, and from all cultural, racial and ethnic backgrounds. Our Council members, who are appointed by the President of the United States and confirmed by the U.S. Senate, make recommendations to the President, Congress and federal agency officials concerning ways to better promote equal opportunity for all individuals with disabilities. In addition to our statutory mandates, NCD's mission is to provide a voice in the Federal Government and to Congress for all people with disabilities in the development of policies and delivery of programs that affect their lives. This was the direction that we received from over 300 disability advocates that convened in Texas in 1996 for a disability policy summit; NCD was charged by these people to investigate their concern regarding the shortcomings in the federal enforcement of disability civil rights laws.

In 1975, when Congress enacted the Education for All Handicapped Children Act, P.L. 94-142—now titled Part B of IDEA)—it found that the special education needs of more than eight million students with disabilities were not being met. Some students were entirely excluded from school; others were not receiving an appropriate education; still others had unidentified disabilities or were misclassified. Of those who did receive educational services, many were educated far away from their local schools (20 U.S.C. Sec. 1400(b)(1)-(6)). Still, Congress recognized that educators have had the ability to instruct these students (20 U.S.C. Sec. 1400(b)(7)).

IDEA is now the most significant aspect of the federal involvement in public education for children and youth with disabilities. Rich or poor, urban, suburban, or rural, all schools and districts are affected by special education. IDEA's basic premise is that all

children with disabilities have a federally-protected civil right to have available to them a free appropriate public education that meets their schooling and related service needs in the least restrictive environment, in regular classes, in the school the student will attend if not disabled. It is a law designed to work for every eligible student.

In the more than two decades since its enactment, IDEA implementation has produced important improvements in the quality and effectiveness of the public education received by millions of American children with disabilities. Today almost six million children and young people with disabilities ages 3 through 21 qualify for educational interventions under Part B of IDEA. Some of these students with disabilities are being educated in their neighborhood schools in regular classrooms. These children have a right to have support services and devices such as assistive listening systems, braille text books, paraprofessional supports, curricular modifications, talking computers, and speech synthesizers made available to them as needed to facilitate their learning side-by-side with their nondisabled peers. Post-secondary and employment opportunities are opening up for increasing numbers of young adults with disabilities as they leave high school. Post-school employment rates for youth served under Part B are twice that of older adults with disabilities who did not benefit from IDEA in school, and self-reports indicate that the percentage of college freshmen with a disability has almost tripled since 1978.

During the course of several research studies on the IDEA, NCD learned that parents of children with disabilities are enthusiastic supporters of the law. They think it is a good law.

Having said this, NCD's assessment studies found that despite these important improvements, the dropout rate for students who receive special education continues to be far higher than that of students who receive general education services. Diploma rates for special education students are far lower than for their peers enrolled in general education services. Unemployment among those with disabilities who want to work, but can't find a job, is approximately 70 percent. Countless numbers of children with disabilities, especially those from low-income, ethnic and racial minority, or rural communities, are still not receiving the full benefit of the law. They and their families struggle daily to obtain the services and supports they need to learn. As a last resort, many families find they must take legal action to force local school districts to comply with the law.

In January 2000, NCD released its evaluation of nearly two and a half decades of federal enforcement of IDEA. Entitled *Back to School on Civil Rights*, this report analyzed the data contained in the Department of Education's state monitoring reports from 1975 to 1998 to determine what has been happening over time. The study measured compliance in the areas of free appropriate public education (FAPE), least restrictive environment (LRE), individualized education plans (IEP), transition services, general supervision, procedural safeguards and protection in evaluation of students with disabilities.

It saddens us to report that every state and the District of Columbia was found to be out of compliance with IDEA requirements to some degree. Federal efforts over several

administrations to enforce IDEA in states where noncompliance persists were found to be inconsistent, often ineffective and without any real teeth. I want to stress that while the statutory framework of IDEA envisioned states as the primary implementers of IDEA, over five administrations, the Federal Government has fallen short in its efforts to ensure the protections of the law for children with disabilities are enforced. This study confirmed what children with disabilities have repeatedly told NCD, that noncompliance has persisted in some states over many years, placing enormous burdens on children and families.

DATA AND SUMMARY ANALYSIS

NCD's *Back to School* report found that the most recent federal monitoring reports demonstrated that every state failed to ensure compliance with the requirements of IDEA to some extent during the period covered by this review. More than half of the states failed to ensure compliance in five of the seven main compliance areas. For example, in OSEP's most recent monitoring reports, 90 percent of the states (n = 45) had failed to ensure compliance in the category of general supervision (the state mechanism for ensuring that LEAs are carrying out their responsibilities to ensure compliance with the law); 88 percent of the states (n = 44) had failed to ensure compliance with the law's secondary transition services provisions, which require schools to promote the appropriate transition of students with disabilities to work or post- secondary education; 80 percent of the states (n = 40) failed to ensure compliance with the law's free appropriate public education requirements; 78 percent of the states (n = 39) failed to ensure compliance with the procedural safeguards provisions of the law; and 72 percent of the states (n = 36) failed to ensure compliance with the placement in the least restrictive environment requirements of IDEA. In the two remaining major compliance areas IEPs and protection in evaluation, 44 percent of the states (n = 22) failed to ensure compliance with the former and 38 percent of the states (n = 19) failed to ensure compliance with the latter.

Currently, the U.S. Department of Education (DoED) has neither the authority nor the resources to investigate and resolve individual complaints alleging noncompliance. The Department does consult with and share enforcement authority with the U.S. Department of Justice (DOJ). DOJ has no independent litigation authority. We found that, between the date it was given explicit referral authority in 1997 and the date this report was published, DoED had not sent a single case to DOJ for "substantial noncompliance," and had articulated no objective criteria for defining that important term. In turn, the Department of Justice, whose role has been largely limited to participation as an amicus in IDEA litigation, does not appear to have a process for determining which cases to litigate.

Despite the high rate of failure to ensure compliance with Part B requirements indicated in the monitoring reports for all states, only one enforcement action involving a sanction (withholding) and five others involving imposition of "high risk" status and corrective action as a prerequisite to receiving further funds, have been taken. The only withholding action occurred once for a temporary period and was overruled by a federal

court. Overall, the DoED tends to emphasize collaboration with the states through technical assistance and developing corrective action plans or compliance agreements for addressing compliance problems. There appear to be no clear-cut, objective criteria for determining which enforcement options should be applied when technical assistance and compliance agreements do not work and when to enforce in situations of substantial and persistent noncompliance.

We worked with the Department of Education for five months to obtain their feedback to the report. We consulted with advocates from across the country on our recommendations. As a result, NCD believes that the *Back to School on Civil Rights* report paints a realistic picture of federal enforcement from 1975 until 1998, when a new system began to be implemented.

RECOMMENDATIONS FOR STRENGTHENING THE IDEA

In the report, NCD makes the following general recommendations to strengthen the IDEA and relevant Executive level programs:

- The Departments of Education and Justice develop national compliance standards, improvement measures, and enforcement action triggers, with input from stakeholders, including students with disabilities and parents, for consistency and clarity in the IDEA enforcement process.

- Congress authorize more funding for Department of Education-sponsored technical assistance programs to support the development of state-level technical assistance networks, self-advocacy and monitoring training for students and parents, as well as free and low-cost legal services for families.

- Congress authorize and fund the Department of Justice to independently investigate and litigate IDEA cases, as well as administer a federal system for handling pattern and practice complaints filed by individuals.

- Congress and the President appropriate the necessary funds for enforcement and technical assistance.

- When Congress and the President approve an increase in the funding to be distributed to local schools under Part B, Congress and the President should appropriate at the same time an amount equal to 10 percent of the total increase in Part B funding to be used to build the Department of Justice's and the Department of Education's enforcement, complaint-handling, and technical assistance infrastructure to effectively enable the federal agencies to drive improvements in state compliance and ensure better outcomes for children. The Department of Education should ensure that this capacity building occurs across-the-board at

state and local school district levels as well, to strengthen accountability connections.

- The Office of Special Education and Rehabilitative Services in the Department of Education should continue to expand its initiatives to serve non-English speaking groups and/or people with limited English proficiency and create culturally appropriate training materials.

- The Department of Education should consult with students with disabilities, their parents and other stakeholders as it develops and implements a range of enforcement sanctions that will be triggered by specific indicators and measures indicating a state's failure to ensure compliance with Part B.

ADDITIONAL CONSIDERATIONS

Beyond the scope of our *Back to School* assessment study, please note that NCD would like to provide you with feedback about IDEA implementation related to: transition of secondary-aged youth; teacher training and preparation; and, issues involving vouchers, regulatory flexibility, and large-scale school reform.

NCD recently completed a report entitled *Transition and Post-School Outcomes for Youth with Disabilities: Closing the Gaps to Post-Secondary Education and Employment.* The report was commissioned by and for the Social Security Administration. This report presents an analysis of research on the status of transition, post-secondary education, and employment outcomes for primarily 14 to 22 year old youth and young adults with disabilities over the past 25 years. Next it identifies what has worked, and what should work in light of unmet needs and unserved populations. Despite advances in education, disability rights policy, the support of federal mandates, and increased funding of programs and initiatives that impact all youth, the post-school outcomes for far too many of our nation's youth and young adults are still poor. The current status translates not only into untapped talent and potential and unfulfilled dreams, but severely limits America's preparation of today's youth for full participation in tomorrow's society. This report brings attention to persistent issues and problems that various national studies on post-school outcomes document. The problems identified in this report are: (a) poor graduation rates from high school; (b) low employment rates after high school; (c) low post-secondary education participation; and (d) an increasing number of youth receiving Social Security benefits and not leaving the benefits rolls. The outcomes reported through statistics resonate to 30 years ago, prior to the benefit of federal laws and regulations.

Teachers are still not receiving adequate training in special education issues. States need to increase the mandated level of college-level teacher training 'special education' coursework beyond the all too general 'Introduction to Special Education' undergraduate-level course for all teacher preparation programs. Special and general education practices reflect teacher preparation, just as teacher preparation drives school

practices. This symbiotic relationship between practice and preparation means that the implementation of promising practices is quite uneven on a national basis. While many students preparing to be teachers benefit from experience with state-of-the-art practices in their education, far too many still do not have access to the quality of practices and preparatory experiences that should have been created by now. Therefore, outmoded and ineffective practices are reinforced and perpetuated.

NCD also has deep concerns regarding proposals pertaining to (1) private school voucher plans and/or charter school options; and (2) increased flexibility for states in relation to federal IDEA requirements. Such proposals have the potential of seriously undermining the education and civil rights of children with disabilities if they are unable to gain the provision of IDEA services and supports to which they are entitled by federal law. Information from around the country (e.g., Massachusetts) indicates that charter schools too often provide unlimited freedom from critical special education requirements. Questions about the constitutionality and effectiveness of vouchers for student with disabilities are also beginning to surface around the country (e.g., Florida). Any educational "reforms" or "innovations" that involve IDEA must first safeguard against exclusion of students with disabilities from services and/or supports, abridgements of student and family rights and responsibilities under IDEA, and ensure that their educational needs are timely met. Until these standards or guidelines are met, state and/or local school districts should only be allowed to have 'flexibility' with non-federal education funds, regardless of which type of reform or innovation they want to try. It is imperative that NCD, children and youth with disabilities, their families, their advocates all be afforded an opportunity to provide their input as proposals are developed and raised to Congress' attention.

CONCLUSIONS—FINAL REMARKS

Congress crafted a statute in 1975 that, if faithfully implemented, will consistently produce quality outcomes for students with disabilities. The U. S. Code defines special education as "specially designed instruction" to meet the "unique needs" of these students; each student's individualized education program (IEP) is to set forth his or her unique needs and individually designed instruction; and, each student's placement is to be based on the IEP and no more restrictive than necessary (20 U.S.C. 1402(25); 34 C.F.R. 3000.552(a)(2)(b)). If IEPs are based on the unique needs of students, if instruction is individually designed, if IEPs are faithfully implemented, and if the LRE requirements are followed, students will achieve quality outcomes while enjoying maximum interactions with their nondisabled peers. Compliance with these IDEA requirements is a sufficient condition for quality outcomes.

Improvements in implementation of IDEA won't happen overnight. It will take the concerted efforts of parents, advocates, states and local school districts, and leaders such as those conducting this Congressional hearing to make it happen. Increasing the federal share of IDEA dollars is one small step, but it is not nearly enough and it should not be

initiated in the absence of other federal activity. We have outlined those activities in the form of about one-half dozen recommendations to this Committee.

As the representative of NCD at this hearing, I want to express our deep appreciation of the important work accomplished by your members. Without knowledgeable and committed professionals working for children with disabilities, they would have no real educational opportunity and the doors of their future would remain closed. Together, we can work to pry these doors open for all such children.

As we begin our shared work with the first administration of the 21st century, the Federal Government is poised to address long-standing challenges to its performance and service to Americans with disabilities. In his *New Freedom Initiative*, President George W. Bush gave his commitment that his administration would work with this Congress to expand educational opportunities for Americans with disabilities, to invest in programs that would promote their reading and learning skills. I am pleased to inform you that NCD is presently working in collaboration with the Department of Education's Office of Special Education Programs (OSEP) and a group of stakeholders to review OSEP's IDEA compliance monitoring programs, and develop recommendations regarding performance benchmarks and enforcement triggers.

It is our hope that this hearing will lead to dialogue, greater understanding of the issues and problems, and more importantly, to action. We ask you to join us in supporting the recommendations we offer today and to make the promises of IDEA a reality for all children with disabilities.

Thank you.

Mr. BURTON. Thank you very much. And I'm sorry I'm a little late getting to the starting line. Let me just start off the questioning by asking the parents of children who are autistic, if we could, at what age did you notice your children were autistic?

Let's start with you, Ms. Brown, real quickly.

Ms. BROWN. I noticed my son was autistic at 18 months, and he was legally diagnosed at 2 years and 4 months.

Mr. BURTON. OK, 18 months.

Ms. Fry, when did you notice your children became——

Ms. FRY. They showed signs at birth, all of them.

Mr. BURTON. All at birth.

And Ms. Antenellis.

Ms. ANTENELLIS. Connor was 18 months.

Mr. BURTON. 18 months. And I guess you're the parents.

Let me just ask you those of you who noticed the signs of autism at 18 months, had you had any kind of inoculations of the children in close proximity of the time that you noticed them to be autistic?

Mr. BROWN. Yes, I did.

Mr. BURTON. How close in proximity?

Ms. BROWN. I started noticing a difference at 12 months with the DPT, and 18 months is what I considered to be the final blow with the MMR.

Mr. BURTON. Ms. Antenellis.

Ms. ANTENELLIS. Same thing. He started to decline around 16 months, right after his shots.

Mr. BURTON. Which shots were they?

Ms. ANTENELLIS. I think it was MMR, but I can't say that was it, because it was a very slow decline.

Mr. BURTON. Was this just the one shot, or did you have a series?

Ms. ANTENELLIS. We had all the shots that were required by law because that's what they told me I should do up until 18 months. He had whatever shots there were at 18 months also, and he has not been vaccinated since.

Mr. BURTON. I was just curious about that.

I guess this is a general question for all of you, and we'll start with you Mr. Lamontagne. Could you give us the top two or three things that you think should be done by the Congress or by the Justice Department to make sure that children who have these disabilities are taken care of properly? And we're going to write these down because we're going to try to pursue these through the Congress, at least I am, and I think my colleagues will.

Mr. LAMONTAGNE. I think the first and obvious one is to fully fund the Congress' commitment to IDEA; second, to incentivize the delivery of service by converting the funding mechanism from a pure block grant—I'll call it that for a lack of a better term—to a reimbursement-for-services program; and third is to shift the model from a bureaucratic one to a delivery-of-services model, which would mean having support services for parents at the school district level, including an ombudsman in the event of a disagreement between the school district and parents.

Mr. BURTON. So you're saying an ombudsman would solve the problem hopefully before there was any legal action?

Mr. LAMONTAGNE. Precisely. An ombudsman whose charge is to be a problem solver, not simply an advocate for one side or the other.

Mr. BURTON. Ms. Brown. Oh, Ms. Bristo has to leave at what time?

Ms. BRISTO. I need to leave at about 25 of.

Mr. BURTON. Why don't we go to you next, and then we'll come back to Ms. Brown.

Ms. BRISTO. The main message we have for you is what I reported to you today: Enforce the existing law. We have heard from parents all around the country that the problem isn't with the law; it's for the failure of any consequences to occur.

In the course of our evaluation, we found that, for example, the Department of Education had only withheld funds once in the entire history of the law. We believe that as long as noncompliance is rewarded with continued funding, or no other real action to create improvements, we perpetuate the problem.

Mr. BURTON. Let's take the State of Indiana for instance; I talked with the people that were charged with the responsibility of making sure the law was followed regarding IDEA. They said when they were contacted by parents like my daughter, who were having a problem with the school, that they would get a hold of the local person in that particular county and that they would pursue it and tell the school if they didn't comply—or the school district, if they didn't comply—the funds would be withdrawn.

Is that what you're talking about?

Ms. BRISTO. Yes.

Mr. BURTON. So there is incentive for them to comply?

Ms. BRISTO. I would direct you to the substance of our report which looks at seven priorities, including at the State level, so you could take a look at your own State.

I am happy to say that the Department of Education has recently begun a process to improve their monitoring mechanism and the National Council is encouraged by that; we believe that's a real step in the right direction. But we really believe that at the heart of this is putting too much of the burden for our civil rights on the shoulders of parents who are working very, very hard over time just to provide the basic services that other kids often take for granted.

Mr. BURTON. OK.

Ms. Brown.

Ms. BROWN. I would like to see the schools held accountable, especially in a situation when the graphs and data and video footage has been presented for them, and how they could continue to deny a program for a child who has made progress under that specific program.

The other thing I can only offer is that anyone who would be brought in as a neutral party to help supervise the IEP meetings and the school before parents have to go—due process, not be paid by the State, somehow the Federal Government is involved in that.

Mr. BURTON. If it was an ombudsman, no matter who paid them, they're supposed to be nonpartisan. But you think they would be if they were paid by the State?

Ms. BROWN. Right. The reason why I say that is because also this past year I attended a seminar, and at that seminar I saw many school officials in my district. The closing statement of that seminar was, "The problem here is, parents who have children with autism want a Cadillac; and I am here to tell you all you have to offer is a Chevy."

Mr. BURTON. Who made that statement?

Ms. BROWN. The conference I attended was Melinda Baird, I believe is how you pronounce her last name.

Mr. BURTON. Oh, she's going to be a witness here. We will ask her about that in a few minutes.

Ms. Schakowsky, why don't I let you have some time, and I will get back to these folks.

Ms. SCHAKOWSKY. Thank you, Mr. Chairman.

Pretty much everything I know about disability issues and disability rights I've learned from Marca Bristo, and today you can continue my education if I could ask you a few questions.

I wanted to ask if you thought the requirements for regular teacher certification should include training on special ed.

Ms. BRISTO. Absolutely. Increasingly, we're learning that the more we can educate all teachers for the diverse Nation that we are in, including people for whom English is a second language, people with disabilities, people in rural areas, the better educated our children would be.

More and more of our disabled children are in mainstream classrooms, and we believe that the recruitment efforts that the First Lady will be undertaking, it's important to target those as well as enhance the requirements for certification to include more than just the basic Special Ed 101 training that currently is the case.

Ms. SCHAKOWSKY. Are we providing services across the board equally or are some children with disabilities getting better results or access to IDEA than others?

Ms. BRISTO. The National Council looks at disability from a cross-disability perspective, so I will situate my comment in that context.

I think you have heard from the parents here today, the children who received the best educational services under IDEA are the ones whose parents were lucky enough to find out what the law was, who had access to other people to help them through the maze, and if all else didn't work, had the ability to retain legal counsel.

Now that's a lot to ask of our parents. Those people stand a much better chance of getting good results for their kids. And to that end we believe that there are existing mechanisms that Congress could support further than they have. The parent training centers, a national network to provide technical assistance to parents to help them understand the rules and regs and what to do when disability affects their lives, we believe is a good place to start.

But in our efforts to reduce litigation, it's important to note that litigation is a really important part of the repertoire of tools. In those instances where the courts have taken some cases, we have some models of enforcement that we would be well served to look at. My own State of Illinois right now, is operating under a court

order to implement the least restrictive environment aspects of the law with the same kind of enforcement triggers and mechanisms and standards that the National Council is calling for; and we're seeing considerable improvements.

Ms. SCHAKOWSKY. We've heard testimony today about the costs of attorneys. Are there low-cost special education attorneys available to represent parents anywhere?

Ms. BRISTO. Again, no. As you probably can ask and have the parents here speak to, not only are there not a cadre of well-funded and well-educated parents, there is also just a dearth of people who are really knowledgeable in this area of law. And increasingly, as people decide whether or not they are going to take these cases, the parents also have to prepare themselves many times for multi years of helping to front those legal expenses until the attorneys' fees kick in.

A lot of people fall by the wayside before then. They simply give up. And I think we have to ask ourselves the question, in those instances when it gets just too burdensome to enforce the law for your child, is it not the children whom we are leaving behind?

Ms. SCHAKOWSKY. And short of attorneys, are there not lay advocates or people who can help the parents, give them information about what their rights are and help them run their way through the system?

Ms. BRISTO. Yes, as I said, the parents' training networks, the independent living centers, the protection and advocacy programs; but again, often these organizations are stressed with an overwhelming number of requests for information, and more needs to be done in this important area.

Ms. SCHAKOWSKY. I really appreciate the real testimony of real-life people and the kind of struggles that you're going through. And there are obvious holes that we have got to fill so that the burden is somewhat lifted and you can provide exactly what your children need; and I certainly pledge my support for that.

Thank you, Mr. Chairman.

Mr. BARR [presiding]. The time of the gentlelady from Illinois has expired.

The Chair recognizes the gentleman from Florida, Mr. Weldon.

Mr. WELDON. Thank you. I have a question which I guess I would like to direct to some of the education professionals we have here on the panel.

IDEA was passed, I guess, 20 or 25 years ago, and there are a lot of people who are arguing that the incidence of autism began to increase significantly in our population. And a lot of times we say "disability," and I think when they hear that, they're thinking the whole gambit of disabilities—cerebral palsy, mental retardation, etc.; but how much of what we're struggling with or dealing with is actually the possible increase—significant increase of autism, or are you seeing significant increases in all disability categories?

Ms. NUNES. What we're seeing is—to answer your question in two components, we definitely are seeing an increase of students identified with autism. We are also seeing—I will speak to San Diego particularly. We are also seeing an increase in other areas, as well. As our medical profession achieves greater ability to help

children who are premature, frequently these children will end up with some disabilities that we need to take care of in the education profession. So it is across the board, but the increase of autism is phenomenal.

When I'm addressing issues regarding IDEA, though, from an educational point of view, I'm looking across all disabilities.

Mr. WELDON. So if I understand you correctly, you're seeing everything increase, but you think autism is increasing more than the others?

Ms. NUNES. At a more rapid rate, yes?

Mr. WELDON. Does anybody disagree with that?

Mr. MCDOWELL. Yes, Representative.

I would not disagree with that. Certainly that experience is being borne out across the country. There are some reasons for it, but no one knows all the reasons for it.

One of the reasons we see the increased instances is because only comparatively recently did the Federal guidelines even mention it as a separate category; before, it was listed with emotional disturbance or emotional handicaps. In 1988, we created our own category for special education; we didn't wait for the Federal law to do it. So our reporting on the incidence of autism as an educational diagnosis, as opposed to a medical one, began in 1988, so we have data from that time. That's one of the reasons.

The other ones, better identification, the refinement in mental health professionals on how they've been able to identify it. We don't know if they simply went undiagnosed or if there is some sort of an epidemic.

I don't think they all went undiagnosed. There's no one who can explain why, other than it is a phenomenon that has occurred.

Mr. WELDON. How much of your resources are expended dealing—and I realize you're just—I'm asking you to shoot from the hip and make estimations on dealing with emotional and behavorial problems associated with the disabilities that you're dealing with; is that a significant component?

The impression I get in looking at a lot of these cases is that the pure educational components—in other words, having a teacher who knows how to teach subjects to a child with a disability—is a relatively—in many of these cases, a relatively narrow component of what you're dealing with and that a huge amount of the associated costs of teaching of educating these kids under the provisions of the act are related to things like physical therapy and behavioral therapy.

I'm interested in that mainly because we call it the Individuals With Disabilities Education Act because we want these kids to get an education. And the costs are proving to be much higher than anybody estimated, and the reason for it is because of these associated, ancillary issues that you have to bring into play; and I think it's important. If we're going to sell to the Congress, our colleagues, why we have to begin to pony up significantly more money to address the issue.

Mr. MCDOWELL. Representative, at the time in question that was one of the major issues that the chairman asked us to address. I can say when Congress reauthorized IDEA at section 1418 and 1474, Congress did ask for a study because you have a number of

these competing interests who say this is drawing money away from that resource, you are robbing Peter to pay Paul. No one can refute that or support that.

For that reason, the Office of Special Education Programs within USDOE has contracted with the Center for Special Education Finance of the American Institutes for Research, and they are presently involved in conducting this massive national study, of which Indiana is a part; and we have also opted to outlay additional money—$800,000 in fact—in order to get a State-specific study for Indiana that would break it down by exceptionality area to give student, building and district types of data to show what those expenses are in eight major areas.

Unfortunately, the preliminary data tabulation will not be available until April 30 of this year, and the final report is due out October 31 of this year. And I am sure that Patty Guard can give you more information on that other than, we are involved in this.

The type of data that they have requested is extraordinary, and the eight questions that they are prepared to answer cover all the questions that Congress has raised about where is this money going, what is it doing, is it really affecting other programs; and that's the type of information that this report is to generate.

Mr. WELDON. I have just one other question if the chairman will indulge me and I realize my time has expired.

One of the reasons you can, if you decide you want to go out to dinner, you can choose from a lot of good restaurants in most American towns, is because you have money in your pocket and everybody wants your money. One of the reasons you couldn't get a decent meal in the Soviet Union is, they had a different system obviously.

There have been some people who have proposed, and I guess this is a question I'd really like to direct more to the parents: Should we really be thinking outside of the box, and instead of putting more money into the system, empowering parents by giving them the resources so they can go out and shop in their community to find the best environment for their kids?

The reason I say this is, when I look through the e-mails from the State of Florida, from parents who have struggled in this area, some of them say they encountered very willing and cooperative teachers and school administrators that wanted to make a difference; but one of the themes you see over and over again is sort of a lack of customer friendliness to dealing with the problems that they are facing as parents.

Your thoughts? Would you rather have the money so that you can shop around amongst various public and private institutions that are designed to teach kids with disabilities, or would you rather just see us put more money into the existing system—in other words, a so-called "voucher." It's a dirty word, I realize, and nobody likes that term; it's been so demonized.

That's really what I'm getting at.

Ms. ANTENELLIS. I think I could answer a little bit of that from a parent viewpoint.

I think, No. 1—if there were standardized good programs out there, I think that is an option we would like, but in many cases my school was forced by me to put a program in. They had nothing,

they had absolutely nothing, so I don't think we have a lot of restaurants to go to.

Mr. WELDON. Well, there's no marketplace because there are no customers.

Ms. ANTENELLIS. But I also, second, think that you mentioned the medical end of it. We have a society where it is all forced upon the school system. Particularly with the disability of autism, no medical coverage provides services. I cannot get speech, I cannot get OT, I cannot get PET for my child because he has a developmental disability and our health insurance won't cover it. So it falls—it's incumbent to have the school system do it. That is the only access he has to the service.

So there may be some definite medical issues that need to be addressed, but the health insurance piece has fallen back. Even in my town when we apply for Medicaid for our special ed kids, it doesn't go to the special education department; it gets kicked back into the town fund. So it is not supporting special education. It goes right back into our town's general fund, not to pay the specific needs of the children that they're billing for.

Ms. NUNES. If I could continue on that conversation, when you were asking about the physical therapy and the related services, one of the increases that we saw was that as insurance stopped accepting students or providing services it fell upon the district or the school districts to then provide those services as a related service. And our definition is to provide access to the general education or to the educational environment. So, yes, there is always a domino effect when one piece of legislation or one decision is made that it will then roll back to usually the education department, to usually fill in.

Mr. WELDON. Thank you very much.

Mr. BURTON [presiding]. Do you have some questions, and then we will go to my colleagues from California.

Mrs. DAVIS. Thank you, Mr. Chairman. I'm not sure I have so much a question as I do a comment, but it sort of plays on what Representative Weldon said, that we don't have the marketplace; and maybe the reason for that is, I'm not sure that the parents know their rights. And I wish I had Ms. Antenellis back when my 24-year-old was 12 years old, and I had a case where the pediatrician wrote a prescription to the school to test my child for a learning disability. But he looked normal, acted normal, and the school said he's just lazy and a daydreamer.

He was not tested. They refused to test. I didn't know I had that right.

That's my concern: Are we getting the cooperation? I'm hearing that now. I know that was 12 years ago with my son, I hear that now in my district that the school, the administration—I don't know if it's the teachers or where it's coming from—are not cooperating with the parents, not wanting to give them the information or even tell them what their rights are.

My concern there is, is it because we're not funding? Is that the administration's and the bureaucracy's problem that they don't have the money, so therefore they don't want to tell the parents that they have the right because it would cost more money?

We had a situation in one district where the school went outside of the county attorney and hired an attorney, spent $200,000 to fight a parent; and the parent spent, like Mrs. Brown did, a lot of money and won. But by the same token, we wasted $200,000 of taxpayers' money; and we have a problem, and I'm not sure how to fix it. And I'm open for suggestions.

Mr. LAMONTAGNE. I will just make the observation that I would wholeheartedly agree that simply fully funding IDEA is not the answer. It's fully funding IDEA, whatever that means under a reformed model, that creates more power in the hands of parents and creates more of a choice—a bottom-up, if you will, demand.

That means an educated parent force, certainly. That means a system that looks to deliver services, not resist giving service. That also means removing what inevitably becomes sort of a battle of dueling agencies when you have social service agencies and educational agencies all competing for a limited resource of money, because they are in fact naturally antagonistic in this situation, much like you've alluded to, Representative.

My wife and I—and she's here with my children—we've been foster parents for 12 years of a special needs child, and we've battled this on his behalf to try to deal with where the responsibility should lay, and lie. And I think it is very important the funding mechanism tries to wrap in, if you will, a package that is going to ultimately be paid by government, a package to deliver a full array of services to help children not only learn but be able to receive the services they need as they progress so they can become members of society.

But to remove it now, which is a top-down bureaucratic system that I think kills, if you will, the ability of parents, that discourages and is a disincentive for parents to go out into the marketplace to look at opportunities. And there is no market out there to try to educate parents to find what is available for them.

I would also say sitting here today, thank God for the mothers and fathers from hell, who have worked so hard for their children.

Mr. MCDOWELL. If I may add to the comments, I don't wish to leave the impression that school people are awful people. They're really not. When I speak to them, I remind them that even though this may be the third or fourth IEP team meeting you have today, this is the parent's first; and never forget that this is their first and don't rush them through it. Be considerate. Let them talk. Let them be a member. Don't sit down there and start dominating it because it's time sensitive.

If you think about it, you have to constantly remind yourself, because having been there—I've been in thousands of IEP team meetings, and I have to remind myself of that too. Because I'll say, it's 4 o'clock, it's Mrs. Brown—it's just generic, not this Mrs. Brown—Mrs. Brown is coming in, and with luck I can get out of here by 5, and I can still make it and pick up so-and-so at 5:30. That is not an uncommon thing to occur.

However, there are other things that are embedded in the idea that are having unfortunate results. One is, Congress put in a mediation part, trying to encourage mediation, but put a section in there that allows the school to essentially punish a parent who doesn't want to go to mediation by forcing them to talk to some-

body about all the wonders of mediation, and if they only understood it, they would go to it. Well that's punitive, and it's off-putting.

Other things embedded in there are simply the use of the term "regular education," it's all throughout the IDEA, and that creates this polarization in schools between regular education teachers and special education teachers and that does not help. There is no such licensing pattern for regular education.

My recommendation is, change it to "general education" because a child with a disability or a child without a disability is part of the school community and a teacher is a teacher is a teacher. And I can guarantee you, as I sit here right now with 27 years of teaching, I don't think anybody here is going to deny the fact that there is that polarization in schools. We're regular educators. That's a special ed problem.

Mr. BURTON. Any further questions, Mrs. Davis?

Mrs. DAVIS. No.

Mr. BURTON. I will now yield to Mr. Cunningham from California.

Let me say, before we do that, we probably do need to refine the law; and I think you have already worked on that in the past, Duke, you've worked on refining the law in the past, haven't you?

Mr. CUNNINGHAM. Yeah, but what I put in there didn't come out of the White House.

Mr. BURTON. But the point is, what we want to get from you today are recommendations on changes in the current statutes that will perfect it and make it more user friendly for the parents, so they have don't have to go through these adversarial programs with the schools.

And so I really mean what I said earlier: We want your recommendations. We want your input. We want your suggestions so we can draft some legislation that we can present to the Congress to try to correct these things, so the parents won't have to go through these things that these ladies and my daughter has.

Representative Cunningham.

Mr. CUNNINGHAM. Thank you, Chairman Burton. First of all, I guess I have to do a disclaimer. I'm not on this committee. And none of my thought would be going toward the committee, but I mentioned, both my wife and sister-in-law are both educators, but I was also a teacher and a coach, both in high school and college level, and dean of a college.

And I also sit on the Appropriations Committee. I make the decisions whether IDEA gets more money or not, or cut. No one, like Chairman Burton, when you walk out of my office, you have no doubt where I stand. I don't tell you one thing and come back with another, and I'm very frank.

On the Appropriations Committee, I support increased medical research. Is it shots that are causing it at the 18-month or 2-year period? Is it genetic? Is a genome program going to help? And I think that's hopeful—maybe not to your children right now, but hopefully, we can help in the future in this whole area. And not just with autistic children, but across the board.

I also support, I think, that our colleges should have basic instruction courses, not just the IEP or not just the credentialed

teachers in special education, but all teachers to have increased courses. I think there ought to be funding for it. I think that ought to be one of your recommendations.

Mr. MCDOWELL. It is.

Mr. CUNNINGHAM. I think both the schools and the Eisenhower grants that we put not just for what you call "normal education" or what the actual term should be, but those teachers should also receive an upgrade in the law as well as what the services are, not just credentialed people.

When I first came here, there was 6 percent funding for IDEA. We've more than doubled that. And I think President Bush, when he talks about focusing some of the things that we are looking at—for example, the money going directly to the school and giving the parents the teachers and the community the ability to direct those dollars instead of Washington, I think that helps your cause because more money can be used for IDEA.

A factor with an Education IRA to where you can set up $2,000 aside for that child the day they're born and when they're 10 years old it's not $20,000; that's over $48,000 with compound interest. You can use that without penalty for a special education child or save it for later on.

What I don't support, the increase of IDEA money, I have witnessed one child in the State of California is receiving $150,000 a year to teach that child. I think that is unreasonable; and it hurts you and it also hurts the school.

On the committee—I was co-chairman of the D.C. Committee—I capped lawyer fees in Washington, DC. I saved $24 million. Did I put it in a general fund? No. I went out—and like you're talking about, you didn't have trained teachers—I trained 33 special educations teachers that went into the classroom with aides to better teach and train you. I support that kind.

But I don't want to increase it to 40 percent and see it going to trial lawyers. I want the money to go to students and their needs.

And one of things I would like to ask Mrs. Nunes, my sister in law, she talked to me about zero tolerance. I think you need to know why. The schools aren't bad. I've seen her cry when a child was underserved, when she was a teacher and she was fighting for those children.

But I know on the other side the zero tolerance that we have, and I would like her to just explain in plain words why this is hurting, just because of the paperwork, and it's becoming more of a check in the box than the administrators and teachers being able to go down to help the kids.

I have seen teachers brutalized in the courtroom where they're quitting the service. You are losing good special education teachers just because of the paperwork and the pressure and stuff. I think you want to keep them there, the trained ones.

Ms. NUNES. The component of the law that requires no IEP or triennial to be overdue, as I stated in the testimony, does not provide us with an opportunity, as we were reporting, to give feedback that there might be some extenuating circumstances that is a reason why the IEP is overdue. The parents may have requested that the IEP be held at a later date due to some family emergency. We

may have a dispute in the assessment plan so we are not able to meet that time line.

The reality of what happens is that reports go in and then they come back with sanction letters for us to then remediate or fix those situations, and what we end up becoming is a system of report generation as opposed to looking at the student and the student needs. And that's a concern to us.

If I could just take my step here and answer your question, Mr. Chairman, about the issues that we would like to address as far as recommendations, when we talk about the funding, again we would like to stress the educational research. I think that my concern about hearing vouchers is that now you have agencies potentially that there's not a standard; that the educational approach isn't appropriate for the child, there needs to be some type of standard that says, OK, it's time to move on, we need to look at something different.

As I stated before, there is not just one educational approach for students with autism or for any other students. For example, students with autism display a wide variety of ranges of ability levels. You may have one student with a diagnosis of autism who does not relate well in group settings, but does very well on an individual basis, as I think we have heard some of the examples here.

However, I have personally been in the classroom with students and taught students with the diagnosis of autism for whom being in an individualized instruction programming such as called out in some strategies is not the best educational environment; and those students learn better in a group environment, in small groups.

So I think that my concern is, we take into account the educational strategies and train teachers.

When we talk about the higher education institutions, I applaud Mrs. Bush in going out and championing that cause for us. What I would like to see are competencies that higher education institutions have to provide more than just an awareness level of the strategies and techniques that are needed for all students and to really be able to demonstrate the knowledge.

And that's the struggle that we're having right now, and that's the recommendation.

Mr. BURTON. Let me say, first of all, the panel has been very helpful, and we will take suggestions to heart. If there are further suggestions, real quickly, we'd like to have them because we want to move on to the next panel.

But I would like to say this, the people who are in the profession of teaching and the experts that help with special needs children really do know what they're talking about, and they can be very helpful; but you also have to consider the parents, because they live with the child 24 hours a day, or at least when they're not in school, and on weekends and everything else. And if a parent feels like they are not getting the proper treatment or education from the system, they ought to have a very big say.

That's why the idea that some form of choice for a parent ought to be there. So if the school isn't doing the job, even though they have the talent to do it, or because they don't want to do it or they have don't want to devote enough time for the child, which is the

case of my grandson, then the parent ought to be able to make sure that child gets the proper attention.

I always believed when there is an incentive to do things, people do it better. If a car salesman, for instance, knows that he will get a bonus if he sells 10 cars instead of 5, he's going to work a little harder. I believe in the educational field if a teacher or a school system is going to benefit because they're doing a little more outstanding job than the sister school, they're going to try harder.

That's one of the reasons why a lot of us feel like there should be some competition in education instead of sticking a child, or a special needs child, into one facility that is not doing a job, when down the street, or a ways away, there is another school doing an outstanding job where they can put the child. If the parent has a choice, they're going to say, hey, I'm going to put my child where he or she is going to get the best education, the best special needs education, whatever it is. If the school that is not performing doesn't do it, they're going to be without students; and pretty soon they will get the message, they are all leaving, we'd better start doing our job a little bit better, or pretty soon we will be without students and maybe without a job.

So that's one of the arguments, one of the major arguments. So I don't know whether it's vouchers or whether it's some kind of choice, but parents ought to be able to have a bigger say because some person who has more of a bureaucratic tendency says, we really think your child ought to get 30 minutes a week instead of 4 hours or 2 hours a week and the parent knows the child is not progressing.

Yes, Ms. Antenellis.

Ms. ANTENELLIS. I want to take my moment in the sun to just give you my 2 cents worth of what I think you need to do.

In addition to the teachers, most autistic children have aides in the classroom. These aides are usually just moms, who are probably the best people to deal with them, but they don't have the training, the training does not filter down to the frontline staff, the recess monitor, the aide, the person in the gym; so when the autistic child has a problem, they can't handle it. They don't get paid much. They don't get the teacher's salary, and they don't get the teacher training.

So I think that the paraprofessionals that work with these children in the school systems also need to be trained and that needs to be included in the budget somehow.

The other thing is, I think school systems that are constantly in violation of children's rights should be taken to task and be made to be accountable. Even if they have an IEP, if they're not providing what's in the IEP, they should be taken to task. If that school system is constantly going to State hearings and being found against, they should be taken to task.

There is no accountability in the school systems in the States right now. Yes, they go back down again and then 2 weeks later, they're not providing the speech. And the parent has to go all the way through the process again to get the speech provided. There's no accountability, and they need to be held accountable.

Mr. BURTON. I can tell you, this morning I talked to the people in State of Indiana in the special education area, and they assured

me if parents bring to their attention in that State—and maybe it needs to be done in every State—that there's violations and noncompliance, they will investigate it and they will withdraw the funds from the school system, and they'll tell them, you will not get these funds if you don't do the job. That's the carrot-and-stick approach that needs to be used all across the country.

All of your ideas and suggestions will be looked at very thoroughly.

Ms. Fry, you have one more comment, real quick?

Ms. FRY. Yes, I have my recommendations.

I have been told very often that there are gray areas. The reason they don't train teachers is because it's a gray area. We don't have to train them specifically. Their idea of training is to send one person to a seminar, have them bring back all the information, photocopy it, pass it out, and everybody gets to read it; therefore, they're trained.

I don't buy it. I think it's time to color in the gray areas and make it a little more specific, get the teachers some training so they understand that when a child is exhibiting a certain behavior, it's not because they're acting out, it's because something is wrong. They're not doing it just to be mean.

Again, accountability. The schools don't seem to have anybody to say, you're not supposed to do this.

I feel that they should provide the education. I send my kids to school for an education. I would hope that's what they're going to get there.

Mr. BURTON. Well, we will take all of your suggestions into consideration. We will draft some revised legislation, and we may even send it out to you folks who testified here today to get your input before we present it to the Congress as a whole. In any event, we will excuse this panel and ask the next panel to come forward.

Do the people who are coming forward need to take a break for about 5 minutes? I see pain on some faces. We will recess for 5 minutes, and we will get started as quickly as possible.

[Recess.]

Mr. BURTON. We will reconvene and I would like for you to stand so I can swear you in, please. This is normal procedure. You are not being singled out.

[Witnesses sworn.]

Mr. BURTON. OK. We'll let you have opening statements.

We will start with Ms. Guard and we will just go right down the row here. Try, if you could—as you heard, restrict your comments to 5 minutes so we can get to the questions as quickly as possible.

STATEMENTS OF PATRICIA J. GUARD, ACTING DIRECTOR, OFFICE OF SPECIAL EDUCATION PROGRAMS, U.S. DEPARTMENT OF EDUCATION; MELINDA BAIRD, JD, KNOXVILLE, TN; GARY MAYERSON, JD, NEW YORK, NY; BILL EAST, EXECUTIVE DIRECTOR, NATIONAL ASSOCIATION OF STATE DIRECTORS OF SPECIAL EDUCATION, INC.; AND ED AMUNDSON, NATIONAL EDUCATION ASSOCIATION

Ms. GUARD. Mr. Chairman and members of committee, last November we celebrated the 25th anniversary of the signing of the Education for All Handicapped Children Act, now called the Indi-

viduals With Disabilities Education Act [IDEA]. As we explore the implementation of IDEA, it is important to take time to reflect on the tremendous progress that has been made in the education of children with disabilities since the passage of this landmark civil rights legislation.

Today, more than 6 million infants, toddlers, children and youths with disabilities are provided early intervention and special education services. Over 95 percent of students with disabilities are being educated in the public schools. Post-school employment rates for youth served under IDEA are twice that of older adults with disabilities who did not benefit from IDEA in school, and the percentage of college freshmen reporting a disability has almost tripled since 1978.

Despite this progress, significant challenges remain. As we review implementation of IDEA, it is important to recognize that this law calls for a Federal, State and local partnership.

It's important to understand the roles of each of these entities in the implementation of this law. The Federal role is to serve as a steward for Federal investments, to develop improved interventions through research and development and to provide financial support and technical assistance to assist States in complying with the Federal law in correcting the systemic problems. The Federal role necessitates ongoing technical assistance to States. Periodic monitoring of compliance with IDEA, directives for corrective actions and different levels of enforcement and sanctions relative to the intensive pervasiveness and persistence of problems within States.

The State role parallels the Federal role in supporting and ensuring the implementation of IDEA. By accepting Federal IDEA funds, States have an obligation to ensure consistent compliance with the IDEA statutes and regulations throughout the State. The State's general supervision role entails not only stewardship of the allocated Federal funds, but also of the much larger State investments that support children with disabilities.

The general supervision role also necessitates an ongoing monitoring presence in the school districts and resolution of parent or student complaints filed with the State. The State agency has the obligation to ensure that each child with a disability is identified and receives appropriate services. In addition, the State plays a critical role in ensuring that districts have an adequate supply of appropriately trained teachers, administrators and other service providers to ensure that children with disabilities receive high-quality instruction.

States also have responsibility for setting performance goals for students with disabilities and assisting school districts with meeting these goals through identification and support of promising practices, development of model demonstration projects in support of other effective research-based practices.

Local districts develop policies and procedures for practical implementation of the State and Federal laws in each school in the district. Local education agencies must make certain that staff throughout the district are knowledgable of the Federal and State requirements and that services are provided to students and families consistent with the IEP developed by a team of professionals and parents for each child with a disability.

Parents play a key role, along with school personnel, in developing, reviewing and revising, if necessary, their child's IEP, and in determining the type and intensity of services the child needs and where the services will be provided. If the parent and local school district staff cannot agree on the content of the IEP, or the recommended placement, the parent can file a complaint with the State if they believe the school district has violated a requirement in the law. The parent can also ask for a due process hearing and mediation must be available to parents who request a due process hearing.

The remainder of my testimony will elaborate on the Federal role. The Part B Grants to States program assists the 50 States and entities in meeting the excess cost of providing special education and related services to children with disabilities. Children with disabilities served under IDEA must be determined to be eligible under 1 of 13 categories.

In recent years, with the exception of the category of autism, the number of students receiving special education and related services has remained relatively stable. The reported numbers of children receiving services under the category of autism grew disproportionately as States and local districts became aware that children with the disorder could be reported as such rather than under other disability categories. We also believe the increase in the category of autism is a result of improved identification and evaluation procedures.

Most funds provided to States must be passed on to local education agencies. However, a portion of the funds should be used for State-level activities such as administration, monitoring, mediation, direct and support services, developing plans for the State improvement program and helping LEAs address personnel shortages.

Mr. BURTON. Excuse me, Ms. Guard. I think this is the information that you have already given to us in your opening statement about the law. I think we're familiar with all of that.

Ms. GUARD. OK. I'm just summarizing my statement. I'm just about finished. I will talk about the monitoring process.

Mr. BURTON. That's fine. Go ahead.

Ms. GUARD. OK.

Another Federal role is monitoring and enforcement of IDEA. Our intent in the monitoring process is to work with States to identify problems as early as possible and then help State and local personnel to acquire the tools and skills they need to correct these problems. We have found that the longstanding systemic problems cannot be quickly corrected. We've tried to use tools and mechanisms that allow States sufficient time to make corrections that will be effective and sustained.

The Department has at its disposal a number of enforcement tools. It is important, however, that these enforcement tools be used appropriately. We fully recognize the urgency of and our responsibility for ensuring compliance with IDEA. The time a child is not receiving appropriate services is time lost that cannot be regained.

Another Federal role is to provide support for the development, dissemination and utilization of effective services programs to im-

prove results for students with disabilities. States and schools must have access to research-based practices that we know work to improve results for students with disabilities. The IDEA Part D National Activities program, which represents less than 1 percent of the annual national expenditure to educate children with disabilities, enhances the capacity of States to develop infrastructures to support the full range and effective implementation of IDEA through a variety of strategies including research, personnel preparation, technical assistance and dissemination, technology and studies and evaluations.

For children diagnosed with autism and related disorders this has meant an increased OSERS focus on funding teacher training, including distance-learning projects to reach teachers in rural areas. It has meant developing model demonstration projects for children with autism that can be matched to the individual needs of the child. The National Academy of Sciences is conducting OSERS-funded research to examine the effectiveness of various interventions for children with autism. Findings of the study are expected to be released in July 2001.

In closing, the IDEA is designed to make sure that children with disabilities have an equal opportunity to meet challenging academic standards, to learn, to stay in school, to graduate and move on to post-secondary education and the world of work. Many of the issues States are dealing with are complex educational issues that all of the education community is addressing. We believe that in most cases States and local districts are working in good faith to improve services to children with disabilities and to correct noncompliance. We also believe that no parent should bear the burden of enforcement just to get an education for his or her child. To that end, we recognize that if we are to fulfill our role, we must not simply monitor the States, but we must hold States accountable and have an ongoing presence providing technical assistance.

By working collaboratively, we can improve the quality of education for children with disabilities. We can focus valuable time and fiscal resources on teaching and learning. Our children deserve nothing less.

I will be happy to take any questions. Thank you.

Mr. BURTON. Thank you, Ms. Guard.

[The prepared statement of Ms. Guard follows:]

Testimony of
Patricia J. Guard
Acting Director, Office of Special Education Programs
U.S. Department of Education
Washington, D.C.
Before the
Committee on Government Reform
United States House of Representatives
Wednesday, February 28, 2001

Mr. Chairman and Members of the Committee:

Last November we celebrated the 25th anniversary of the signing of the *"Education for All Handicapped Children Act"*, now called the *"Individuals with Disabilities Education Act" or "IDEA"*. As we explore the implementation of IDEA, it is important to take time to reflect on the tremendous progress that has been made in the education of children with disabilities since the passage of this landmark civil rights legislation.

Over the last 25 years, IDEA has been successful in ensuring that children with disabilities have access to a free appropriate public education. Prior to IDEA, in 1970 for example, schools in America educated only one in five students with disabilities. Many States had laws excluding certain students, like those who were blind, deaf, emotionally disturbed, or mentally retarded. Over one million students were excluded from public schools and another 3.5 million did not receive appropriate services. Many children, almost 200,000 with mental retardation or mental illness, were institutionalized.

In contrast, today more than six million infants, toddlers, and children with disabilities are provided early intervention and special education services. Over 95 percent of students with disabilities are being educated in public schools. Post school employment rates for youth served under IDEA are twice that of older adults with disabilities who did not benefit from IDEA in school. And the percentage of college freshman reporting a disability has almost tripled since 1978.

Despite this progress, significant challenges remain. Whereas Public Law 94-142 issued a national challenge to ensure access to education for all children with disabilities, the 1997 Amendments to IDEA articulated a new challenge which is to improve the quality of that education so that children with disabilities can, to the maximum extent possible, meet challenging standards that have been established for all children, and be prepared to lead productive, independent adult lives. The IDEA 97 amendments focus heavily on ensuring that children with disabilities have access to the general curriculum and that they are included in general assessments that States use to assess the success of their educational systems and to hold those systems accountable for improving student

results. The IDEA 97 Amendments also expand the role of parents in the decisionmaking regarding evaluation, eligibility, development of the Individualized Education Program (IEP) and placement.

As we review implementation of IDEA, it is important to recognize that this law calls for a Federal, State and local partnership. It is important to understand the roles of each of these entities in the implementation of this law. The Federal role is to serve as a steward for Federal investments, to develop improved interventions through research and development, and to provide financial support and technical assistance to assist States in complying with Federal law and correcting systemic problems. The Federal role necessitates on-going technical assistance to States, periodic monitoring of compliance with IDEA, directives for corrective action, and differential levels of enforcement and sanctions relative to the intensity, pervasiveness, and persistence of problems within States.

The State role parallels the Federal role in supporting and ensuring implementation of IDEA. By accepting Federal IDEA funds, States have an obligation to ensure consistent compliance with the IDEA statutes and regulations throughout the State. The State's general supervision role entails not only stewardship of the allocated Federal funds but also of the much larger State investments that support children with disabilities. The general supervision role also necessitates an ongoing monitoring presence in the school districts and resolution of parent or student complaints filed with the State. The State agency has the obligation to ensure that each child with a disability is identified and receives appropriate services. In addition, the State plays a critical role in ensuring that districts have an adequate supply of appropriately trained teachers, administrators, and other service providers to ensure that children with disabilities receive high-quality instruction. States also have responsibility for setting performance goals for students with disabilities and assisting school districts with meeting these goals through identification and support of promising practices, development of model demonstration projects and support of other effective research-based practices.

Local districts develop policies and procedures for practical implementation of the State and Federal laws in each school in the district. Local educational agencies (LEAs) must make certain that staff throughout the district are knowledgeable of the Federal and State requirements and that services are provided to students and families consistent with the IEP developed by a team of professionals and parents for each child with a disability. Parents play a key role, along with school personnel, in developing, reviewing and revising, if necessary, their child's IEP, and in determining the type and intensity of services the child needs and where the services will be provided. If the parent and local school district staff cannot agree on the content of the IEP or the recommended placement, the parent can file a complaint with the State if they believe the school district has violated a requirement of the law. The parent can also ask for a due process hearing and mediation must be available to parents who request a due process hearing.

The remainder of my testimony will elaborate on the Federal role.

Within the Department, the Office of Special Education and Rehabilitative Services (OSERS) administers the IDEA, which consists of both formula and competitive grant programs: Part B, including the Preschool Program; Part C, Infants and Toddlers with Disabilities Program; and Part D, national activities programs.

The Part B Grants to States program assists the 50 States, the District of Columbia, Puerto Rico, the Secretary of the Interior and Outlying Areas in meeting the excess costs of providing special education and related services to children with disabilities. In order to be eligible for funding, States must serve all children with disabilities ages 3 through 21 years, except that they are not required to serve children ages 18 through 21 if services are inconsistent with State law. Funds are allocated to States based on a variety of factors, including population and poverty. The FY 2001 appropriation includes $6.34 billion for the Part B program. The 2001 Federal share represents 15% of the national average per pupil expenditure, and 13% of the excess costs of educating children with disabilities. This amount will provide approximately $992 per child for an estimated 6.4 million children with disabilities ages 3 through 21 who are expected to be served. Children with disabilities served under IDEA must be determined to be eligible under one of thirteen categories. In recent years, with the exception of the category of autism, the number of students receiving special education and related services has remained relatively stable. The reported numbers of children receiving services under the category of autism grew disproportionately as states and local districts became aware that children with the disorder could be reported as such, rather than under other disability categories. We believe the increase in the category of autism is also a result of improved identification and evaluation procedures.

Most funds provided to States must be passed on to local educational agencies. However, a portion of the funds should be used for State-level activities such as administration, monitoring, mediation, direct and support services, developing plans for the State Improvement program, and helping LEAs address personnel shortages.

The Preschool Grants program also provides formula grant funds to States ($390 million in FY 2001) to assist with the cost of providing a free appropriate public education to all children with disabilities ages 3 through 5. The Part C Infants and Toddlers with Disabilities program provides funds ($384 million in FY 2001) for early intervention services for infants and toddlers birth through age two and their families.

The Part D National Activities programs support a wide range of research, training, technical assistance and technology investments. These investments provide tools to and opportunities for States, school districts and schools to more effectively and efficiently implement IDEA. The 2001 appropriation includes approximately $327 million for these programs.

Another Federal Role is monitoring and enforcement of IDEA. OSERS is responsible for assessing the impact and effectiveness of State and local efforts to provide early intervention services to infants and toddlers with disabilities and their families, and a free appropriate public education to children and youth with disabilities. For twenty years following the passage of PL 94-142 in 1975, we were implementing a statute that was primarily procedural in nature, and most monitoring findings, therefore, focused on the procedures used to make and implement decisions, rather than the impact of instruction. OSERS has been working hard since the enactment of IDEA 97 to administer the Act in a way that drives and supports improved results for children and youth with disabilities without sacrificing any effectiveness in ensuring that the individual rights of children with disabilities and their families are protected. We have recognized that we, at the Federal level, can have the greatest positive impact on the learning and opportunities afforded children with disabilities by ensuring that State systems are accountable for results for all children, including children with disabilities.

In 1998, OSERS reinvented its system for monitoring State compliance with IDEA after extensive input from a broad base of professional, parent and advocate groups. This new Continuous Improvement Monitoring Process is data driven and focuses on State responsibilities for continuous improvement and accountability for compliance and for improving student results. The new monitoring system focuses on those issues most critical to protecting the rights of children and their families and on the States' general supervision responsibilities, including monitoring and dispute resolution. This new system is different from previous OSEP monitoring in that it is ongoing, rather than episodic. It includes partnership with State agency personnel, parents, advocates and other agencies at all points of the process including planning, data collection, and implementation of improvement strategies.

This continuous improvement model is customized for each State according to the State's needs. Critical to the success of the Continuous Improvement Monitoring Process is the Steering Committee. The Steering Committee is a stakeholder group including representation from parents, advocates, State agency personnel and others that have an interest in improving results for children with disabilities. Through the Steering Committees and enhanced opportunities for input from the public, we have seen increased involvement of parents, advocates and other State agencies in the monitoring process. We anticipate this will result in a greater likelihood of systemic changes that, in turn, will have a positive impact on better results for children with disabilities.

With a more collaborative overall process that holds States accountable for addressing deficiencies, we have already seen positive results. As a direct result of the new system, one State has revised its funding formula removing incentives for restrictive placements, and another State has revised its monitoring system to better ensure that services were received and rights were protected at the local level. In addition, a number of States have improved their systems of complaint resolution, making them more responsive to parent complaints, resolving the complaints in a more timely and effective manner. Strong, effective State complaint resolution is less costly and less adversarial than due process hearings and court cases.

Our intent in the new monitoring process is to work with States to identify problems as early as possible, and then help State and local personnel to acquire the tools and skills they need to correct these problems. We have found that longstanding systemic problems cannot be quickly corrected. We have tried to use tools and mechanisms that allow States sufficient time to make corrections that will be effective and sustained. The Department has at its disposal a number of enforcement tools. It is important, however, that these enforcement tools be appropriately used. We fully recognize the urgency of and our responsibility for ensuring compliance with IDEA--the time a child is not receiving appropriate services is time lost that cannot be regained. When problems are found that can be corrected within a year, the Department generally requires the State to implement a corrective action plan or, in cases where the problems are more serious, the Department designates the State as a high-risk grantee and requires corrective actions as conditions for receiving a grant award. If the problems cannot be corrected within a year's time, the Department can offer the State a compliance agreement that gives the State up to three years to correct the identified problems. In cases where a State is not appropriately exercising its general supervision responsibility and the identified problems are significant violations of the statute and regulations, we can withhold the Federal funds or, in accordance with the 1997 Amendments to IDEA, refer the matter to the Department of Justice.

Another Federal role is to provide support for the development, dissemination and utilization of effective services and programs to improve results for students with disabilities. States and schools must have access to research-based practices that we know work to improve results for students with disabilities. The IDEA, Part D National Activities programs, which represent less than 1 percent of the annual national expenditure to educate children with disabilities, enhance the capacity of States to develop infrastructures to support the full and effective implementation of IDEA through a variety of strategies including: research, personnel preparation, technical assistance and dissemination, technology, and studies and evaluations. For children diagnosed with autism and related disorders, this has meant an increased OSERS focus on funding teacher training, including distance learning projects to reach teachers in rural areas. It has meant developing model demonstration projects for children with autism that can be matched to the individual needs of the child. The National Academy of Sciences (NAS) is conducting OSERS-funded research to examine the effectiveness of various interventions for children with autism. Findings of the NAS study are scheduled to be released in July, 2001. Later this year, OSERS will fund a major initiative to improve the capacity of schools to intervene early with children experiencing particularly challenging problems in reading or behavior. In addition, OSERS funds twenty-seven State Improvement grants, awarded on a competitive basis, that primarily support the professional development needs of the State.

OSERS also funds a technical network that supports the implementation of IDEA. These investments include six Regional Resource Centers that provide technical assistance to meet the needs of States as they administer IDEA. Four Partnership grants for policymakers, local administrators, service providers, and parents respond to the

needs of each of these groups as they carry out their roles in implementing IDEA. Members of the Partnerships include, among others, the Chief State School Officers, the National Governor's Association, the State Boards of Education, the National Education Association and the American Federation of Teachers. The FY 2001 appropriation provides funds for an $8 million investment in technical assistance to States to support monitoring and systemic improvement activities. The National Early Childhood Technical Assistance System (NECTAS) at the University of North Carolina assists state departments of education by providing training, teleconferences and materials on important topics such as autism.

The technical assistance network supported under Part D also includes major technical assistance centers across the age ranges birth through 21 and across major topical areas such as access to the general curriculum, assessment, and behavior. An example of a national technical assistance center on a topical area is the Consortium for Appropriate Dispute Resolution in Special Education (CADRE) at the University of Oregon. Prior to 1997, a number of States had developed effective mediation systems. California, for example, had 993 requests for mediation from 1991-1992. Only 14 percent of these cases went on to hearings. Mediation is generally significantly less costly than due process. In 1997, IDEA was amended to require States to offer mediation as a voluntary option to parents and LEAs as an initial process for resolving disputes. CADRE is a national center on dispute resolution that provides technical assistance to State departments of education on implementation of the mediation provision in IDEA 97. CADRE also supports parents, educators and administrators to benefit from the full continuum of dispute resolution options that can prevent and resolve conflict and ultimately lead to informed partnerships that focus on results for children and youth.

Recent data seem to indicate a trend away from formal hearings. For example, in 1996 with over 5.6 million children receiving services under IDEA, there were 7,532 requests for due process hearings. Only 3,555 resulted in hearings. The remaining 3,977 (58%) were settled by means other than a formal hearing. This compares with 1998 when over 5.9 million children received services. There were 9,827 requests for hearings with 3,315 going to hearing and 6,512 (66.2%) being settled without a hearing. It is expected that, with implementation of the mediation requirement in IDEA 97, the next few years will see an increase in this trend toward settlement of disputes through means other than formal due process hearings.

Part D funds also support a network of Parent Training and Information Centers. From the beginning of special education legislation, families of children with disabilities have been considered important partners in meeting the needs of children with disabilities. IDEA includes key principles to guide families and professionals to work together to enhance the educational opportunities for their children. IDEA requires active parent participation throughout the educational process including the development of the child's Individualized Educational Program (IEP). The overall goal is to maintain an equal and respectful partnership between schools and families. To that end, today, OSERS funds over 90 projects to empower families, including Parent Training and Information Centers in each of the 50 States, DC, Puerto Rico, Virgin Islands, American

Samoa and Palau. The training and information provided by the parent centers help ensure that parents have the knowledge and skills to help their children succeed. In addition to helping parents better understand the nature of their children's disabilities and their educational and developmental needs, the centers provide training and information on how parents can work with professionals serving their children, including development of the IEP. The Parent Training and Information Center in Indiana, IN*SOURCE, has developed and supported a cadre of parents of children with disabilities who have volunteered to participate in training and to serve and support other families in their local communities. Currently there are 321 parents serving as Regional Parent Resources with at least one in 73 of 92 Indiana counties. In 1999-2000, IN*SOURCE made contacts with over 16,000 parents and professionals.

In closing, the IDEA is designed to make sure that children with disabilities have an equal opportunity to meet challenging academic standards, to learn, to stay in school, to graduate and to move on to postsecondary education, and the world of work. Our experience with IDEA has demonstrated that all children can benefit from an education, regardless of specific disability, socio-economic status or ethnic or linguistic background. Many of the issues States are dealing with are complex educational issues that all of the education community is addressing. States are working with large numbers of school systems that are struggling to meet the ever-changing needs of a diverse community. We believe that in most cases, States and local school districts are working in good faith to improve services to children with disabilities and to correct noncompliance. We also believe that no parent should bear the burden of enforcement just to get an education for his or her child. To that end, we recognize that if we are to fulfill our role we must not simply monitor the States but we must hold States accountable and have an ongoing presence providing technical assistance. By working collaboratively we can improve the quality of education for children with disabilities. We can focus valuable time and fiscal resources on teaching and learning. Our children deserve nothing less.

I will be happy to take any questions you may have. Thank you.

Mr. BURTON. Ms. Baird. If you have a prepared statement for the record, we will be glad to use it in the record; but if you could stay as close to 5 minutes, it really would be helpful, so we can get to questions.

Ms. BAIRD. I will try to be unlike most of my colleagues in the legal profession and keep it short.

Mr. BURTON. Thank you.

Ms. BAIRD. My name is Melinda Baird, and I'm very honored to be here today, and I appreciate the opportunity to speak to the committee.

I'm an attorney in private practice in Knoxville, TN, and I've been working in the field of special education for approximately 16 years. It may not surprise you to know that I have a different perspective and view than some of the witnesses that have testified today. I believe very strongly that in most cases the IDEA is working.

Over the past 12 years I have provided hundreds of workshops and in-service training seminars for thousands of teachers, administrators and parents of students with disabilities. I would like to say at the outset that I have the utmost respect and empathy for all parents of children with disabilities, including those with children who are autistic.

For the past 4½ years I have been privileged to represent school districts in Tennessee, Alabama and Florida in litigation concerning the IDEA and section 504. One misconception I hope to correct is that parents are advocates, and school districts are not. I would also like to dispel the notion that school districts have unlimited funds and are anxious to pursue litigation.

Litigation in special education is a major concern for parents and for school systems. However, I believe we do need to keep it somewhat in perspective. According to the data compiled by the U.S. Department of Education, more than 6 million students were identified in 1998 and 1999 as being eligible under the IDEA.

I annually prepare a yearly summary of all Federal and State court decisions affecting special education, and I've attached this to my testimony. For school year 2000–2001, my summary includes a total of 77 decisions. Of these, parents prevailed in 42 percent of the cases, and school districts prevailed in 58 percent of the lawsuits. I have prepared such a summary for approximately the past 6 years, and the edge of majority goes back and forth between parents and schools rather consistently.

This number does not reflect the hundreds of decisions in due process hearings conducted at the administrative level. However, I think it is remarkable that on average each year less than 100 lawsuits are filed in Federal and State court out of a total of more than 6 million students receiving special education and related services.

I know there's been testimony today concerning the federally funded protection and advocacy organizations. I can only speak to my personal experience and information. I can tell you that in the States of Alabama and Tennessee particularly, there are extremely active and aggressive protection and advocacy organizations providing free and low-cost legal representation to parents of students with disabilities, including parents of children with autism. Fami-

lies also have options that I know you're aware of, such as filing complaints with the State, with the Office for Civil Rights or with the U.S. Department of Education.

Schools, on the other hand, must fund all of their legal costs with no Federal financial assistance. Most school districts do not have insurance coverage for these costs, and it is for this reason that school districts are very reluctant to pursue litigation unless they have carefully considered the merits of the case.

Without exception, the cases in which I have represented school districts have involved a difference of opinion as to what services are appropriate and required to be provided. I can say that I have never worked with a school district that wanted to deny appropriate services to a student with disabilities. In every case I have encountered administrators and teachers who sincerely believe that they were providing appropriate services to these students and who wanted to provide these services.

One of the most active areas of litigation involves parental requests for particular methodologies, and without a doubt the issue receiving the most national attention here today and across the country is educational methodologies for children with autism. As I said, I practice mainly in Tennessee and Alabama. In both of these States intensive statewide training has been conducted and is being conducted, and significant financial resources have been committed to provide local school districts with the latest training in a wide variety of methodologies, including Applied Behavior Analysis, Discrete Trial Training, and those being the methodologies used by the Lovaas methodology.

I would like to give you some information that I obtained this morning, and I'll be happy to provide it to the committee. In doing research on Education Administration Online, which is an online data base reporting special education decisions, I was surprised myself to see a very startling trend, and I think it's a positive trend in the cases involving children with autism. There are a total reported of 218 cases involving children with autism. That includes 59 State and Federal court decisions and 159 due process hearing decisions from the administrative hearing. That is total, period. There are no cases reported prior to 1994.

I can tell you from my own research that prior to 1996, parents won approximately two-thirds of all autism cases, but after 1996, parents are not winning that level, and schools, in fact, are winning two-thirds of the cases. The cases peaked in 1998 with 52. In 1999, there were 33. In the year 2015—and this year so far there are no reported cases. About half of those cases involve parents seeking reimbursement for some of the methodologies that you have heard today. I think these statistics indicate that schools are receiving training and that they are getting their act together, so to speak, in knowing how to provide services for children with autism.

The IDEA has done wonderful things for millions of children with disabilities and hopefully will continue to do so. I hope that the committee will recognize the efforts of schoolteachers and administrators to advocate on behalf of children with disabilities, not only those with autism.

The IDEA was reauthorized, as you know, in 1997. We got Federal regulations in 1999. I have been on the road all over this country trying to help schools understand what they're supposed to do. It's a big burden, but I believe they have risen to the challenge. We don't need more laws and regulations. We do need full funding at the 40 percent promise.

And I'd just like to say in closing that I think it would be wrong to assume that all complaints filed against school districts are without merit, but I think it would be equally wrong to assume that all complaints filed against school districts have merit. I think the fact that we have the small number of disputes that we have is, in fact, evidence that the system is working, not evidence to the contrary, and I thank you, and I'll be happy to answer any questions.

[The prepared statement of Ms. Baird follows:]

TESTIMONY BEFORE THE

COMMITTEE ON GOVERNMENT REFORM

CONGRESSMAN DAN BURTON, CHAIR

FEBRUARY 28, 2001

Melinda Baird, Esquire
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My name is Melinda Baird, and I am honored to provide this testimony for the Committee today. I am an attorney in private practice in Knoxville, Tennessee, and have been working in the field of special education law for almost sixteen years. My practice is devoted exclusively to the representation of school districts in special education matters. I formerly served as an attorney in the Office of Special Education Programs for the Tennessee Department of Education and as Associate Publisher for Education and Disability Publications for LRP Publications.

Over the past twelve years, I have provided hundreds of workshops and in-service training seminars for thousands of teachers, administrators, and parents of students with disabilities. I have attended hundreds of IEP meetings and reviewed hundreds of IEPs. For the past four-and-a-half years, I have represented school districts in Tennessee, Alabama, and Florida in litigation concerning the IDEA and Section 504 of the Rehabilitation Act of 1973.

The reauthorization of the IDEA in 1997 resulted in sweeping changes in the provision of special education and related services to students with disabilities. During the past four years local school districts have worked diligently to implement new requirements for inclusion of students with disabilities in the general curriculum, discipline of students with disabilities, and testing of these students. Despite the best efforts and good intentions of lawmakers, the paperwork burden for special education has increased rather than decreased. Although federal funding for special education programs has increased, the increasing number of students identified under the IDEA and the increasing demand for new programs and services continues to strain local budgets. In my opinion and based on my experience, local school districts are doing an admirable job of providing appropriate special education and related services to these students, and are rising to the challenge of meeting the mandate and increasing expectations of the law.

According to data compiled by the U.S. Department of Education, more than six million students were identified in school year 1998-99 as being eligible under the IDEA.[1] Almost half of these students were identified as learning disabled. I annually prepare a yearly summary of federal and state court decisions affecting special education, which I have attached for your information and review. For school year 2000-2001, my summary includes a total of 77 decisions. Parents prevailed in 33 (42%) of these cases, with school districts winning in 44 (58%) of the lawsuits. Of course, this number does not reflect the hundreds of decisions in due process hearings conducted at the administrative level. However, I think it is remarkable that, on average, less that one hundred lawsuits are filed in federal and state court out of a total of more than six million students receiving special education and related services. The Committee members

[1] Source: 22nd Annual Report to Congress on the Implementation of the IDEA.

should remember that in each state there is a federally funded agency providing free or low-cost legal representation to parents of students with disabilities. Therefore, families of students with disabilities are able to initiate a legal action against their local school district either at no cost or low cost whenever they believe their child's rights have been violated. Parents also have the option of filing a complaint with the Office for Civil Rights and their State Department of Education, and of requesting formal mediation at no cost to them. School districts must fund their legal costs without federal financial assistance, and many districts do not have insurance coverage for litigation costs. For this reason, school districts usually do not pursue litigation without carefully considering the merits of each case.

Without exception, the cases in which I have represented school districts have involved a difference of opinion as to what services are "appropriate" and therefore required to be provided under the IDEA. I have never worked with a school district that wanted to deny appropriate services to a student with disabilities. In every case, I have encountered school administrators and teachers who sincerely believed that they were providing appropriate educational programs and services to these students and who wanted to provide these services.

One of the most active areas of special education litigation involves parental requests for a particular educational methodology. The case law is clear that parents do not have a right to insist on a particular methodology if the school district is providing special education and related services that are "reasonably calculated" to provide meaningful educational benefit to the child.[2] However, school districts are confronted

[2] Bd. of Education of the Hendrick Hudson Cent. Sch. Dist. v. Rowley, 458 U.S. 176, 206-207, 102 S.Ct. 3034, 3051, 73 L.Ed.2d 690 (1982).

with a steady stream of parental requests for methodologies designed for children with learning disabilities, autism, speech/language impairments, and other disabilities. Some of these methodologies are supported by research literature, and some are not. It is the school district's responsibility to provide "appropriate" educational services, not the particular methodology desired by parents. It is also education's responsibility to seek out and explore newly developed methodologies in order to provide "appropriate" educational services that keep pace with current research and best practices. Without a doubt, the issue receiving the most national attention is the education of children with autism.

I practice mainly in Tennessee and Alabama. In both of these states, intensive statewide training has been conducted and significant financial resources have been committed to provide local school districts with the latest training in a wide variety of educational methodologies designed for children with autism, including Applied Behavioral Analysis/DTT. In 1999 and 2000 I co-presented a series of national workshops on legal issues in autism attended by more than 1400 educators, attorneys and parents from across the United States. I have attached a copy of my outline for your review and information. For the past two years, the National Institute on Legal Issues of Educating Students with Disabilities has offered sessions devoted exclusively to legal issues in autism. The education of children with autism with appropriate methodologies is a top priority for educators and administrators, and States and local school districts have been zealous in their efforts to obtain and provide training for teachers, aides, and others who work with these children.

Prior to 1996, local school districts lost approximately 75% of all lawsuits initiated by parents of children with autism. However, after 1996 local school districts have won the majority of these lawsuits. I attribute this trend to the national movement launched by States and local school districts to provide training on effective methodologies for educating children with autism and to develop appropriate educational programming for these children.

The field of special education law is very emotional. I admit to being passionate about it myself. I understand and acknowledge that many parents feel that they must fight to get appropriate services for their children with disabilities. However, I hope the Committee will not overlook the fact that school personnel often feel that they must fight parents in order to provide appropriate educational services to these students. I personally have initiated several due process hearings on behalf of school districts in an effort to get permission to evaluate children who needed special education and related services. I have also advocated on behalf of a school district that sought to fund a residential placement for a student with a serious emotional disturbance at a cost of approximately $100,000 per year. The battle to get appropriate educational services for children with disabilities is not always fought by parents. At times, it is necessary for school districts to challenge parents for the right to provide appropriate educational services for these children.

I understand and acknowledge that there are parents who are not satisfied with the educational programs offered to their child, or with the educational progress made by their child. But it is equally important to recognize that teachers and administrators are

frustrated when parents place unreasonable demands on them and request programs and services that are not required in order to fulfill the law's mandate.

Schools are working hard to ensure that each child with disabilities is provided an appropriate education in the least restrictive environment. I often remind my clients that the law guarantees a free appropriate public education to the child, and that our responsibility is to the child. Sometimes this means that the child's parents will not agree with the school's recommendations. In those cases, the law provides a complex scheme of procedural rights and the availability of free or low-cost legal representation for parents of students with disabilities. I can testify that the parents I encounter are well aware of their legal rights and freely take advantage of the legal process.

My husband is a retired educator with twenty-eight years of experience as a special education teacher and administrator. He has worked in special education since before the enactment of the IDEA's predecessor, the EAHCA, in 1975. I have worked in this field since 1985. We have both witnessed many changes in the provision of educational services to students with disabilities. The IDEA has done wonderful things for millions of children with disabilities, and will continue to do so. Our public schools employ thousands of teachers and administrators who are committed to providing appropriate educational services to these children. Every day I work with these committed and caring professionals. I hope that the Committee will recognize their efforts to advocate on behalf of children with disabilities.

The IDEA is a complex law regulating the provision of special education and related services to children with disabilities that guarantees significant procedural protections for their parents. The law's protections are more than sufficient to protect the

rights of parents and to guarantee the provision of appropriate educational programs and services for children with disabilities. Schools don't need more laws and regulations – they need full funding of the 40% federal promise for supporting special education programs. Schools also need your support and recognition for the wonderful job done daily by our teachers, administrators, and related service personnel.

It would be wrong to assume that all complaints filed against school districts are without merit. It would also be wrong to assume that all complaints filed against schools have merit. The fact that we have disputes between school districts and parents of children with disabilities is proof that this system is working, not proof that the system is flawed.

Thank you for the opportunity to offer this testimony.

Sincerely,

Melinda Baird

Melinda Baird

The Year in Review: What Are the Courts Saying About Special Education?

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I. DISCIPLINE OF STUDENTS WITH DISABILITIES

1. Balbi v. Ridgefield Pub. Schs., 33 IDELR 97 (Conn. Sup. Ct. 2000); For the parents.

A 16-year-old student who had been found no longer in need of special education and related services was expelled for threatening another student with a knife and stealing personal property. A state court ordered the school district to expunge the student's records and overturned the expulsion after the parents claimed that their son was disabled and still eligible for special education. The school was also ordered to re-institute the student's special education eligibility and to convene an IEP team. Although the student was not classified as a special education student at the time of the misbehavior, his former eligibility was sufficient reason for the school district to treat him as a special education student for disciplinary purposes.

2. Board of Education of Frederick County v. J.D.,III, 33 IDELR 182 (4th Cir. 2000); For the school district.

J.D. was an honors student whose academic performance began to deteriorate during his ninth grade year. Although he passed all of his courses, J.D. was clearly not performing to the level of his intellectual ability. During the ninth grade, he was disruptive and disrespectful in class, got into fights, and began smoking marijuana. J.D.'s physician diagnosed him as having ADHD and prescribed Ritalin to be administered during the school day. J.D.'s behaviors worsened during the tenth grade, and he was hospitalized after physically attacking his therapist. J.D. was eventually diagnosed with ADHD, Bipolar Disorder, Obsessive-Compulsive Disorder, and Marijuana Abuse. When he was released from the hospital J.D. returned to school and passed all of his honors courses.

Throughout this time, J.D. was never evaluated by the school district for special education and related services. School officials denied allegations that the parents had repeatedly sought an evaluation. Prior to his eleventh grade year, J.D. was arrested for assaulting three police officers and was later hospitalized for psychiatric treatment. J.D.'s drug use continued, and he was often truant from school. Eventually, J.D.'s parents placed him first in a therapeutic boarding school in Connecticut, and later in a drug treatment facility in Utah. J.D.'s parents initiated a due process hearing seeking reimbursement for the costs of these private placements.

A hearing officer ordered the school district to pay for the costs of both private placements, finding that it failed to identify and evaluate J.D. as a student with disabilities. On appeal, a federal court reversed the hearing officer's decision, finding that J.D.'s behavior was caused by his "social maladjustment," and that he did not qualify as a student with an "emotional disturbance." The Fourth Circuit affirmed the trial court's decision.

3. Richland Sch. Dist. v. Thomas P., 32 IDELR 233 (W.D. Wis. 2000); For the parents.

A student diagnosed as learning disabled was involved in a vandalism incident in which $40,000 worth of property as two elementary schools was destroyed. The student admitted to police that he drove the "get-away car" for two friends who vandalized the schools. Because the student was disabled, the school conducted a "manifestation determination" prior to his recommended expulsion, and easily found that the student's behavior had nothing to do with his disability. Afterwards, the boy's mother took him for an independent psychological evaluation. A clinical psychologist diagnosed the boy with ADD and dysthymia, and concluded that these "disabilites" led to his involvement in the vandalism incident.

After an ALJ set aside the expulsion, the school appealed the decision. A federal court upheld the ALJ's decision based on the testimony of the clinical psychologist that young males with ADD are chemically attracted to risk-taking and thrill-seeking behavior and do not think about the consequences of their behavior. The ALJ was not persuaded by the testimony of the school psychologist, who testified that because the student made a conscious decision not to enter the buildings with his accomplices, he demonstrated some control and did not want to be involved to the same extent -- contraindicating the impulsivity associated with ADD.

4. Demers v. Leominster Sch. Dept., 32 IDELR 201 (D. Mass. 2000); For the school district in part; the parent, in part.

A special education student was expelled after he drew a picture of the school surrounded by explosives and the superintendent with a gun to his head. School officials reportedly told the parents that the boy would be allowed to return to school if they

obtained a psychiatric evaluation. Instead, the parents filed suit in federal court seeking money damages under Section 1983 and an injunction to stop their son's expulsion.

The federal court dismissed the action for failure to exhaust administrative remedies, and instructed the parents to request an expedited due process hearing to resolve the matter.

5. Randy M. v. Texas City ISD, 32 IDELR 168 (S.D. Texas 2000); For the school district.

A 13-year-old boy with a learning disability and a friend allegedly tore off the breakaway pants of a female student. The school district convened an IEP meeting, and the IEP team determined that the action was not a manifestation of the boy's disability. The team recommended that the student be suspended and sent to the alternative school. The parents initiated a due process hearing seeking an injunction to stop the suspension. The hearing officer ruled in favor of the school district, and the parents appealed to federal court.

The federal trial court affirmed the hearing officer's decision, finding that the school district acted appropriately and was "justified in taking stern and aggressive remedial action. In addition, the district had offered several opportunities for the parents to provide evidence that the student's actions were caused by a disability.

6. Parent v. Osceola County Sch. Board, 32 IDELR 144 (M.D. Fla. 1999); For the school district.

A child with emotional and learning disabilities had a history of behavior problems. In the ninth and tenth grade, he received numerous disciplinary sanctions for fighting, disobedience and profanity. On one occasion, while he was riding on the school bus, he slashed another student's face with a box cutter. As a result, he was placed in a juvenile detention center and was suspended from school. A staffing committee convened a manifestation determination meeting to determine the relationship between his misbehavior and his disability, and concluded that there was no connection because the student planned to bring the weapon on the school bus. The principal recommended that the student be expelled for the remainder of the school year, and the staffing committee decided to place the student in an alternative school for the remainder of the school year. During the student's tenure at the alternative school, the student only missed 2 days of school, earned passing grades in all classes, and performed well in the behavior management program there. He briefly left the alternative school to serve a sentence at a residential school, having been found guilty of aggravated battery with a deadly weapon due to the slashing incident. A meeting was held to determine the student's placement for the following school year. The principal recommended a continuation of the alternative school placement and the committee agreed with this view. The parent requested due process. An ALJ found that the student received FAPE at the alternative school and directed that he remain there. The parents appealed.

The court ruled for the school district, finding that the School's continued placement of student at alternative school was appropriate under the circumstances. The alternative school provided the student with a reasonable educational benefit. Although the student was only offered limited extra-curricular activities and did not have a reading instructor certified to teach special education at the alternative school, his behavior improved while he was there and he showed progress through the educational system as evidenced by earning passing grades in all courses, including reading. The alternative school also satisfied the LRE requirement. It was well established in the case law that schools have been allowed to remove students whose disruptive behavior poses a danger to other students from a regular education setting, and place them in a more restrictive environment. The circumstances surrounding this case justified such a placement. The student engaged in repeated episodes of misconduct in the public school. In contrast, his behavior improved at the alternative school due to a small student population and the behavior management program that was available there. Moreover, there was ample evidence to show that while the student's behavior improved at the alternative school, he would still be a danger to himself and others if placed at the school.

II. EVALUATIONS AND ELIGIBILITY

7. Holmes v. Millcreek Township Sch. Dist., 32 IDELR 1 (3rd Cir. 2000); For the school district.

The parents of a profoundly deaf fifth-grader objected to the school district's proposal to conduct a reevaluation using a psychologist accompanied by a sign language interpreter. Rather, the parents demanded that the school district evaluate their daughter by a psychologist who was proficient in sign language. The parents privately obtained such an evaluation and requested reimbursement in the amount of $400.

A hearing officer agreed with the parents and awarded reimbursement for the private evaluation. However, a review officer reversed this award. On appeal, a federal court ruled that the school district was required to pay for the private evaluation because parts of the evaluation had been relied on in the formulation of the girl's IEP. The school district appealed to the Third Circuit. The circuit court reversed the trial court's ruling, holding that the school district's original evaluation was appropriate and denying the parents' request for reimbursement. According to the Court, the fact that the IEP team had accepted some of the recommendations of the private evaluation did not obligate the district to pay for the evaluation. It was also irrelevant that the school district's evaluator was not fluent in American Sign Language (ASL). The Court acknowledged that an ASL-fluent psychologist may have been preferable, but noted that the parents' own experts admitted that the school psychologist was capable of conducting an appropriate evaluation with the assistance of a sign language interpreter. The court also stated that the school psychologist was better suited to evaluate the girl because he was already familiar with the child, her educational progress, and the curriculum requirements.

8. <u>Corchado v. Board of Education, Rochester City Sch. Dist.</u>, 32 IDELR 116 (W.D.N.Y. 2000); For the parents.

Sadrach is a 10-year-old fourth grader who suffered from multiple and complex medical difficulties including a seizure disorder, ADHD with aggressive tendencies, a psychomotor delay, mild asthma, and learning disabilities. During the first grade, he periodically needed home and hospital tutoring because his seizures and asthma prevented him from attending school. During the second grade, Sadrach's mother submitted a formal referral for special education evaluation. The district's committee on special education rejected it, finding that Sadrach had made progress, that his achievement was average for his grade placement, and that his medical problems were not significantly impacting his overall progress. The parent obtained an independent medical evaluation that concluded that Sadrach had significant learning disorders and/or neurological problems. During this evaluation Sadrach had a seizure lasting approximately 30 seconds. Testing indicated that he was reading at a beginning second grade level, his reading comprehension was at the end of the first grade level, math problem solving was at the end of the first grade level, and math computation was at a mid-second grade level. The evaluator strongly recommended that Sadrach be identified as eligible for special education services.

The school district refused to accept the independent evaluator's recommendations. Significantly, the district discounted the results on the grounds that the testing was completed in English while Sadrach's dominant language was Spanish. The district's evaluation, completed in Spanish, concluded that Sadrach's full scale IQ is 130. The district's position was that although Sadrach has a seizure disorder and ADHD, these disorders do not negatively impact on his academic performance in the classroom. The parent requested a due process hearing to challenge the district's decision.

A hearing officer agreed with the school district that the child was not eligible for special education and related services and a review officer affirmed this decision. On appeal, the federal court reversed and held that the evidence established that Sadrach was eligible for special education and related services under the categories of "other health impaired," "learning disabilities," and "speech impairment." Specifically, the administrative record confirmed that Sadrach continued to have regular uncontrolled seizures that affected his alertness in class. Also, the record documented his long history of speech impairment – the independent evaluator found that he had deficits in his ability to register auditory information in short-term memory, integrate information in active working memory, and process information at the phonological level. Finally, the district's own psychological testing results acknowledged a startling discrepancy between Sadrach's ability and achievement levels. Therefore, the court determined that Sadrach's disabilities adversely impacted his educational performance and directed the school district to develop and implement an IEP for him.

III. PLACEMENT

A. Free Appropriate Public Education

9. Board of Education of the County of Kanawha v. Michael M., 33 IDELR 185 (S.D. W. Va. 2000); For the parents.

The parents of an eight-year-old boy with autism supplemented their son's public school program with home-based LOVAAS therapy. When the school district refused to pay for the LOVAAS program the parents initiated a due process hearing. A hearing officer ruled in favor of the parents and ordered the school district to reimburse them past and prospective costs of providing the LOVAAS program.

On appeal, a federal court affirmed the hearing officer's decision. The court found that the school district failed to prove that its program had benefited the child. Moreover, the court found that the parents proved that the child's progress was attributable to the LOVAAS therapy. While the school district offered, "skimpy conclusions and quibbles over perceived evidentiary and procedural flaws," the parents "established a direct nexus between the supplemental home-based program and [the student's] progress."

10. Burilovich v. Board of Educ. of the Lincoln Consolidated Sch., 32 IDELR 85 (6th Cir. 2000); For the school district.

The parents of a kindergartener with autism consulted with Dr. Patricia Meinhold regarding their son's educational needs. Dr. Meinhold recommended a home-based LOVAAS program. The parents, accompanied by Dr. Meinhold, attended an IEP meeting chaired by the school district's new supervisor of special education. The administrator verbally agreed to implement Dr. Meinhold's recommendations, including funding for a home-based LOVAAS program. This agreement was not written down. Following the IEP meeting, the special education staff persuaded the administrator that the LOVAAS program would not be appropriate for the child. A second IEP meeting was convened to finalize the student's IEP. At this meeting, the school district proposed placing the child in a regular education classroom with a 1:1 aide. The parents rejected the IEP and initiated a due process hearing seeking reimbursement for the LOVAAS program.

A hearing officer ruled in favor of the school district, finding that the district's IEP offered FAPE for the child. This decision was affirmed by a federal trial court and the Sixth Circuit.

The court rejected the parents' argument that the verbal agreement to provide in-home LOVAAS constituted a formal IEP recommendation. The court held that an offer must be written into an IEP in order to be valid and enforceable. The court also ruled that the school district was not required to invite the parents' autism expert, Dr. Patricia

Meinhold, to the IEP meeting, noting that Dr. Meinhold's written report was considered by the IEP team members.

11. T.S. v. Lee's S ummit R-7 Sch. Dist., 32 IDELR 237 (W.D. Mo. 2000); For the school district, in part.

The parents of a seven-year-old child with autism claimed that their child suffered regression as a result of the inappropriate program provided by the school district. A hearing officer found the evidence insufficient to prove that the child's regression had been caused by the school's actions. However, the hearing officer did order the school district to provide a summer program for the child. On appeal, the federal court affirmed the hearing officer's decision. The court found no proof of what caused the child's regression, but noted that she had recouped many of the skills she had lost. The court found that the provision of a summer program would be sufficient to remediate any regression attributable to the school district.

12. O.F. v. Chester Upland Sch. Dist., 32 IDELR 114 (E.D. Pa. 2000); 32 IDELR 167 (E.D. Pa. 2000); For the school district.

O.F., a 9-year-old student with a severe emotional disturbance, was physically threatened by another student in the presence of school employees. She became agitated and started screaming, and ran into the principal's office where she was restrained by three district employees. Local police arrived, handcuffed O.F. and placed one of her legs in a restraint. O.F. was removed from school by ambulance and taken to a hospital. Eventually, O.F. was transferred to a residential school for students with emotional disabilities. The student's guardian filed a lawsuit, charging the school district with violating the IDEA, ADA, Section 504, the U.S. Constitution, and Section 1983. The guardian also asserted a claim for false imprisonment and sought money damages and injunctive relief requiring immediate implementation of crisis intervention procedures. The school district moved to dismiss for failure to exhaust administrative remedies. The court ruled that administrative exhaustion was not required on the IDEA claim because money damages are not available in a due process hearing. The court dismissed the Constitutional claims for failure to state sufficient factual allegations upon which to base the claims. The false imprisonment claims were dismissed because the school district was protected by governmental immunity. The court also dismissed all §1983 claims based on alleged violations of the IDEA and Section 504.

13. Steinmetz v. Richmond Comm. Sch. Corp., 33 IDELR 155 (S.D. Ind. 2000); For the school district.

The parents of a five-year-old student with autism rejected the IEP proposed by the school district and sought reimbursement and prospective funding for a home-based LOVAAS program. A hearing officer and appeals panel ruled in favor of the school

district. The parents appealed to federal court. The court affirmed the due process decisions, characterizing the dispute as one over competing methodologies. The court found that proof that the ABA program was superior did not establish that the school district's proposed program was inappropriate.

14. Fermin v. San Mateo-Foster City Sch. Dist., 33 IDELR 30 (N.D. Cal. 2000); For the school district.

The parents of an eight-year-old child with a visual impairment and cerebral palsy alleged that the school district had failed to provide FAPE for two school years and sought reimbursement for the costs of two years' of private schooling. The school district had offered to place the child in a split pre-K/Kindergarten classroom designed for students with orthopedic impairments. This classroom offered a variety of related services, including augmentative communication devices. A hearing officer found that the school district had offered FAPE, and that the district's failure to provide written notice of its placement proposal did not constitute a denial of FAPE. The hearing officer also found that the district's decision to exclude music therapy in the student's program was within the district's discretion so long as the IEP provided FAPE. Finally, the hearing officer found that the student had made more than minimal progress in the previous placements provided by the school district. On appeal, the court granted summary judgment to the school district.

15. Moubry v. Independent Sch. Dist. No. 696, 33 IDELR 92 (D. Minn. 2000); For the school district.

The parents of a student with apraxia alleged that their child's reading program was inappropriate because it did not include the Orton-Gillingham methodology. These parents lost four successive due process hearings on this issue, and lost one appeal to federal court. In this appeal, the federal court denied all of the parents' claims, finding that it was immaterial whether the student could have made better progress in reading if provided the Orton-Gillingham methodology, so long as the child was making progress in the district's reading program.

16. Sackets Harbor Cent. Sch. Dist. v. Munoz, 33 IDELR 154 (N.Y.Sup.Ct. 2000); For the parents.

In this rather bizarre case, a school district administrator proposed resolving an impasse about the educational program for a four-year-old child with autism by majority vote of certain members of the IEP team rather than by a consensus. According to the school district, the voting membership of the IEP team selected a school-based program for the child. The parents initiated a due process hearing to dispute this outcome, and alleging that several members of the IEP team who had "knowledge or special expertise about the child" and who supported their request for an in-home ABA program had not

been allowed to "vote." The hearing officer and a state review officer found that if the votes of all eligible persons had been counted the child's IEP would have recommended a 36-hour per week ABA program. Therefore, the school district was ordered to provide prospective funding for the ABA program. However, the state review officer denied retrospective reimbursement for the ABA program.

On appeal, the state court affirmed the state review officer's decision, but also awarded retrospective reimbursement for the ABA program finding that the review officer's refusal to award reimbursement was "arbitrary and capricious." The court refused to allow the school district to raise for the first time an objection to the "voting" method used by the IEP team because the district had failed to object to this previously.

17. Schmidt v. Bd. of Education of Baltimore County, 33 IDELR 35 (D. Md. 2000); For the school district.

The parents of a student with learning and emotional disability with a history of disruptive and violent behavior sought district funding for the student's placement in a private school. The school district recommended placement in a public school for students with emotional disturbance. The administrative law judge ruled that the district's proposed placement was appropriate. The parents appealed, claiming that the ALJ improperly assigned the burden of proof, exceeded his authority, and incorrectly changed the student's disability classification.

The federal court upheld the district's placement, ruling that any procedural errors committed by the judge were outweighed by the evidence showing that the student should be placed in the public school. The record established a long history of learning and emotional difficulties that the public facility was specially designed to address. The private school chosen by the parents was not designed to deal with these problems.

B. Least Restrictive Environment/Inclusion

18. Lillbask v. Sergi, 33 IDELR 180 (D.Conn. 2000); For the school district.

A guardian representing a student with multiple disabilities appealed an adverse due process hearing decision regarding placement of the child in a special development center. The guardian appealed, seeking placement of the child in a mainstream setting. During the pendency of the appeal, the child remained in a mainstream setting in a public school pursuant to the "stay put" rule. The federal court affirmed the hearing officer's decision, finding that the proposed placement was highly specialized and would provide extensive services for the child. In addition, the court agreed that the severity of the child's disabilities made it unlikely that he could benefit from an inclusion setting. However, the court refused to consider what the school district alleged was the "hostility" of the guardian in pursuing representation of the child. The court pointed out that the

IDEA "seeks to help disabled children by creating a system of rights for their parents, even hostile parents, to advocate on their behalf."

19. Beth B. by Susan and Tom B. v. Clay, 33 IDELR 96 (N.D. Ill. 2000); For the parents.

The parents of a child with Rett's Syndrome challenged the school district's proposal to place him in a self-contained special education classroom. During a lengthy hearing process that remained pending for several years, the student continued to be educated in a regular classroom pursuant to the "stay put" rule. Eventually, a hearing was completed and the hearing officer ruled in favor of the school district. The school district asserted that "stay put" did not apply because during the pendency of the hearing the child had matriculated from elementary to middle school.

On appeal, the federal court ordered the school district to continue the student's placement in a regular education setting in the district's middle school. The court found that the student's advancement to junior high school did not affect "stay put" or the district's obligation to continue the status quo. The fact that the middle school environment was more complex did not justify a denial of a federal statutory right.

20. M.T. v. Board of Education of the City of Chicago, 33 IDELR 95 (N.D. Ill. 2000); For the school district.

The parents of an eleven-year-old student with severe mental retardation and a seizure disorder rejected the school district's proposal to educate the child in a regular school setting. Instead, the parents requested that the district place the child in a therapeutic day school and classify him as autistic. A hearing officer upheld the district's proposed placement and found that it offered the student some educational benefit.

On appeal, the federal court affirmed the hearing officer's decision. The school district's proposal would place the child in a setting with nondisabled peers, while the parents' preferred placement would segregate the child. The evidence also showed that the child had made significant social and academic progress in a mainstream setting.

21. Board of Educ. of Montgomery County v. Hunter, 32 IDELR 95 (D. Md. 2000); For the parents.

A ten-year-old child with epilepsy and multiple disabilities was placed in a private special education facility at the school district's expense for the first and second grades. When her IEP for the third grade was developed the school district proposed placing the child at a learning center located in a regular elementary school. The parents rejected this placement and initiated a due process hearing seeking continued funding for the private

placement. A hearing officer agreed with the parents and ordered the school district to continue funding the private school.

On appeal, a federal court affirmed the hearing officer's decision. Although the IDEA has a preference for mainstreaming, in this case the record clearly supported the hearing officer's conclusion that a regular education setting would be inappropriate for this student. The child needed stability, was frightened by unfamiliar environments, and would be confused by a large school setting.

22. Doe v. Arlington County Sch. Bd. , 30 IDELR 362 (E.D. Va. 1999); *aff'd.*, 32 IDELR 58 (4th Cir. 2000); For the school district.

The special academic needs of a 10-year-old student with mental retardation and ADHD could not be met sufficiently in a regular education placement. The parents challenged her educational program, which called for special education in academic instruction and regular education for other subjects and all activities, and favored a full inclusion program. The court found no evidence the district programs violated the LRE requirement. The student was unable to benefit academically from placement in regular education for academic subjects and made little progress when placed in regular education for academic subjects. She was easily distracted in that setting, and was several grade levels behind her regular education classmates. In contrast, the student made significant progress when placed in special education for academics. The evidence contradicted the parents' assertion that with the appropriate aides and services, the student could benefit from a full inclusion placement. Thus, the court upheld the district's programs.

23. Reed v. Lincoln-Way Community High Sch. Dist. No. 210, 32 IDEL 197 (N.D. Ill. 2000); For the school district.

The parents of a twenty-year-old student with behavioral/emotional and speech/language disabilities who was arrested for assaulting school staff and a bus driver unilaterally removed her from a day school placement. The school district proposed a more restrictive environment due to her uncontrollable and unpredictable behavior. The parents objected to the placement recommendation and initiated a due process hearing to resolve the placement issue. The hearing officer held that the school district's proposed placement was appropriate. On appeal, a federal court affirmed the hearing officer's decision. The court noted that the parents' failure to hold the student accountable for her behavior and their frequent withdrawal of their daughter from day schools had resulted in her failure to progress. The court found that a residential placement was needed in order to limit the parents' contact with the student and to ensure her chance for success. The parents were entitled to receive regular written progress reports and an advocate.

C. Homebound Instruction

24. Jasa v. Millard Pub. Sch. District No. 17, 32 IDELR 57 (8th Cir. 2000)

Sean is a child with severe disabilities due to spinal meningitis and requires constant medical care and supervision. Sean lived at home with his parents until January 1997, and the school district provided him with a program of educational services in his home. Then, in January 1997, his parents moved him, for non-educational reasons, to the Ambassador, which was a licensed nursing facility located a few miles from his home and in another school district. After this move, the school district refused to continue providing services to Sean at his residence. Parents went to due process, arguing that he had a right to those services under federal and state law.

The case wound up on appeal before the 8th Circuit, which ruled in favor of the school district, finding that the school was not required to provide services at the nursing facility under federal or state law. There was no dispute that School District was providing FAPE at its own facilities or in the parents' home, and remained willing to do so in the future. Parents unilateral actions in placing Sean at the private nursing facility without consent or approval from school district or IEP team foreclosed them from obtaining services at the nursing facility under the 1997 IDEA Amendments and prior case precedent in the 8th Circuit (The court cited to *Foley v. Special Sch. Dist.* as support for this position.) The 1997 IDEA Amendments definitively resolved whether IDEA requires services for parentally placed private school students. A proportionate amount of federal funds must be made available for this group of students. When parents unilaterally place a child with disabilities in a private school or facility, they have "no individual right under the IDEA to special education and related services in question and no right to a federal court decree mandating that those services be provided at a particular location." What is most significant about the court's ruling was its refusal to recognize a nursing facility as any different than a regular private school for these purposes. Parents attempted to argue unsuccessfully that the 1997 Amendments did not govern the outcome of their case because Sean was placed at the nursing facility for noneducational reasons. The 8th Circuit rejected their argument, finding that the relevant IDEA provision expressly referred to unilateral placements in a "private school or facility." According to the court, to limit the interpretation of the term facility in this context to educational facilities would be contrary to the word's plain meaning. Nor were parents entitled to the services they sought at the nursing facility under the authority of Nebraska state law, as the state department's latest regulations were interpreted consistently with 1997 IDEA Amendments.

D. Services for Private School Students

25. John T. v. Delaware County Intermediate Unit, 32 IDELR 142 (E.D. Pa. 2000); For the parents, in part.

The parents of a ten-year-old boy with Down Syndrome filed this action pursuant to the IDEA, Section 504, and state law, seeking a court order requiring the school district to provide special education services at a parochial school. The parties agreed that the child would be entitled to provide FAPE if the child were enrolled in a public school. The parents contended that state law obligated the district to provide FAPE to students enrolled in private schools.

The federal court granted the parents' request for a preliminary injunction. The Section 504 was denied because 504 does not mandate the provision of the services at the parochial school. The IDEA does not require the provision of special education and related services to private school students who have the opportunity to receive FAPE in a public school. However, the court held that state statutes required the district to provide special education and related services for all students who were not enrolled in public schools.

IV. PROCEDURAL SAFEGUARDS

A. Attorney's Fees

26. Daniel S. v. Scranton Sch. Dist., 33 IDELR 179 (3rd Cir. 2000); For the parents.

The parents of a student with disabilities filed a petition to recover their attorney's fees for attending an IEP meeting that was convened after the initiation of a due process hearing. The Third Circuit held that an IEP meeting is convened as a result of an administrative proceeding, and therefore fees are recoverable, if the request for a hearing acts as a catalyst for reaching consensus on the IEP. The court held that fees are recoverable where the "mere threat of a scheduled hearing [induces] the parties to agree to meetings in which they would not otherwise have participated."

27. Lucht v. Molalla River Sch. Dist., 33 IDELR 89 (9th Cir. 2000); For the parents.

The parents of a student with autism filed a complaint with the state department of education. The state department conducted an on-site investigation and issued findings of fact and conclusions of law in favor of the parents, and ordering the district to convene

an IEP meeting. The parents subsequently sought attorney's fees in connection with those IEP meetings.

The IDEA's "attorney's fees provision" authorizes fees for "any action or proceeding brought under this section." The Court interpreted this language to include the state's complaint resolution process. According to the Court, the choice of the word "any" in describing "action or proceeding" was significant. The Court also pointed out that Congress could have specifically limited recovery of attorney's fees to due process hearings if it had wanted to do so.

B. Summary Judgment, Exhaustion of Administrative Remedies, and other Procedural and Jurisdictional Issues

28. Zearley v. Ackerman, 33 IDELR 156 (D.D.C. 2000); For the parents.

The school district verbally agreed to fund a residential placement for a nineteen-year-old student with a serious emotional disturbance, but after the student was placed at a facility the district failed to make timely payments for the costs. The parents of the student initiated a lawsuit seeking reimbursement for the residential placement and money damages. The court found that the district clearly had failed to provide an appropriate education for the student and awarded summary judgment on the IDEA claims. The parents were also permitted to pursue their Section 1983 claims. The court followed precedent set by the Third Circuit that favors the ability to recover compensatory and punitive damages for 1983 claims based on violations of the IDEA.

29. Jaynes v. Newport News Sch. Bd., 33 IDELR 121 (E.D. Va. 2000); For the school district.

The parents of a nine-year-old student with autism initiated a due process hearing seeking reimbursement of costs for a private school placement. The parents and the school district had first reached an impasse over the student's placement in 1993. The parents subsequently withdrew their child and placed him in a private school. The due process hearing was initiated almost five years after the parents had initially placed the child in a private school. The parents claimed that the withdrawal was justified because the school district had failed to provide their child with a free appropriate public education, and had failed to inform them of their procedural rights. The school district was unable to rebut the parents' allegations. A hearing officer awarded the parents reimbursement for five years, from 1993-1998. On appeal, a state review officer reduced the award and applied a two-year statute of limitations. The parents appealed to federal court seeking reinstatement of the original award.

The federal court applied a two-year statute of limitations to claims filed after 1995. Further, the court found that the hearing officer's finding that the school district had failed to notify the parents of their procedural rights was sufficient in itself to justify

an award of tuition reimbursement. The court rejected the parents' contention that they were entitled to reimbursement for the full five years on the grounds that the school district's actions constituted a continuing violation. To allow such relief would place an undue burden on the school district.

30. Mapp v. William Penn Sch. Dist., 33 IDELR 119 (E.D. Pa. 2000); For the school district.

The parent of a student with ADHD reached an agreement with the school district whereby her son would be placed at public expense in a private school and provided transportation to the private school. The student began having significant behavior problems on the bus. Thereafter, the parties agreed that the mother would be paid to accompany her son on the bus. Instead of accompanying her son on the bus, the mother obtained alternative transportation at her own expense. When the district refused to reimburse the mother for the costs of the alternative transportation, she initiated a due process hearing alleging that the school district failed to address her child's special education transportation needs. The parent prevailed in the hearing and was awarded transportation reimbursement. Subsequently, the parent initiated a federal lawsuit seeking damages and declaratory relief. The parent also claimed that the district had subjected her to retaliation and harassment. In this action, the parent asserted claims that the district failed to comply with the substantive and procedural requirements of the IDEA, and violated the ADA, Section 504, Section 1983, Section 1985, and Section 1988. The district moved to dismiss on the grounds that the parent had failed to exhaust administrative remedies on all but the transportation claims.

The court dismissed the claims on behalf of the student for failure to exhaust administrative remedies. The mother's independent claims were dismissed for failure to state a claim upon which relief can be granted, and because she did not have standing as an "individual with a disability" pursuant to the ADA and Section 504.

31. James v. Upper Arlington City Sch. Dist., 33 IDELR 122 (6th Cir. 2000); For the parents.

The parents of a student with dyslexia sought tuition reimbursement for the student's private school education retroactive to 1989, which was over six years before they initiated a due process hearing. The hearing officer held that the parents did not follow proper procedures and denied their request and the review officer affirmed. The District Court also denied the parent's claim for reimbursement, holding that the parents knew of their rights and the statute of limitations had run no longer than four years after the cause of action arose in 1989. The parents appealed the decision to the 6th U.S. Circuit Court of Appeals.

The 6th Circuit held that while the parents could not receive reimbursement for the period between 1989 and 1994, they could pursue such a claim from 1994 forward. The parents knew their rights and could have pursued them beginning in 1989 when they

unilaterally placed the student in private school. However, they chose not to until 1996. Thus, regardless of whether a two-year or a four-year statute of limitations applied, their claim dating back to 1989 was time-barred. The parents again approached the district regarding the provision of services to the student in 1994, but a district official told them to delay re-enrolling the student in the district for a couple years until a teacher could be properly trained. Their new cause of action arose at that point and enrollment of the student in the district was not a prerequisite for the cause of action to begin accruing. To hold otherwise would have allowed the district "to slough off any response to its duty" to provide FAPE to the student.

32. Mrs. M. v. Bridgeport Bd. of Education, 32 IDELR 236 (D.Conn. 2000); For the school district.

The federal court refused to permit a class of minority students to circumvent the IDEA's administrative procedures by proceeding directly to court on their claim that the school system over-identified minority students as mentally retarded. Rather, the court ruled that each of the plaintiffs was required to first exhaust his/her due process hearing rights prior to filing a federal court action. The court observed that identification is a substantive issue that must be decided on a case-by-case basis.

33. Hawkins v. Maine Sch. Admin. Dist. No. 57, (D.Me. 2000); For the school district.

The court denied the parents' request to admit additional testimony from a physician who had contributed information to a neuropsychologist who evaluated their son. At the underlying due process hearing the hearing officer denied the parents' request for reimbursement for the costs of a neuropsychological evaluation because it had been performed by a technician who was not certified to conduct such an evaluation.

34. Rose v. Yeaw, 32 IDELR 199 (1st Cir. 2000); For the school district.

After a ninth grader began experiencing asthma problems at his high school the school system changed air filters and cleaning procedures at the school building. The school system eventually developed two accommodation plans providing for home tutoring during medical absences, extended time to complete coursework, and relocation of the student's classes in a different wing of the building. The parents objected to the school system's efforts to remedy the situation, and negotiations continued. The parties initiated two requests for due process hearings that were eventually withdrawn. After negotiations failed, the parents initiated a federal lawsuit charging the school system with discrimination, retaliation, and failure to implement their son's IEP.

The federal court dismissed the claims for failure to exhaust administrative remedies under the IDEA. On appeal, the First Circuit affirmed the trial court's dismissal

of all claims. The extended negotiations and two withdrawn hearing requests did not satisfy the exhaustion requirement. Also, the school system's presentation of test results showing that the air quality in the student's school was normal outweighed the parents' claim that their son would suffer "irreversible damage" if made to return to the school.

C. Hearing Officers and Due Process Issues

35. Veazey v. Ascension Parish Sch. Bd., 33 IDELR 36 (M.D. La. 2000); For the parents.

The parents of a student with profound deafness initiated a due process hearing to challenge the school district's proposal to move their son from his neighborhood school to another public school where the district had consolidated a program for students using cued speech. The hearing officer ruled that the school district had absolute discretion in making class/school assignments. The parents appealed this decision to a state appeals panel. The appeals panel appointed to review the decision included an individual who had previously recused himself from hearing the initial due process hearing due to his stated bias in favor of the school district after reviewing the facts of the case. The panel affirmed the hearing officer's decision, and the parents filed an appeal to federal court.

The federal court vacated and remanded the case for a new due process hearing. The court held that the inclusion on the panel of an individual who had previously recused himself due to bias denied the parents' right to a fair hearing.

36. Wyner v. Manhattan Beach Unified Sch. Dist., 33 IDELR 98 (9th Cir. 2000); For the school district.

The parents of a student with a learning disability in reading resolved a pending due process hearing by reaching a settlement agreement with the school district whereby the district agreed to provide tutoring for five hours per week. This agreement was entered as an order by a hearing officer. Afterwards, the district provided tutoring for 40 minutes per day, five days per week – a shortfall of 20 minutes per session. The parents informally sought for almost two years to obtain the additional tutoring, but were ultimately unsuccessful. Eventually, the parents initiated a due process hearing seeking to enforce the terms of the settlement agreement. The hearing officer held that he did not have jurisdiction over the enforcement of settlement agreements, and instructed the parents to file a complaint with the state department of education. The parents initiated a federal lawsuit seeking enforcement of the settlement agreement. A trial court upheld the hearing officer's decision. The parents appealed to the Ninth Circuit.

The Court affirmed the lower courts' ruling in favor of the school district, agreeing that the hearing officer did not have jurisdiction to enforce compliance matters. Moreover, the state law explicitly authorized the state department of education's compliance office to pursue enforcement actions.

37. <u>Mr. J. v. Bd. of Education</u>, 32 IDELR 202 (D. Conn. 2000); For the school district, in part.

The parent of a sixteen-year-old boy with ADHD requested that the school district fund a residential placement for his son after the boy's educational and social performance began to deteriorate. The district reached a settlement agreement with the parent whereby it would fund only the educational and clinical portions of the residential placement and pay $3,000 in attorney's fees. Eventually, the parent initiated a due process hearing and demanded that the district pay for the total cost of the residential placement and approximately $40,000 in attorney's fees and costs. A hearing officer upheld the settlement agreement and, in addition, ordered the district to pay for the residential placement for one year. Both parties appealed to federal court.

The federal court upheld the settlement agreement, finding no evidence to support the parent's claim that he had signed the agreement under fraudulent conditions. The court also ruled that hearing officers have authority to enforce settlement agreements. The court awarded attorney's fees since the parent did obtain funding for the residential placement. However, the amount of fees was reduced 5 percent because the attorney failed to keep detailed records of her time expended on the case. The parent was awarded one-half of his expert witness fees due to the expert's limited involvement and brief testimony.

38. <u>Board of Education of the Avon Lake City Sch. Dist. v. Patrick M.</u>, 32 IDELR 176 (6th Cir. 2000); For the parents.

A nineteen-year-old student with ADHD, ED, and LD was expelled after bringing a gun, ammunition, and a knife to school. The parents enrolled the boy in a private school and initiated a due process hearing seeking funding for the unilateral placement. A hearing officer ruled in favor of the school district, but the parents prevailed on appeal to a review officer. Meanwhile, the private school initiated an action against both the school district and the parent to recover payment. The school district paid the costs of the placement in a settlement agreement with the private school. Thereafter, the school district appealed to federal court. The federal trial court reversed the review officer's decision and ruled in favor of the school district. The parents appealed to the Sixth Circuit, seeking funding for the private placement and damages.

The Court dismissed the parents' claims because the settlement agreement rendered the claims moot. In fact, the case had been moot prior to the federal trial court's decision although neither party raised a mootness argument. Since the case was moot, the review officer's decision was final and the parents were the prevailing parties. The court remanded the case to the trial court to determine whether the parents were entitled to attorney's fees.

D. Parents' Rights

39. Soraruf v. Pickney Community Sch., 32 IDELR 4 (6th Cir. 2000); For the school district.

A school district's failure to include parents in the placement decision did not deny FAPE where the placement selected was appropriate. A dispute arose over the educational placement of a 14-year-old with autism. When his placement in a trainable mentally impaired classroom was discontinued due to space limitations, his parents and the school district could not agree upon a new placement. Parents requested a hearing on the issue. In the interim, the special education coordinator notified the parent's attorney that the school system would offer a program similar to one which was operated by another school system that all parties had found satisfactory, but was unavailable to Matthew because he was not a resident of that system. She then went ahead and finalized the IEP and placed Matthew in that program without including parents in the deciding committee.

The federal district court held that the school committed a procedural violation of the IDEA by allowing the SPED supervisor to unilaterally decide Matthew's placement. The court ordered an individualized education planning committee to be reconvened within 30 days, the meeting was held and the parties agreed to a new placement. However, the court found that this procedural violation did not amount to substantive violation of the IDEA and dismissed the case. A circuit court upheld the district court's decision. The circuit court found that the district court correctly determined that the proposed placement of Matthew in a program for educably mentally retarded students did provide FAPE, and the IDEA claim was properly dismissed. Claims brought under Section 504, the ADA, and state disability laws were also properly dismissed given determination that school district did not deny FAPE and this was premise for these claims. Parents tried to argue that "Maximum Potential" language in the language of the state's (Michigan) special education law should be read into the IDEA's definition of educational benefits in this case, but court disposed of this notion as follows: under 6th Circuit precedent, an appropriate public education "does not mean the absolutely best or potential maximizing education for the individual child." Accordingly, the court held that the school was only required to provide an educational program that was reasonably calculated to provide educational benefits.

40. Mill Valley Elementary School v. Eastin, 32 IDELR 140 (N.D. Calif. 1999); For the parents.

The district's failure to make a formal, written placement officer to a student with a disability entitled parents to private school tuition reimbursement. When it was time for kindergarten, the parents of a student with a suspected disability sought to enroll the student in school. The student's preschool teachers thought he might have autism, and his

social skills were underdeveloped. The parents requested that the district complete an assessment of the student and consider his need for special education. The parents then changed their mind and opted to continue his enrollment at the preschool, which also had a kindergarten program, and did not follow up on applying to the district's kindergarten program. Still, the district proposed a speech and language assessment, but the parents didn't respond. When it was time for first grade, the parents placed the student in a private school and renewed their contacts with the district. Again, they informed the district of their belief that the student was disabled and needed special education, and requested a meeting to develop an IEP. The district repeatedly informed parents that prior to convening an IEP, it would need to conduct an assessment of the student first to determine eligibility. The parents finally allowed the district to conduct a partial assessment, but based on the results, the school maintained that a further assessment of the student was needed. The district requested a due process hearing and sought a determination that it had the right to conduct a full assessment of the student prior to going forward with the IEP process.

Prior to the hearing, the parents ultimately agreed to the full assessment, the IEP meeting was finally held, and the parents declined to consent to the IEP that was drafted at this meeting. The student was diagnosed with hyperreflexia syndrome, a mild form of autism. The school district went forward with due process to determine whether its IEP satisfied FAPE. At due process, the hearing officer found that the district failed to provided FAPE and awarded parents reimbursement for the private school beginning from the time they finally consented to the full assessment. The school district appealed that determination.

The district court found that the district's IEP was deficient for several reasons: The district failed to make any firm commitment to anything other than an unspecified, modified, regular education plan and this was more than a technical error. The district never actually offered a placement at any specific school. The district's IEP was described as a "Skeletal" outline of a plan. The only evidence of a proposed placement was that the district was "looking into" three different schools. On the other hand, the private school, although uncertified in special education, was deemed appropriate. Thus, parents were entitled to reimbursement at the private school but only beginning from the time parents finally gave their consent to a comprehensive assessment. Importantly, the parents' lack of cooperation with the assessment process was taken into account in awarding this remedy. Parents also received reimbursement for an IEE and psychological services.)

41. <u>Robertson v. Arlington Cent. Sch. Dist.</u>, 33 IDELR 123 (2nd Cir. 2000); For the school district.

The Second Circuit affirmed the dismissal of a Section 1983 claim based on the parent's allegation that school officials intentionally placed her daughter, a student with a cortical visual impairment, in the same class with a boy who had previously abused her. The school district denied the parent's allegation that she had informed the school district

of the previous abuse. There was no evidence to substantiate the parent's claims. Moreover, the court was suspicious of the parent's claimed inability to recall the specific date on which she had notified school officials of the abuse in light of her detailed records of other factual events related to the case.

42. Liberty County Sch. System v. John A., 33 IDELR 33 (S.D. Ga. 2000); For the parents.

The parent of a 17-year-old student sought special education services for her son after the district found him ineligible for such services. At due process, a hearing officer found that the student qualified for services due to his ADHD and ordered the district to develop an IEP for him. The hearing officer further ordered the district to perform a comprehensive evaluation. The school district refused to comply with the order, arguing that it was improper to provide special education services prior to the completion of a comprehensive evaluation. The parents filed an action in federal court seeking implementation of the hearing officer's order.

The federal court ordered the district to implement the hearing officer's order as soon as possible. While the due process decision was not ideally drafted, it was evident that the hearing officer ordered two IEP meetings. The first meeting was for the purpose of developing an IEP based on the information already known about the student, and the second would allow the district to develop an IEP following a comprehensive evaluation. The school district had a right to appeal the hearing officer's decision, but its refusal to comply with the final order was a violation of the IDEA's stay-put provision. Until the district succeeded in reversing the hearing officer's final order, it was required to treat the order as the last agreed-upon placement of the student.

43. Briley v. Bd. of Education of Baltimore County, 32 IDELR 119 (D. Md. 2000); For the school district.

Emily, a student with ADHD and ODD, had an extensive history of various behavioral problems, emotional disturbances and learning disabilities. Her emotional issues, together with alcohol and drug abuse, led to suicide attempts and a psychiatric commitment at the age of twelve. With prior notice to and financial assistance from the Baltimore Public Sch. System, the student was enrolled at a private residential school in Idaho that provided highly structured, therapeutic treatment for emotionally troubled, learning disabled children, where she received between three and six hours of therapy each day. After her stay at the private facility Emily was no longer actively suicidal, attended class and displayed increasing confidence. Due to financial constraints, her parents brought her back to Baltimore public schools and requested special education services.

A school psychologist determined that Emily was learning disabled and needed continued special education services, but that she did not have an "emotional disturbance" pursuant to the IDEA. The IEP team determined that her needs could be met through a public education program and developed an IEP that provided for both direct and indirect special education services. The IEP offered placement in a structured classroom for more than half of the school day and in a regular classroom setting for the remainder at a high school. The parents unilaterally placed Emily in a private residential school in Massachusetts without prior notice to the school district, and subsequently initiated a due process hearing seeking tuition reimbursement. A hearing officer denied reimbursement and found that the IEP was procedurally and substantively compliant.

On appeal, the federal court affirmed the decision of the hearing officer. The court found that the school's failure to contact the previous residential placement while developing its IEP, the district's failure to include a regular education teacher from the private school on the IEP team, and the district's failure to observe Emily in a regular education setting were not significant procedural violations of the IDEA. The court that there were no procedural or substantive violations that deprived Emily of FAPE.

44. <u>Birmingham v. Omaha Sch. Dist.</u>, 33 IDELR 29 (8th Cir. 2000); For the parent.

An eighteen-year-old girl with mental retardation and cerebral palsy complained to teachers that her mother was abusing her. In compliance with state law, the alleged abused was reported to the state human services agency. The girl was taken out of her home and placed in protective custody, but parental rights were not terminated. A probated judge determined that the girl was competent to choose where she wanted to live, and the girl chose to remain in protective custody for the following year. At the end of the school year an annual IEP review was scheduled. The girl's mother was not notified of the meeting, but she found out about the meeting and asked to attend. The school district denied the mother's request to attend the IEP meeting. The school district consulted with the girl's social worker. The social worker recommended that the girl be allowed to graduate so that she could concentrate on independent living skills. At the meeting, the team members discussed the possibility of early graduation. IEP team members asked the girl if she wanted to graduate early, and she indicated that she did. Thereafter, the girl was graduated from the school district. No prior notice was given to the mother of her daughter's graduation.

The mother initiated a lawsuit seeking money damages and attorney's fees, and alleging that the school district's failure to provide prior notice of her daughter's graduation violated the IDEA, Section 504, Section 1983, and the ADA. The trial court applied a 30-day statute of limitations and dismissed the claims. On appeal, the Eighth Circuit vacated the dismissal and reinstated the action. The Court found that the school district's failure to provide prior notice to the parent and to permit her to attend her daughter's IEP meeting were significant procedural violations of the IDEA. The IDEA Amendments of 1997, which provide to transfer of parental rights to students upon

reaching the age of majority, did not become effective until June 4, 1997. The student graduated in 1995. Therefore, the mother was clearly entitled to receive notice of the IEP meeting and proposal for graduation. The Court rejected the application of a 30-day statute of limitations and instead applied a three-year statute of limitations.

45. Somerville Bd. of Education v. Manville Bd. of Education, 32 IDEOR 227 (N.J. Super. 2000); For the parents.

Two divorced parents living in different school districts shared a joint custody arrangement whereby their child alternated residence each week. Officials from the two school districts verbally agreed to share the costs of the student's education by paying for the same on alternating years. This "gentleman's agreement" proved satisfactory until a new special education supervisor was hired in one of the two school districts. This new administrator refused to continue contributing to the costs of the child's program. The second school district sued the recalcitrant school district seeking payment for half of the child's educational program.

The court ordered the two school districts to continue to share the financial costs of the student's program, construing domicile laws liberally. According to the court, this result was fair in this unique situation and enabled the student to have an uninterrupted right to FAPE.

V. REMEDIES FOR SPECIAL EDUCATION VIOLATIONS

A. Reimbursement for Private School Tuition and Privately Obtained Services

46. John T. v. Delaware County I.U., 32 IDELR 142 (E.D. Pa. 2000)

The issue facing the court was whether a unilaterally enrolled parochial school student with Down Syndrome was entitled to receive special education and related services at public expense. The parents of this ten-year-old child filed this lawsuit alleging violations of the IDEA, Section 504, and state law. The school district denied that it was required to provide services and requested joinder of the state department of education as a co-defendant. The federal court granted the parents' request for a preliminary injunction requiring the school district to begin providing special education services to the child. The court recognized that neither the IDEA nor Section 504 require the provision of these services at private schools where there is no evidence that the public school had denied FAPE to the student. However, the court held that the state law did require public schools to provide special education and related services to all private school students in need of these services.

47. Nein v. Greater Clark County Sch. Corp., 32 IDELR 171 (S.D. Ind. 2000); For the parent, in part.

Lucas is a twelve-year-old student with severe dyslexia who was identified as a child with disabilities in the first grade. When first identified as eligible for special education and related services, Lucas' I.Q. was measured at 95. After receiving special education services for three years, Lucas still could not read and his I.Q. had dropped by twenty points. Lucas' parents withdrew him from public school and placed him in a private school without giving notice to the school district. A hearing officer found in favor of the parents and ordered the school district to reimburse them for the costs of Lucas' private placement. On appeal, a review officer reversed the judgment. The federal court agreed with the original hearing officer and found that the school district had failed to provide FAPE. However, the court reduced the reimbursement award by one-half because the parents had failed to give notice to the school district of their intent to remove their son.

48. Joshua W. v. USD 259 Bd. of Education, 32 IDELR 137 (10th Cir. 2000); For the school district.

Joshua was a seventeen-year-old student with a turbulent personal and educational history who had been adjudicated a juvenile offender. After his parents divorced in 1980, Joshua lived with his father. Joshua pled guilty to a charge of aggravated assault after he threatened his mother with a knife while she attempted to transport him to a military school. In an effort to avoid her son's incarceration, Joshua's mother applied for his admission to Three Springs, a residential facility located in Tennessee. Meanwhile, Joshua's mother asked the school district to locate and pay for a residential placement for her son. The mother's school district asserted that the school district of the father's residence was legally responsible for funding the residential placement because Joshua usually lived with his father.

The Tenth Circuit refused to hold either school district financially responsible for the residential placement, finding that the mother's unilateral decision to enroll Joshua in Three Springs was a manipulative action designed to fraudulently obtain funding for a residential placement chosen by the mother outside of the IEP process.

49. Independent Sch. Dist. No. 284 v. A.C., 32 IDELR 143 (D. Minn. 2000); For the school district, in part.

The school district proposed placement of a seventeen-year-old girl with emotional/behavior disorder in a day treatment facility. The student had a history of disruptive behavior, truancy, depression, and low self-esteem. An independent evaluator testifying on behalf of the parent opined that the girl must be in a secure, residential

facility in order to receive appropriate educational services due to her history of truancy and leaving school campus. The school district's psychologist agreed that it would be difficult to provide appropriate educational services to the girl unless she was forcibly detained. Despite these opinions, the school district refused to pay for the costs of a residential placement. Rather, the school district offered to fund the educational portion of a residential placement, or to provide a day treatment program. A hearing officer found in favor of the parent and ordered the school district to pay for the entire costs of a residential program and to provide compensatory education services. A review officer affirmed this decision.

On appeal, the federal court reversed the order to pay for residential placement, but affirmed the order to provide compensatory education services. The court held that the student's educational and non-educational need could be untangled. In this case, the court held, the girl's *unwillingness* to attend a day treatment program was not related to an *inability* to attend such a program. Since the student clearly was able to attend a day program, the school district was not liable for the costs of a residential program. The school district was required to provide compensatory education services because of its delay in convening an IEP team meeting.

50. Butler v. Evans, 33 IDELR 62 (7th Cir. 2000); For the school district.

A sixteen-year-old girl was committed by her parents to a psychiatric hospital after she began experiencing auditory and visual hallucinations and became paranoid/suicidal. Prior to this hospitalization, the school district was in the process of developing an IEP to place the girl in a residential facility. The parents initiated a due process hearing seeking reimbursement for approximately one year of psychiatric hospitalization. A hearing officer ordered the school district to reimburse the parents for the costs of their daughter's psychiatric treatment. However, an appeals panel reversed and held that the treatment she received was medical, and not educational.

On appeal, a trial court affirmed the appeals panel's decision. Later, the Seventh Circuit also affirmed, holding that the student's hospitalization was for medical reasons, not for special education or related services. The court noted that the IEP formulated for the girl with her parents' agreement did not provide for psychiatric treatment, which was the primary reason for her hospitalization.

51. Robert M. v. Hickok, 32 IDELR 169 (E.D. Pa. 2000); For the school district.

The parents of a thirteen-year-old student with learning disabilities and a speech/language impairment rejected the IEP proposed by the school district. The district wanted to placed the student in regular education classes, with one hour per week of consultation for the student's regular education teachers with a special education teacher and 30 minutes of speech therapy per week. The parents felt that this proposal would constitute a "giant leap backwards" for their son, who had always been educated in

private schools. A hearing officer ruled in favor of the parents. This decision was reversed by a state appeals panel.

On appeal, a federal court affirmed the appeals panel decision and denied the parents' request for reimbursement for private school tuition. The court found that the school's proposal would place the student in the least restrictive environment and was appropriate given the student's average intellectual level. Moreover, the parents could not show any benefit of the private school other than a lower student-teacher ratio.

52. B.A. v. Cape Elizabeth Sch. Comm., 32 IDELR 200 (D.Me. 2000); For the school district.

B.A. was identified as a student with learning disabilities prior to the fifth grade. During the 5th through 7th grades, she received direct special education instruction for math, reading, and writing, but remained in a regular education classroom for social studies and science. B.A. made A's and B's in social studies and science. Her teachers testified that these grades were not modified and reflected her true level of mastery of course objectives. All of B.A.'s teachers believed that she was making meaningful progress. Despite her apparent academic success, B.A.'s parents withdrew her from public school and placed her in a private, out-of-state school for students with learning disabilities. B.A.'s parents initiated a due process hearing seeking tuition reimbursement and alleging that the school district had failed to properly address their daughter's social and emotional needs. After a four-day hearing, a hearing officer ruled that the school district had provided FAPE.

On appeal, the federal court upheld the hearing officer's decision. The court noted that the parents were objecting to the hearing officer's factual findings rather than to his legal conclusions, and held that decisions regarding fact-finding were best left to the original trier of fact.

53. Gorby v. Grasmick, 32 IDELR 231 (D.Md. 2000); For the school district.

The parents of an eight-year-old first grader with dyslexia and an IQ in the superior range of intelligence met numerous times with school officials to develop an IEP for their son. The parents had applied earlier for their son's admission to a private school for students with dyslexia. The school district developed a proposed IEP that offered 9 hours per week of special education services and 29.5 hours per week in regular education. Although the parents agreed with the goals and objectives in the proposed IEP, they insisted that the school district pay for placement in the private school. A hearing officer upheld the school district's proposed IEP, and the parents appealed to federal court.

The federal court denied the parent's request for tuition reimbursement and dismissed their claims against the school district. The judge found the school district's evidence to be more credible that that offered by the parents. Notably, the parents' expert

witnesses had not observed the student in the classroom, nor had they talked with the child's teachers.

56. <u>J.D. v. Pawlet Sch. District</u>, 33 IDELR 34 (2nd Cir. 2000); For the school district.

The parents of a ninth grader requested that their son be evaluated for special education eligibility due to their concerns about his emotional condition. The boy tested in the top 2 percent of the population intellectually. In the eighth grade the student had made achievement test scores placing him at the 10th – 12th grade level in all subjects. The student earned A's and B's in all subjects, but continued to experience some passive/aggressive behaviors at school. An eligibility team determined that the student was not eligible for special education and related services pursuant to the IDEA, but that he was eligible under Section 504. The district offered to provide counseling and peer support training. The parents rejected this proposal and unilaterally placed their son in a private school. A hearing officer ruled in favor of the school district and on appeal to federal court.

The Second Circuit agreed that the student's emotional/behavior problems were not adversely impacting his educational performance and that he did not qualify for special education and related services.

57. <u>Board of Education of Oak Park and River Forest H.S. District No. 200 v. Kelly E.</u>, 32 IDELR 62 (7th Cir. 2000); For the parents.

Two sets of parents succeeded in obtaining due process orders requiring their respective school districts to provide reimbursement for private school placements. The two school districts sued the State in separate actions seeking partial payment of these expenses. In one case, a trial court held that school districts could obtain a State contribution toward payment of private school reimbursement. In the other case, the court rejected the school district's request for a State contribution. A consolidated appeal was brought before the Seventh Circuit. The sole issue on appeal was whether the IDEA entitles a local school district to reimbursement from the State for some or all of the expenses when a school district is ordered to reimburse parents for private school tuition. The Court rejected the school district's request for a State funding contribution, holding that nothing in the IDEA requires States to contribute to local school districts more than 75% of the State's IDEA Part B allocation.

58. <u>M.S. v. Board of Education of the City School Dist. of the City of Yonkers</u>, 33 IDELR 183 (2nd Cir. 2000); For the school district, in part.

A student with a learning disability was enrolled in a district program known as PEARLS, an acronym for "program for early and rapid learners." The student had a full scale IQ of 109, but he was performing significantly below his intellectual potential in reading, spelling, and math. A private psychologist determined that the student was eligible for special education and related services as a student with learning disabilities. The school district accepted the private psychologist's recommendations and wrote an IEP that provided for one period of resource room services per day. In response to the parent's concern that the IEP goals and objectives were not specific enough, the district reevaluated the student and convened an IEP meeting to develop his fourth grade IEP. The parent rejected the district's offer of an additional period of resource room services per day, choosing instead to enroll the student in a private school for students with learning disabilities. The parent then initiated a due process hearing seeking tuition reimbursement.

The school district prevailed at the initial due process hearing and on review by a state review officer. However, on appeal the U.S. District Court reversed and awarded the parents tuition. On appeal, the Second Circuit reversed the tuition award. The Court agreed with the trial court that the district's placement was inappropriate. However, the Court also found that the trial court failed to give proper deference to the hearing officers' determinations that the private program was inappropriate. While the parents were not subject to the same stringent IDEA mainstreaming requirement imposed on school districts, they were still required to consider the IDEA's requirement that students be mainstreamed to the maximum extent possible. The Court held that hearing officers could consider that factor in deciding whether the parents' placement is appropriate.

59. <u>Bell v. Education in the Unorganized Territories</u>, 33 IDELR 184 (D. Me. 2000); For the parents.

The parents of a nineteen-year-old student with autism and an IQ of 43 initiated a due process hearing to challenge the school district's intent to graduate their son with his senior class in the summer of 2000. Graduation would terminate the district's earlier agreement to fund a private school placement. A hearing officer ruled that the school district's proposal to graduate the student was appropriate and that the school district had provided FAPE to the student. The parents appealed and sought a preliminary injunction to halt the school district's effort to award a high school diploma to their son. The federal court awarded the injunctive relief and refused to order the parents to post a bond to cover the intervening placement costs.

60. <u>Linda W. v. Indiana Dept. of Education</u>, 32 IDELR 66 (7th Cir. 1999); For the school district, in part.

Ryan, a student with dyslexia, received an individually tailored educational program in the public school system. Ryan's parents objected to the proposed educational plan developed for his eighth grade year. During the summer between his

seventh and eighth grade years, the parents placed Ryan at a private school in Massachusetts and requested a due process hearing seeking tuition reimbursement. A hearing officer ordered the school district to provide remedial instruction in reading and compensatory tutoring services to allow Ryan to "catch up" with his classmates. The hearing officer did not order the school system to pay for prospective private school placement. The parents appealed this decision to federal court.

The trial court affirmed the hearing officer's decision. On appeal to the Seventh Circuit, the Court affirmed the trial court's ruling. The Court based its decision on the Burlington standard set by the U.S. Supreme Court giving trial courts broad discretion in awarding private school reimbursement. The Court held that school districts are not required to reimbursement parents for private school costs when deficiencies in a child's educational program can be remedied with minor adjustments. The court stated, "[P]arents must establish much more than that the original plan is deficient. If that were enough, then the costs to school districts of administering the Act would skyrocket, for educational professionals frequently disagree among themselves how best to cope with a pupil's learning problems." Commenting on the fact that the school was ordered to provide some remedial instruction, the Court also stated, "If this were enough by itself to justify moving the child to a private school with compulsory reimbursement, then there would be an exodus from the public schools." The Court also denied attorney's fees, pointing out that the parents' recovery of approximately $1,000 for privately acquired tutoring services was "paltry" compared with the relief they were seeking.

B. Compensatory Education Services

61. Everett v. Santa Barbara High Sch. Dist., 32 IDELR 175 (C.D. Cal. 2000); For the parents.

This student was first identified in kindergarten as a student with learning difficulties. During the first grade through the sixth grade, the student participated in a special reading program offered by the school district. When he entered the seventh grade, the student's mother requested that the school district evaluate her son to determine whether he was eligible to receive special education and related services. However, the district took almost one year to complete the evaluation. Finally, the school district determined that the student was eligible under the IDEA and developed a proposed IEP offering to place the student in resource classes for up to two periods per day. The parents did not object to the IEP. However, the school district placed the student in a program that was not taught by a certified special education teacher. The following year the school district did not provide any special education services for the student. After the boy had disciplinary problems the parents obtained home instruction for him. During this time, they also purchased a home computer and related equipment and became interested in the Lindamood-Bell reading program. The parents thereafter had their son assessed by a Lindamood-Bell trainer, who determined that the boy had

significant deficits in work attack, word recognition, spelling, contextual reading, decoding, receptive oral communication and oral comprehension skills. The parents requested a due process hearing and sought placement for their son in a private school. A hearing officer ruled in favor of the school district on all claims.

On appeal, a federal court reversed and ordered the school district to pay tuition reimbursement, one year of compensatory education, and attorney's fees. The court held that the hearing officer erred by placing the burden of proof on the parents, and allowed the parents to introduce additional evidence at trial because they were not adequately represented at the hearing. The fact that the student could not read on grade level and was not able to graduate with his class persuaded the court that the school district had failed to provide FAPE to the student.

62. State of West Virginia v. Board of Education of the County of Monongalia, 33 IDELR 186 (W.Va. Sup.Ct. 2000); For the parents.

A lawsuit filed in state court in 1994 took almost six years to complete due to numerous continuances and other delays. At the outset of the litigation, the court appointed a "special master" to hear this case and make recommendations to the court. The special master found that the school district erred in trying to make up for earlier denials of FAPE by "making up" additional amounts of services. The special master recommended that the school district provide two years' of compensatory education services beyond the normal age of eligibility, develop a new IAEP, and pay for a medical evaluation. The school district filed an action in federal court seeking declaratory and injunctive relief. This action was dismissed for failure to exhaust administrative remedies. On appeal, the State Supreme Court affirmed the decision of the special master below.

63. Appleton Area Sch. District v. Benson, 32 IDELR 91 (E.D. Wis. 2000); For the parents.

K.T. has a cognitive disability, spastic quadriplegia, and cerebral palsy. She uses a motorized wheelchair and has a service dog. Although she earned enough academic credits to participate in a graduation ceremony, the school determined that she required additional services because several of her IEP goals had not been met. Therefore, the school created an IEP for the following year that called for her combined placement at the high school and in community settings to develop functional skills. The parents initiate a due process hearing to contest the IEP. The administrative law judge ruled in favor of the parents, concluding that the IEP failed to provide K.T. with FAPE. On appeal, a federal court affirmed the ALJ's ruling. The court approvingly found that K.T.'s proposed placement provided transition services that had not been provided in the past, including community experiences, pre-employment opportunities, and instructional services. However, the fundamental flaw in the IEP was its failure to address K.T.'s need

to generalize life skills such as shopping, cooking, cleaning, and grooming from the classroom to the community.

64. Strawn v. Missouri State Board of Education, 32 IDELR 118 (8th Cir. 2000); For the parents.

The parents of a student with multiple disabilities, including profound deafness, cerebral palsy, mental retardation and spastic quadraparesis sought to have her admitted to a state school for the deaf. However, Lauren was deemed ineligible for admission due to severe delays, and a lack of age-appropriate self-help skills. Instead, Lauren was placed for several years at the state School for the Severely Handicapped, where communication skills were neither a priority nor the subject of intensive focus. Despite this placement, Lauren's teacher had some knowledge of sign language that she used with Lauren. Lauren showed significant and sudden improvement. She was once again referred to the school for the deaf, where she continuing making significant progress in her sign language vocabulary, self-care, communication, and socialization skills. The parents requested a due process hearing claiming that Lauren had been denied FAPE during the time she was at the school for children with severe disabilities. A due process panel awarded Lauren two years of compensatory education services. The parents disputed this award, claiming that Lauren was entitled to one year of compensatory education for each of the years she had spent in an inappropriate placement. A federal trial court dismissed the claim as untimely, finding that it was barred by laches, and held that Lauren had received FAPE.

The Eighth Circuit applied a two-year statute of limitations to the compensatory education claim. The court rejected the parents' argument that the statute of limitations should be tolled because Lauren is a minor, stating "tolling the statute of limitations for an entire childhood would frustrate federal policy...." However, the circuit court reversed the trial court's decision that Lauren had received FAPE and finding that the education she had received at the state school for children with severe disabilities was "wholly deficient." The court remanded the case to the due process appeals panel to determine the proper award of compensatory education.

C. Money Damages

65. Covington v. Knox County Sch. Sys., 32 IDELR 29 (6th Cir. 2000); For the parents.

Jason, now 20, has multiple mental and emotional disabilities, and attended the Knoxville Adaptive Education Center from 1990 until he graduated with a special education diploma in May 1996. His mother alleged that on several occasions, Jason was locked in a time-out room that could only be unlocked from the outside, and his was left there for several hours at a time without supervision—often not being allowed to leave the room for lunch. The room was described as being approximately 4 ft X 6 ft, dark and vault like, with a concrete floor, no furniture, no heat, no ventilation, and only one small reinforced window at least five feet above the floor. She claimed that at least once, Jason was made to take off his clothes before entering the room and that due to his long period of confinement, he was forced to relieve himself on the floor of the room and remain there in his own excrement. Initially, the parent filed a complaint with the Tennessee Dept. of Education and the Knox County School System responded in a letter that denied the allegations in part and attempted to explain the actions of school officials, but offered no other relief. The parent then sought due process, citing inappropriate discipline, including abusive confinement in a locked time out room. No due process hearing was ever held.

For a period of three years, the hearing and related discovery were repeatedly scheduled, delayed, and re-scheduled. There was evidence suggesting, and district court found, that the parent was largely responsible for the delays. Although the due process hearing had not been held, the parent pursued her legal action in federal court, alleging violations of the Jason's constitutional rights and raising state-law claims of intentional infliction of emotional distress and false imprisonment. This complaint did not even mention the IDEA. The district court dismissed the case, finding that administrative exhaustion was required under the IDEA because the complaint involved the school's disciplinary practices and it was undisputed that the use of the time-out room as a disciplinary measure was mentioned in the student's IEP and therefore, was a matter subject to the IDEA.

On appeal, the circuit court ruled for the parent, recognizing an exception to the doctrine of administrative exhaustion given the unique facts presented in this particular case. Initially, the 6th Circuit expressed its agreement with courts that decided that a mere claim for money damages is not sufficient to automatically bring the claim outside of the administrative exhaustion requirement, the unique factual circumstances of this particular case required such treatment. (As other courts recognized, if it were otherwise, a plaintiff seeking money damages could get around the IDEA's administrative exhaustion requirement by simply appending a claim for damages.) The court pointed to the following as justification for the court's decision that administrative exhaustion in this case would be futile and was not required. The injured child had already graduated from the special education school, his injuries were wholly in the past and money damages were the only remedy that could make Jason whole. Accordingly, the district court's decision was reversed, and the case was remanded to the district court for further proceedings.

66. O.F. v. Chester Upland Sch. District, 32 IDELR 114 (E.D. Pa. 2000); For the parents.

A student with disabilities was threatened by another student in the presence of school employees. She became agitated and started screaming, and ran into the principal's office where she was restrained by three district employees. Local police were summoned, handcuffed the girl, placed her legs in restraints, and removed her by ambulance. The girl was subsequently transferred from a hospital to a residential school for students with severe emotional disturbance. The student's guardian filed a lawsuit charging the school district with violating the IDEA, ADA, Section 504 and Section 1983, and a claim of false imprisonment. The guardian sought money damages and injunctive relief requiring immediate implementation of her crisis intervention procedures. The school district filed a motion to dismiss for failure to exhaust administrative remedies.

The federal court held that exhaustion was not required for the IDEA, ADA, and 1983 claims because both sides agreed that money damages were not available relief from an IDEA administrative hearing (citing W.B. v. Matula). The Section 1983 claims based on violations of federally protected rights were allowed to proceed. However, the 1983 Constitutional claims were dismissed because the parents failed to assert sufficient factual allegations to support these claims. The court also dismissed the false imprisonment claims because the school district was a governmental entity that was immune from such tort actions.

67. R.B. v. Bd. of Education of the City of New York, 32 IDELR 226 (S.D.N.Y. 2000); For the parent.

The IEP team for a student with a behavior disability recommended that the student be place in private school and the parents agreed. However, despite the IEP the school district made no attempt to locate a private school that would accept the student. After the next school began, the school district developed an interim education plan but subsequently failed to implement this plan as well. The parent initiated a due process hearing seeking an order to force the school district to implement the private placement. A hearing officer ruled in the parents' favor but the school district failed to comply. The parents filed this action in federal court seeking a private school placement and money damages. The federal court held that, based on the U.S. Supreme Court's decision in Franklin v. Gwinett County Pub. Schs., "nothing in the IDEA precludes a claim for money damages under Section 1983 and that, in fact, the IDEA expressly contemplates such claims." In addition, the court held that the parent's claims based on violations of the ADA and Section 504 sufficiently alleged bad faith and gross misjudgment to survive a motion to dismiss.

68. Scott C. V. Bethlehem Area Sch. Dist., 33 IDELR 93 (E.D. Pa. 2000); For the parents, in part.

The parents of a fourteen-year-old boy with an emotional disturbance and learning disabilities sued the school district and six employees, including all of the members of the student's IEP team, alleging that the district's placement of the boy in partial hospitalization program was inappropriate. The parents alleged violations of the IDEA, ADA, and Section 1983. A hearing officer ruled in favor of the parents and ordered the school district to provide home schooling to the student. However, an appeals panel reversed and upheld the district's proposal to return the student to the partial hospitalization program. On appeal, the federal court dismissed the claims against the individual administrators and teachers but allowed the claims against the school district to continue.

69. O'Havre v. Board of Education for Jefferson County Sch. Dist., 33 IDELR 94 (D. Colo. 2000); For the parents, in part.

The parent of fraternal twin boys with disabilities alleged that the school district violated the IDEA, Section 504, Section 1983, and state tort law. The complaint alleged that the school district improperly disciplined the students and that administrators were "overzealous" in their scrutiny of the boys. Here, the court considered the school district's motion to dismiss. The court dismissed all claims except the assault and battery claims and allegations of discrimination pursuant to Section 504.

70. Weixel v. Board of Education of the City of New York, 33 IDELR 31 (S.D. N.Y. 2000); For the school district.

Rose suffers from chronic fatigue syndrome. Her mother initiated a lawsuit seeking $5 million in damages against the school district. The complaint alleged that the school district discriminated against Rose on the basis of her disability by refusing to place her in certain classes, and by refusing to promote her to the eighth grade. The federal court granted the school district's motion to dismiss all claims because the parent failed to allege facts to establish that she was eligible for special education and related services under the IDEA, and failed to allege facts to establish that her medical condition substantially limited her ability to learn.

VI. SECTION 504 OF THE REHABILITATION ACT OF 1973

71. Shirey v. City of Alexandria Sch. Bd., 33 IDELR 60 (4th Cir. 2000); For the school district.

The parent of a student with dwarfism filed an OCR complaint alleging that the school district had failed to develop an appropriate emergency preparedness plan after her child was not evacuated during a bomb threat and an unplanned fire drill. The parents and

the school district entered into an agreement to resolve the complaint. Pursuant to the terms of this agreement, the student's parent agreed to drop the pending OCR complaint in exchange for the board's agreement to adopt a new emergency preparedness plan. Pursuant to the evacuation plan, the student, and other disabled students, would be sent to a designated "safe" room in the school where a responsible adult and an alternative relief person would be assigned, and a special flag and cell phone would be placed to facilitate communication with the school and emergency officials. If actual evacuation were necessary, emergency personnel would rescue children directly from the safe room.

After this agreement was entered, there was a false fire alarm at school. The student was sent to the safe room according to the new evacuation procedures, but was left alone for approximately 2 minutes when the designated personnel assigned to the room received permission to leave for personal reasons, and while her relief person was en route to the safe room. The parent filed suit in federal district court, claiming the school district's actions violated Section 504 and the ADA. The parent appealed after summary judgment was granted in favor of the school board.

The 4th Circuit affirmed the award of summary judgment in favor of the school board, but for different reasons than the district court. Contrary to what the district court ruled, parents' prior OCR agreement did not constitute a waiver of any rights or claims they possessed under federal discrimination laws. Nonetheless, the school board's actions did not exclude the student from safe evacuation procedures during an emergency. As to the false fire alarm incident, it was clear that the school board developed and implemented a revised evacuation plan to safely evacuate children. The court noted that while it was sympathetic to the child's distress during the confusion of a fire alarm, they could not agree that "imperfect execution of an otherwise reasonable evacuation plan" constituted disability discrimination. The court noted that minor errors in carrying out an evacuation plan were not a sufficient basis for discrimination. No was there any discrimination which occurred in relation to the earlier bomb scare. The court determined that the disability discrimination with respect to this incident was addressed through the previous OCR action and no additional relief was due.

72. <u>Doe v. Eagle-Union Community Sch. Corp.</u>, 32 IDELR 117 (S.D. Ind. 2000); For the school district.

A 17-year-old student in his junior year who had been diagnosed with clinical depression was determined to be disabled and in need of services pursuant to Section 504. A plan was developed that included twelve intervention strategies. When the student received some "incompletes" in his courses, the high school counselor sent a note to the student's mother offering another Section 504 conference to explore the possibility of homebound instruction for the student. The Section 504 conference was never held. Subsequently, the student tried out for the basketball team but was not chosen for either the varsity or junior varsity teams. The parent brought claims against the school district under the IDEA, ADA, Section 504 and Section 1983. Specifically, they alleged that the district threatened the parents by suggesting homebound instruction as a possible

alternative for the student and alleged that he was excluded from the high school basketball team on the basis of his disability. A hearing officer and, subsequently, a review officer ruled in favor of the school district. The parent appealed to federal court.

The court dismissed all claims against the school district. From from being a threat, the letter written to the parent by the guidance counselor was intended to alert the student and his parents to the school's continuing concern for the student's welfare and progress and to propose an additional option to bring academic and other aspects of educational success to the student. Additionally, the coach's decision not to put the student on the basketball team was not based on the student's disability. Moreover, prior Seventh Circuit precedent (Knapp v. Northwestern University) had previously refused to define athletics as a major life activity.

73. Rick C. v. Lodi Sch. Dist., 32 IDELR 232 (W.D. Wis. 2000); For the school district, in part.

The parents of an eighth grader with an emotional disability alleged that the school district had failed to properly identify her son as learning disabled and failed to ensure that her son was in a safe environment. The parent alleged that her son was harassed by other students who called him names like "retard, reject, and stupid," taunted him by saying that he had sex with his mother, and placed a vulgar drawing in his book bag. The parent appealed from an adverse decision of a hearing officer and alleged violations of the IDEA, Section 504, and Title IX. The federal court dismissed the IDEA and Title IX claims, but allowed the Section 504 claims to continue.

74. Doe v. Woodford County Bd. of Educ., 32 IDELR 174 (6th Cir. 2000); For the school district.

A high school student was temporarily suspended from playing basketball while the school district obtained medical information regarding his hemophilia and hepatitis B and the potential risks to other players on the team. The suspension lasted three weeks and the student was then cleared to play basketball. However, the suspension caused the student to become depressed to the point that he decided not to play for the team. The parent sought money damages and alleged violations of the ADA, Section 504, FERPA, and Section 1983, contending that the school district's temporary suspension of the student constituted illegal discrimination. The federal trial court dismissed all of the parent's claims. On appeal, the Sixth Circuit affirmed this dismissal. Under the circumstances, the school district's actions were justified and reasonable to balance the student's rights against the potential danger of exposing another student to disease. There were no facts upon which to base a FERPA complaint. The only communication regarding the student's health condition was shared by the coach, the principal, and the student.

75. Paul v. Henrico County Pub. Schs., 32 IDELR 173 (E.D. Va. 2000); For the school district.

A fourteen-year-old boy with ADD and dyslexia was placed in a private school by recommendation of his IEP team and his parents' agreement. By transferring to a private school, the boy became ineligible to play as a member of the public school's baseball team. The parents alleged that the school district had discriminated against their son on the basis of his disability and sought a preliminary injunction requiring the school district to allow their son to play on the baseball team.

The court denied the parents' request for injunctive relief. The student did not have standing to pursue the 504 claims because he was no longer enrolled in a public school and, therefore, was not "otherwise qualified" under Section 504 to participate on the team. The reason for the student's removal from the team was his transfer to a private school, not his disability status. It would have been a "fundamental alternation" of the athletics program to allow a private school student to play on the school's team.

76. Weber v. Cranston Sch. Comm., 32 IDELR 141 (1st Cir. 2000); For the school district.

The mother of two students with disabilities filed a lawsuit alleging that the school district retaliated against her in violation of Section 504 and Section 1983. The parent alleged that the school district convened IEP meetings without providing her an opportunity to participate, denied her access to her children's educational records, adopted a defensive plan to intimidate her, and improperly threatened to report her to the state's social services agency. The federal court dismissed the claims and the parent appealed. The First Circuit affirmed the dismissal because the parent had failed to exhaust her administrative remedies pursuant to the IDEA prior to filing a federal lawsuit.

VII. MISCELLANEOUS

77. Falvo v. Owasso Indep. Sch. Dist. I-011, 33 IDELR 152 (10th Cir. 2000).

A teacher's practice of allowing students in her classroom to grade each others' tests and other papers and to call out their own grades violated the Family Education Rights and Privacy Act.

BUILDING A BLUEPRINT FOR APPROPRIATE AND DEFENSIBLE AUTISM PROGRAMS

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I have worked in the field of special education law for fifteen years as a Director of Program Compliance for the Tennessee Department of Education, Associate Publisher for LRP Publications, and in the private practice of law. In that time, I have worked with hundreds of local school districts and met hundreds of parents of students with disabilities. Never have I encountered a more volatile special education law issue than autism or more zealous advocates than parents of children with autism. The purpose of my part of these workshops is to analyze the case law on autism for factual and legal patterns and distill those strategies that win - and lose - these lawsuits.

I. Why Is This Topic "Hot?

A. Activity/Expense of Litigation - Autism is the fastest growing area of litigation in special education and the most expensive type of case for a school district to defend. To properly defend an autism suit, school districts usually must hire expensive outside experts to counter the claims of parents' experts.

B. Judicial Unfamiliarity with the Disability - Judges typically are unfamiliar with the diagnosis, etiology and characteristics of autism. Autism is generally viewed as mysterious and therefore subject to the testimony of experts produced by parents and school districts.

C. National Publicity - Just cruise the Internet and search under "LOVAAS" or "autism" to locate thousands of sites devoted to this topic! Here are a few selected samples of the information being shared:

... A 1996 article available on the Internet describes a program in Alaska utilizing a modified form of LOVAAS instruction. The article states, "Like smallpox, autism may soon become an affliction of the past." In fact, the program director claims,

'Functionally, I think we can get 100% of the kids free of autism. Many will grow up to be on the nerdy side -- they won't be social butterflies -- but they'll be normal." (www.cridder.com/morgue/press/news/autism.html)

... A family from Great Britain posted an article touting the benefits of LOVAAS instruction that states, "If a child is diagnosed as being autistic in America, medical insurance companies pay for LOVAAS treatment as a matter of course." (www/jaymuggs.demon.co.uk/james.htm)

... "Allergy Induced Autism" promotes dietary changes and restrictions as a scientific method of treating autism. (www.kessick.demon.co.uk/aia.htm)

... Perhaps the most recent "cure" for autism being advertised is the use of secretin. (www.autism.com/ari.secretin2.html)

...The Founders and Directors of "The Option Institute" claim to be able to reverse autism through the application of a program based on a "nonjudgmental and accepting attitude." (www.son-rise.org/history.html)

...A physician is claiming that autism is a biological disorder of the brain caused by the mother's exposure to toxic chemicals during pregnancy and can be successfully treated by a complex process of biodetoxification. (www.ephca.com/news9811.htm)

D. Parent Networking - the list of parent-provided informational sites on the Internet is voluminous. Just search under "autism" of "LOVAAS" to locate hundreds of sites.

E. Lack of Local Program Development - many school districts assume that their "one size fits all" preschool program will withstand a parental challenge and request for in-home programming and other related services.

F. Higher Incidence of Autism - Autism recently has been declared a "national health emergency" by the Centers for Disease Control. The incidence of diagnosed cases of autism is increasingly on the rise throughout all parts of the world.

G. Burgeoning Pool of "Experts" - a growing number of "experts" is developing in this field, representing both parents and school districts. Representation of both schools and parents in autism litigation has become a lucrative business.

II. Pros and Cons of Litigating Autism Cases (from the schools' viewpoint)

Cons:

1. Expense of Fighting
2. Relative Low Cost of Paying for In-Home Instruction (for one child)
3. Negative Relationship with Parents
4. Expense of Setting Up a Defensible Program

Pros:

1. Precedent (parents waiting in the wings)
2. Long-Term Benefits of Developing a Sound Program
3. The LRE Factor/Duty to the Child
4. Can lead to Residential Placement

III. Case Law on Autism[1]

A recent LRPnet/AOL on-line search of "autism" yielded 127 decisions. Of these, 34 were from state or federal court with the remainder from the administrative levels. Following is a brief synopsis of those decisions rendered within the past three years.

1. Mr. X. v. New York State Education Department, 26 IDELR 854 (S.D.N.Y. 1997). The school district proposed an IEP for a three-year-old child with autism that offered placement in a center-based program for five hours per day, five days per week. In addition, the LEA would provide a one-to-one assistant who would provide 25 hours per week of Applied Behavior Analysis/discrete trial therapy and individual and group speech/language therapy. The parents rejected the IEP and requested funding for a 40-hour per week in-home LOVAAS program. A hearing officer and review officer held in favor of the LEA's proposed IEP. The parents filed an appeal and joined as defendants the state department of education and the local board of education.

[1] Portions of the case summaries were reprinted from the IDELR with the permission of LRP Publications.

The Court refused to dismiss the state department of education, finding that it was proper party to the suit because the SEA is responsible for the review officer's decision. The Court found that the proposed IEP was inappropriate because it was not reasonably calculated to provide educational benefit to the child and failed to incorporate the recommendations of several experts. In addition, the Center did not employ an aide who was qualified to provide ABA instruction.

2. Spring-Ford Area Sch. Dist., 27 IDELR 1083 (SEA PA 1997). The parents of a sixteen-year-old student with pervasive developmental disorder contested the appropriateness of the school district's proposed IEP and assessment. After a due process hearing, the school district was ordered to provide fifteen weeks of compensatory education to the student and appoint a case manager to monitor the implementation of the IEP. Both parties appealed. On appeal, the review panel determined that the student was entitled to one year of compensatory education. The school district failed to respond when the student's academic progress and behavior deteriorated during the school year. However, the review panel reversed the hearing officer's order requiring the school district to appoint a monitor to oversee the implementation of the student's IEP, finding no statutory authority for this remedy.

3. Board of Education of the City Sch. Dist. of the City of New York, 27 IDELR 1000 (SEA NY 1998). The school district violated a 12-year-old autistic student's rights when it failed to develop a behavior modification plan to be included in the student's IEP.

4. Mr. and Mrs. "B" v. Board of Education of the Syosset Sch. Dist., 27 IDELR 685 (E.D N.Y. 1998). The parents of a five-year-old child with an autistic disorder alleged that the State Department of Education's guidelines established a policy against providing home-based instruction for children with autism. The court granted the school district's motion to dismiss because the parents' claims were unsupported by the evidence.

5. Hartmann v. Loudon County Board of Education, 118 F.3d 996 (4th Cir. 1997). The Fourth Circuit reversed a trial court's decision requiring placement of an eleven-year-old student with autism in a regular classroom setting.

6. Flour Bluff Indep. Sch. Dist., 25 IDELR 1121 (SEA TX 1997). The school district proposed a preschool program offering three hours per day for a child with autism. The LEA program focused on communication skills, cognitive development skills, motor development skills, fine arts skills, and

social/emotional development skills in addition to providing a behavior management plan, transportation, O.T., family therapy, speech therapy, and ESY. The parents did not object to the IEP, but wanted the school district to provide a 1:1 aide for their child and funding for a home-based LOVAAS program as a supplement to the school program.

The hearing officer upheld the school's proposed program because it offered opportunities for socialization with nondisabled peers, generalization of skills and participation in typical childhood activities that was not possible in a home-based setting. However, the LEA was ordered to provide reimbursement for the LOVAAS over the summer during which it failed to provide ESY services.

7. CM v. Board of Public Education of Henderson County, 29 IDELR 866 (W.D.N.C. 1999). The parents of a seven-year-old child with autism moved to North Carolina due to their interest in the TEACCH program. However, they removed their autistic child from the TEACCH class after reading Catherine Maurice's book, "Let Me Hear Your Voice" and began in-home LOVAAS instruction. A hearing officer concluded that the parents' choice of LOVAAS methodology could not be forced upon the school so long as the LEA's program was appropriate. The parents appealed the administrative decision and alleged violations of Section 504, the ADA, Section 1983, and the 14th Amendment. On appeal, the federal district court affirmed the hearing officer's decision and dismissed the complaint with prejudice.

8. Central Berkshire Public Schools, 25 IDELR 916 (SEA MA 1997). The parents of a ten-year-old student with autism requested a due process hearing to challenge the school district's refusal to provide an autism consultant during the student's transition from elementary to middle school. The hearing officer ruled in favor of the district, finding that the student had not evidenced any serious behavior problems in the home or at school over the past year, and that there was no evidence that the school staff would be unprepared to respond to future behavior problems.

9. Gonzalez v. Puerto Rico Dept. of Education, 26 IDELR 985 (D.P.R. 1997). Pending the development of a final IEP for a 14-year-old student with autism, the court held that the "stay put" placement was the out-of-state residential school the student was currently attending.

10. In re: G., 27 IDELR 451 (DOD 1997). A hearing officer ruled that the Dept. of Defense. Dependent Elementary and Secondary Schools (DDDESS) denied a five-year-old student with autism a FAPE. The evidence showed that the student made little educational progress and actually regressed while attending

DDESS programs. Nevertheless, the DDESS continued to propose similar programs for several years. The parents successfully sought reimbursement for a home-based LOVAAS program for three years.

11. Liberty Local School District, 27 IDELR 806 (SEA OH 1998). A hearing officer awarded one-and-a-half years of compensatory education services to an 18-year-old student with autism.

12. Azle Indep. Sch. District, 26 IDELR 931 (SEA TX 1997). A hearing officer awarded reimbursement for the costs of a home-based LOVAAS program and compensatory speech/language therapy to a four-year-old student with autism. The hearing officer found that the school district did not provide all of the required speech/language therapy sessions provided in the child's IEP or adequate 1:1 instruction. The child made little progress in the school program, yet had demonstrate significant progress in the LOVAAS program.

13. Burilovich v. Bd. of Education of Lincoln Consol. Schs., 28 IDELR 277 (E.D. Mich. 1998). A seven-year-old autistic child's parents objected to the school district's proposed IEP and sought reimbursement for a forty-hour per week LOVAAS in-home program. A due process hearing officer ruled in favor of the parents, but a review officer reversed in favor of the school district. The review officer held that the LOVAAS program is a significantly more restrictive environment than the school's proposed program, provides minimal contact with peers, does not provide communication training, and fails to provide needed related services of speech, language, and O.T. The parents appealed to federal court, and the court affirmed the administrative decision. The Court held: (1) the LOVAAS package is not individually tailored to meet the unique needs of the child; (2) the school district's proposal is the only one that will place the child in a group setting where he can interact with non-disabled children; and (3) the least restrictive environment does apply to a child with autism.

14. Lexington County Sch. Dist. One, 27 IDELR 1182 (SEA SC 1998). A hearing officer upheld the school district's proposed IEP for a three-year-old child with autism. The district program was taught by a teacher trained in ABA therapy and the child was to receive 1:1 ABA instruction for a minimum of ten hours per week. In addition, the child would have opportunities for mainstreaming with nondisabled children. The hearing officer denied the parents' request for funding for an in-home ABA program.

15. Board of Education of the Manistee Area Schs., 27 IDELR 425 (SEA MI 1997). A school district was not required to provide a full-time paraprofessional to assist an eight-year-old student with autism who was unilaterally enrolled in a

parochial school. Under IDEA 97, school districts are only required to spend a "proportionate share" of federal Part B funds in providing special education and related services to voluntarily enrolled private school students. The cost of providing an aide would exceed the school's proportionate share of federal funding.

16. Tobi K. v. Independent Sch. Dist. No. 196, 27 IDELR 482 (D. Minn. 1998). A school district complied with the procedural requirements of the IDEA with regard to the education of a six-year-old child with autism. The child's parent fully participated in the IEP process and in all decisions regarding the child. In addition, the district's proposed IEP offered the child the ability to make educational progress and provided mainstreaming opportunities via a reverse integration program with regular kindergarten students.

17. San Diego Unified Sch. Dist., 28 IDELR 244 (SEA CA 1998). The school district was ordered to fund twelve hours of behavior intervention therapy for a student with autism and provide reimbursement for costs associated with transporting the student to a private psychologist for the therapy.

18. Jefferson Parish Sch. Board v. Picard, 27 IDELR 824 (E.D. La. 1998). The parents of a seventeen-year-old student with autism alleged that their son's placement in a self-contained life skills classroom was inappropriate and violated the LRE requirements of the IDEA. The parents also objected to the student's removal from school for two separate days following incidents of hitting several individuals. A hearing panel awarded four months of compensatory education due to the district's failure to provide an adequate amount of mainstreaming opportunities. On appeal, a federal district court ruled that the student's placement in the life skills classroom was appropriate and in compliance with the LRE requirements, and provided adequate mainstreaming opportunities. Also, the court held that one of the two days of removal denied the student a FAPE because he was not a danger to himself or others at the time of the removal. However, the second day of removal was appropriate (after the student gave one of the classroom aides a black eye) because the student was a clearly a dangerous at the time of this incident. The court awarded one day of compensatory education for the single day of inappropriate removal.

19. Taunton Pub. Schools, 27 IDELR 108 (SEA MA 1997). The IEP developed for a three-year-old child with autism/pervasive developmental disorder was inappropriate because it was procedurally and substantively flawed. The district failed to evaluate the child, refused to consider valid and timely evaluations submitted by the parents, and ignored the recommendations of individuals who worked with and evaluated the child. The hearing officer

concluded that the child required in-home ABA instruction in order to benefit from his education, especially in view of the evidence submitted by the parents that the child had made significant advances in the program.

20. Board of Education of the Roslyn Union Free Sch. District, 27 IDELR 1113 (SEA NY 1998). A ten-year-old boy with autism did not required an after-school program in order to receive FAPE because he was making progress in his school program.

21. Redlands Unified School District, 28 IDELR 1256 (SEA CA 1998). The parents of a three-year-old child with autism requested funding for an in-home, discrete trial training program. The school district offered placement in a preschool autism classroom with ten hours per week of in-home behavioral intervention services. The school district's program utilized an eclectic methodology that included, but was not limited to, discrete trial training. A hearing officer concluded that the school district's program did not offer the student FAPE because it did not provide speech/language therapy; failed to provide 1:1 instruction; did not provide adequate parental involvement; and the program had no openings at the time the district proposed it. The hearing officer ordered the school district to fund the in-home program, finding that it appropriately addressed the student's individual needs and was designed to provide educational benefit. The hearing officer also awarded reimbursement for the costs of private speech/language therapy obtained by the parents.

22. Board of Education of the Middle Country Central Sch. District, 28 IDELR 75 (SEA NY 1998). A review officer reversed a decision awarding the parents of a fifteen-year-old student with pervasive developmental disorder reimbursement for the costs of private math tutoring. The student was making passing grades in math and there was no evidence that she needed any additional instruction in that subject.

23. Sch. Board of Martin County v. A.S., 29 IDELR 964 (Fla.Dist.Ct.App. 1999). A due process hearing was convened to determine the appropriate location of services for a child with autism. The parties agreed that the child needed 15 hours per week of discrete trial training ("DTT") on either a 1:1 or 2:1 setting, but disagreed as to the location of these services. The parents wanted the DTT to take place in their home, and the school district offered the DTT in a school-based program. At the hearing, the administrative law judge determined that 15 hours per week of DTT in either a 1:1 or 2:1 setting was appropriate. The issues were limited to a determination of the location of the program and a clarification of whether the services would be provided in a 1:1 or 2:1 setting. At the conclusion of the hearing, the ALJ ordered the school district to provide 1:1 speech therapy for 1 hour per day and awarded reimbursement for an independent educational

evaluation. In addition, the ALJ determined that the parents were "prevailing parties" for purposes of attorneys' fees. The school district appealed and the state court reversed and vacated the ALJ's order. The court held that the ALJ exceeded the scope of his authority by ordering services that were not requested by the parents (speech therapy) and erroneously finding that the parents were "prevailing parties."

24. Renner v. Board of Education of the Pub. Schs. Of the City of Ann Arbor, 30 IDELR 885 (6th Cir. 1999). The parents of a preschooler with autism disputed the amount of discrete trial training (DTT) offered by the school district. The district offered placement in a preschool program for 3 hours/day, four days/week and speech therapy. The parents rejected this proposal and began a LOVAAS program for 35 hours per week. In response, the district offered to place the student in a new program pursuant to a one-month trial period for four hours a day, five days weekly, which also incorporated some DTT direction into each school day. The parents initially agreed to this proposal, but eventually rejected it based on their contention that the child was not receiving adequate amounts of discrete trial training. The parent requested a due process hearing, withdrew the child from school and increased the home-based DTT program. A level one hearing officer found the IEP to be flawed, and ordered one-on-one DTT sessions over an extended school year along with substantial reimbursement for the home program. A level II hearing officer reversed, upholding the integrity of the district's IEP as adequate and valid. The parents appealed to district court, asserting claims under the IDEA, Section 504, the ADA, Section 1983, state special education law, and state disability law. The district court granted summary judgment in favor of the district, and the parents appealed again.

The circuit court found the level I hearing officer's determinations with regard to the student's IEP to be incorrect. Contrary to his findings, the student's IEP team members did not lack the background, experience or training to assess the student's needs because they lacked experience with autism and DTT. The court agreed with the findings of the magistrate judge who ruled that the student's IEP team was properly constituted with appropriately qualified personnel to formulate an educational program for the child. Thus, the IEP team was on firm ground when it chose to incorporate only part of the DTT program and **did not need to have any additional experts in autism or DTT to validate their status**. Thus, there was no error in the judge's conclusion that the student's unique needs were met in the IEP offered by the district and **the level I hearing officer reached an improper determination giving "undue emphasis" to the opinion of a leading proponent of the technique, who was also the parent's expert**. Further, the IEP team's failure to consult with the parent's expert in and of itself did not create a deficiency in the student's IEP. Nor did the IEP team's failure to prescribe the number of hours of DTT called for by this expert amount to an IEP violation. Having concluded that the district's actions satisfied federal special education standards, the court evaluated the student's state special education law claims and held that they must fail as well, even given Michigan's recognition of a maximizing standard which enhanced federal requirements. **The application of**

the state standard was left up to the reasonable discretion of state officials and did not require the best education without consideration of fiscal or geographic constraints, and given the findings with respect to the compliance with federal law, the court concluded that the district's educational plan for the student also satisfied the higher standards imposed under state law. Accordingly, the circuit court affirmed the decision below.

25. T.H. v. Board of Education of Palatine Community Consol. Sch. Dist., 30 IDELR 764 (N.D. Ill. 1999). The parents of a five-year-old child with autism objected to the district's proposed placement and IEP. The parents requested funding for a 35 hour per week in-home program (LOVAAS). The school district proposed placing the child in a cross-categorical preschool classroom for 2 ½ hours per day, four days per week. This placement would include 90 min. per week of speech therapy, 60 min. per week of social work, and 60 min. per week of occupational therapy. The school district lost at the administrative level and on appeal to federal court. The district lost mainly due to its failure to develop a transition plan that would include ABA/discrete trial training; failure to provide an aide to help the child transition to the preschool program; and failure to develop a program that was individualized for this child. In addition, the parents provided testimony from 5-6 expert witnesses from several major universities while the school district's witnesses were the preschool coordinator and special education staff.

26. New Prairie United Sch. Corp., 30 IDELR 346 (SEA Ind. 1999). A hearing officer upheld the IEP for a 16-year-old student with autism/Asperger's disorder who was placed at district expense in an out-of-state, residential school. The hearing officer found that the district did not commit any procedural violations, that twice monthly family therapy was required for the student to receive a FAPE, that the district was obligated to fund either 12 visits to the school by the parents per year, or 12 visits home by the student in lieu of parent visits, and that the parents were not entitled to reimbursement for the costs of certain phone calls they made. The parents appealed to the state board of special education appeals.

The appeals board granted the district's motion to strike or dismiss the audio-tape of the pre-hearing conference because the parents secretly recorded the meeting without informing the district. The appeals board found that twice monthly family therapy was necessary, with one session by telephone and one with at least one parent present at public expense or, in the alternative, the district could fund the child's home visit. Expenses other than airfare relating to the student's presence at the due process proceedings were not reimburseable, nor were the parents' personal phone calls.

27. Williams Bay Sch. Dist., 29 IDELR 1141 (SEA WI 1999). The school district placed a 13-year-old student with autism in a special school for students with disabilities where he received consultative occupational therapy, individual speech therapy for 60 minutes per week, group speech therapy for 40 minutes a week, and private occupational and speech therapy. The parents requested a due process hearing, claiming the student's current placement was not the LRE, challenging the amount of related services, and seeking compensatory education to make up for the lack of an extended year program.

The ALJ found that the district failed to consider whether the student could be appropriately educated in a less restrictive environment. The student was never placed in regular education, with or without supplemental supports and services. One of the witnesses stated that with a 1:1 aide, the student was capable of attending and benefiting from regular education classes. The student's current placement provided no opportunities for mainstreaming, and he functioned on a higher level than many of his classmates. Based on these findings, the district was ordered to place the student within the district, and assign a full-time 1:1 aide to him. Second, the ALJ found that the student required instruction in functional speech, which was not incorporated into his IEP. The district was directed to amend the student's IEP to reflect this need, and provide another hour of weekly speech therapy. Next, the ALJ found the student required individual occupational therapy in order to receive a FAPE. The student had deficits in various areas that would best be addressed through individual occupational therapy. The district was directed to complete the assistive technology evaluation it started and to develop an assistive technology plan for the student. Lastly, the ALJ determined there was no evidence the student required extended year services, as he did not substantially regress over the summer months. Accordingly, the student was not entitled to compensatory education.

28. Houston Ind. Sch. Dist., 30 IDELR 321 (SEA TX 1999). The parents of an 11-year-old student with autism requested a due process hearing, challenging the district's proposal to place their child in a behavior adjustment class at a district elementary school. The district's placement offered social skills instruction, behavioral training, parent training, and extended year services. The parents objected to the proposed placement and sought funding for private school placement.

The hearing officer upheld the district's proposed placement, finding that the district had attempted to place the student in regular education without success before proposing the behavior adjustment class. The student's individual educational needs could not be met in a regular education setting, as he needed a small, structured class taught by a special education teacher. The proposed class offered the student a chance to make progress, with the eventual goal being a return to regular education once his behavior and social skills allowed. The

proposed IEP also included the related services of counseling, parent training and transportation.

29. Richmond Community Sch. Corp. 30 IDELR 208 (SEA Ind. 1999). A hearing officer found that the proposed district IEP for a 3-year-old student with autism offered the student a FAPE in the LRE and denied the parents' request for reimbursement of the costs of an in-home ABA program. An appeals board upheld the hearing officer's decision, finding the proposed district program offered the student a FAPE in the LRE because it was calculated to provide the student with educational benefit. Since the district offered the student a FAPE, the district was not obligated to reimburse the parents for the costs of the in-home ABA program. The board rejected the parents' claim that the IEP team did not include an individual with expertise in autism, noting that the state did not provide a separate certification for autism. The individuals on the student's IEP team were knowledgeable about autism, and had received appropriate training.

30. Special Sch. Dist. #1, 30 IDELR 419 (SEA MN 1999). A 7-year-old student with autism had participated in a home-based discrete trial training program for three years at public expense. The district proposed changing the student's placement to the district's classroom based autism program. Under the proposed placement, the student would receive at least 10 hours of DTT, 1:1 assistance, a modified curriculum, extended school day services, transportation, speech/language services and adaptive physical education. The district also developed a transition program. The parents objected to the change, preferring the district fund 84 hours per week of in-home DTT.

The hearing officer rejected the parents' assertion that district personnel were not trained to work with the student, finding the proposed teacher was qualified to teach autistic children, and had experience in DTT. Turning to the proposed IEP, the hearing officer concluded it was appropriate with two modifications. The program as a whole was calculated to provide the student with a FAPE, but the transition plan was deficient. The transition plan covered too short a time period, and lacked sufficient contact between the student and the teacher prior to the placement change. The other deficiency in the proposed district program was the number of hours of DTT. The district offered 10 hours a week, which the hearing officer found insufficient, ordering 20 hours instead. The program preferred by the parents, 84 hours of DTT per week was not appropriate according to the hearing officer, as it failed to address the student's needs.

31. Frederick County Schools, 29 IDELR 1012 (SEA MD 1999). A school district proposed placing a 3-year-old student with autism in a district program for students with autism. The program was child-centered, employed assorted educational methodologies, utilized augmentative communication, offered

opportunities for mainstreaming, and included a home component. The parents wanted the student placed, at district expense, in a private, in-home early intervention program that utilized the discrete trial training methodology. First, the administrative law judge determined any procedural violations the district committed did not deny the student a FAPE. Although one of the notices the parents received regarding an ARD meeting did not fully comply with the notice requirements, the error was harmless. The district's rejection of the placement preferred by the parents without calling for a county ARD meeting was not in error. There was no evidence the district placement was determined prior to the development of the IEP. The parents fully participated in the placement process, even when their advocate left an ARD meeting early. Second, the ALJ determined the district evaluations were appropriate except for the portion dealing with occupational therapy. The district evaluation concluded indirect occupational therapy was called for, while an outside evaluation indicated the student required individual, small group and classroom-based occupational therapy. Because the proposed IEP only offered the student consultative occupational therapy twice a year, and she required additional services, the portion of the IEP addressing occupational therapy denied the student a FAPE. The district was ordered to amend the student's IEP to include daily occupational therapy, in individual and small group sessions. Turning to the proposed placement, the ALJ concluded the district program offered the student a FAPE. The district program utilized various methodologies, and addressed all of the student's individual educational needs. Since the district program offered the student a FAPE, the choice of methodologies was left to the district. The district program was also the LRE, as it offered opportunities for interaction with regular education students. The student's IEP could be fully implemented in the district program. The parents' assertion that the district staffers were not qualified was rejected by the ALJ, in light of the fact that all staffers had experience working with students with autism. Accordingly, the district program offered the student a FAPE in the LRE, and the district was not obligated to place the student in the program requested by the parents.

IV. Special Considerations in Litigation

A. The new "stay put" regulation (34 CFR § 300.514(c))

The new IDEA regulations provide that a hearing officer's ruling in favor of the parents of a child with disabilities creates a new "stay put" placement during pendency of further litigation. The provision has significant implications for parents of children with autism and their school districts.

B. Educational methodology arguments

Board of Education of the Hendrick Hudson Central Sch. District v. Rowley, 458 U.S. 176 (1982). The Act does not require schools to "maximize the potential of [students with disabilities] commensurate with the opportunity provided to [nondisabled] children." The Court cautioned that courts lack the "specialized knowledge and experience" necessary to resolve "persistent and difficult questions of educational policy..." Thus, once a court determines that the requirements of the Act have been met, questions of methodology are for resolution by the states.

Lachman v. Illinois State Board of Educ., 853 F.2d 290 (7th Cir. 1988). "Rowley leaves no doubt that parents, no matter how well motivated, do not have a right under the Act to compel a school district to provide a specific program or employ a specific methodology in providing for the education of a disabled child."

VI. Recommendations

A. Retain experts in autism for litigation

B. Train LEA staff in autism generally.

C. Retain experts in program development.

D. Focus on including the essential components of a program for autistic children:

1. Longitudinal
2. Age-appropriate
3. Community-based
4. Functional

E. Strive to use an eclectic approach based on the needs of the individual child:

1. TEACCH
2. ABA/DTT
3. Systematic teaching
4. Extensive speech/language therapy
5. Behavior management techniques/functional behavior assessment
6. Parent training (including in-home visits)
7. Opportunities for integration/socialization

8. Emphasis on generalization of skills
9. Communication system (PECS, for example)

F. Obtain and consider all records in the possession of the parents (logs, tapes, data sheets, drill sheets).

G. Discuss/consider any evaluations provided by the parents.

H. Staff and teacher training is critical (esp. for pre-K and Kindergarten teachers)

I. Consider need for full day or ESY services

J. Train Kindergarten and Pre-K teachers to advise central office staff of children suspected of having or known to have autism/PDD/Asberger's Syndrome.

Mr. BURTON. Mr. Mayerson.

Mr. MAYERSON. Yes. My name is Gary Mayerson, and I want to be sure we don't miss, Mr. Chairman and members of the committee, to thank you for giving me the opportunity to speak, and I will try to confine my comments to the 5 minutes, if I can.

Mr. BURTON. Sure.

Mr. MAYERSON. Initially, just by way of background, I was for many years a commercial trial lawyer, almost 17 years, and I left the practice of commercial trial in order to become a—basically to launch my own firm concentrating in educational rights for children with autistic spectrum disorders, principally an IDEA-type litigation, and I did it because of what was going on around the country of children being denied those services. And I saw it time and again, and not in any particular geographic region. I saw it in New York. I saw it in Greenwich. I saw it in Tennessee. I did the first ABA case in Alaska, TX. I have now represented children with those autistic spectrum disorders in approximately two dozen States now. So while I never got my flying license, I know you made reference to Representative Lantos, I certainly do fly the IDEA statute around the country a lot.

And basically I'm here asking Congress to put me out of business because what I'm hoping that will be done is that there will be the sufficient funding, not simply throwing money at school districts. I don't think that's the answer. I think it is a question of making sure that the money, just like with a charity, gets to the people it was intended to serve. That doesn't mean padded administration upon administration. It means money actually going directly to the services that are necessary.

And the other one is the accountability context. There really are—I believe that while there are enough lawyers out there that are ready to take retainers to work for school districts, there are precious few attorneys who are ready, willing and able to represent children with disabilities, and in particular children with autistic spectrum disorders. The learning curve is very high, the pay is erratic at best, and the results can be catastrophic if for any reason you fail the child. So for all those risk factors I think a lot of people shy away from that. It's very difficult to find people who are willing to take on that kind of case.

Now, I do agree that there are a number of school districts around the country who are doing a fine job complying with the IDEA statute or making every reasonable good faith effort to do so. I deal with a number of those districts around the country. I'm able to resolve cases before they become a full-blown litigated dispute. That's the way it should happen, and ideally I shouldn't even be involved with it. But unfortunately there are far too many school districts around the country who, because of whatever reason, fear of precedent, fear of finances, desire for control, whatever it is, it doesn't matter, they stonewall the parents. They tell the parents they can't provide it, they can't find the people to provide it, they don't have the money for it, or sometimes they even tell the parents, we are going to provide it, and then 6 months go by and nothing happens, and meanwhile the child who has this incredibly limited window of opportunity is dying on the vine.

I must speak briefly about one intervention in particular, which is included in my submission. That is the Applied Behavior Analysis intervention. The reason why this is so important for these children is that it is the only scientifically supported intervention which is proven to remediate much of the symptomatology of autism and to get rid of the behaviors and the interfering behaviors that prevent these children from fully mainstreaming. There is a very seminal study from 1987; Dr. Ivar Lovaas. There was a 1993 followup study. Both of these studies show with very intensive intervention of ABA, given over a 2 to 3-year period, approximately 47 percent of these children in these control and experimental groups were able to mainstream and go into regular education with their typically developed peers and be considered, "indistinguishable."

Whether they're indistinguishable or not for me is not the important thing. The fact is they're succeeding in the classic, least restrictive environment setting, and I don't care that it is not 100 percent, because like any intervention or medical intervention, some people are allergic to penicillin. Does that mean we shouldn't give penicillin to children with ear infections? No. It's the first and only scientifically supported intervention that's come out to remedy the impact of autism. That's huge. We don't have any other interventions with that kind of track record.

The Surgeon General of the United States in 1999 came out with a report on mental health where he called Dr. Lovaas' 1987 study a, "well-designed study;" talks about 30 years of behavioral intervention and research on that. So this is not something that's experimental, it's not something that's new. It's just something that's been proven, and yet school districts will stonewall the parents and say, we are not going to give it to you, or we want to choose a different methodology, and our methodology is the same old special education that we've been giving for the last 50 years. That's not right. That goes against the whole grain of what the IDEA statute was designed to implement.

I've got a number of important examples of how school districts have victimized families in my written presentation. Ms. Baird had mentioned the fact that she gives several hundred presentations, or she's given hundreds of presentations. One of the presentations that I have highlighted in my package is one called "How to avoid Parents' Demand for LOVAAS." That's not what IDEA says. You don't go around spending taxpayer money educating people on how to avoid parents' demands; or Ms. Baird's own most recent one, How to Build a Legally Defensible Autism Program.

And just in closing, I know that my time is already up. I could stand here for quite a bit of time, and I apologize if I have gone over at all, but my comments are contained in my written submissions. Thank you very much.

Mr. BURTON. Thank you, Mr. Mayerson.

[The prepared statement of Mr. Mayerson follows:]

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February 23, 2001

Via Federal Express

Hon. Dan Burton, Chairman
House of Representatives
Committee on Government Reform
2157 Rayburn House Office Building
Washington, D.C. 20515-6143
Attn: Ms. Beth Clay

Re: Summary of 2/28/01 Testimony Re IDEA Compliance

Dear Chairman Burton:

Initially, I want to thank the Committee for giving me the opportunity to provide evidence on this most important issue.

By way of background, after more than fifteen years as a commercial trial lawyer, I withdrew from a Manhattan law partnership in order to launch my own law practice dedicated to representing children, adolescents and young adults diagnosed with autistic spectrum disorders in educational rights matters. Normally, these matters involve due process hearings arising under the IDEA statute. To date, I have represented children in approximately two dozen states including Tennessee, Alaska, Utah, Texas, California, Illinois, Indiana, Oregon, Kansas, Louisiana, New Jersey, New York, Connecticut and Pennsylvania.

Unfortunately, while there apparently are enough lawyers and law firms prepared to work on a steady retainer basis for school districts (or the insurance companies which insure school districts), there are relatively few lawyers in the country who are ready, willing and able to represent children with autistic spectrum disorders. The subject matter is complicated, the learning curve is steep, the pay is uncertain and erratic, and the risks of failure can be catastrophic to the child and the child's family. There clearly are easier ways to earn a living.

The good news is that there are *some* excellent and responsible school districts in the country which will make every good faith effort to comply with the IDEA statute. There are *some* school districts which will invest the time and resources necessary to meaningfully tailor a program of educational services to meet the unique and ***individual*** needs of the ***child***. This, of course, goes to the very essence of the IDEA statute and what Congress intended.

Unfortunately, as the Committee might imagine, I do not get many calls from parents who want to give an award to their local school district. My typical case involves a situation where, at the very least, a school district is attempting to tailor the ***child*** to meet the fiscal or administrative convenience of the district. All too often, the dispute will rise to the level of a "scorched earth" litigation, where the school district will spend tens and sometimes hundreds of thousands of dollars in attorneys' fees to defend a proceeding which could and should have been resolved for a mere fraction of the defense cost. Is the school district afraid of establishing a "precedent?" Is the school district's special education administrator under pressure to reduce the district's special education budget? Does the school district have a longstanding one-size-fits-all approach to special education? Does the district's legal counsel view a full-blown educational dispute as a lucrative "cash cow," regardless of the ultimate result? Is the school district attempting to send a message to the family and other would-be IDEA litigants that their best bet would be to "get out of town" and move to a different school district? This Committee certainly can draw its own conclusions as to what factors might be at play in an individual case.

School districts will invariably contend that they provide an "appropriate" educational program which is tailored to the individual needs of the child. School districts which view the word "appropriate" as a mere *mantra* to be repeated over and over in the presence of parents often will go to great lengths to create the ***appearance*** of IDEA compliance. I see my job as being an IDEA detective of sorts, to look behind what the school district is saying to the public, and finding out precisely what the school district is actually doing for children with disabilities. All too often, there exists a stark contrast between the "virtual reality" of what the district is saying, and the actual reality of what the district is doing. In my experience, this contrast is most apparent in implementing effective (i.e. demonstrably proven) interventions for children diagnosed with autistic spectrum disorders.

Thirty years ago, a diagnosis of autism was akin to the child and the child's family receiving a death sentence. There was no intervention at the time which was scientifically proven to remediate the symptoms of autism, and certainly none which was capable of getting material percentages of such children to succeed in mainstream educational settings with their same age, typically-developed peers. To the extent that these children were being educated at all by school districts, it was virtually always in a classic, if not generic, "special education" classroom setting. Traditional special education, however, failed to remediate the pervasive impact of autism. Accordingly, these children often were institutionalized by the time they reached adolescence, all at a tremendous cost and loss to society, the child and the child's family.

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The field of autism was turned on its head in 1987. In that year, UCLA professor Dr. Ivar Lovaas, a psychologist who had emigrated to this country from Norway in the 1950's, published an NIH-funded scientific study in a respected peer review journal (Appendix 1) which proved that it was possible to remediate the effects of autism in a meaningful and lasting way. In Dr. Lovaas' now seminal 1987 study, preschool age children diagnosed with autism were given a one-on-one, data-based teaching intervention called Applied Behavior Analysis ("ABA"). The experimental group in the study received the one-on-one ABA intervention for forty hours each week, over a two to three year time frame. ABA had never before been delivered at this intensity level.

By the end of the 1987 study, many of the subjects who had been in the 40 hour per week experimental group had achieved IQ gains of more than 30 points, projecting them from a mentally retarded range to levels within the range of "normal" intelligence. No autism intervention had ever before accomplished such a result. What is even more astonishing is that fully 47% of the experimental group receiving ABA at 40 hours per week was able to ***succeed*** in mainstream grade school and be considered asymptomatic and "indistinguishable" from their same age, typically-developed peers. (See Appendix 1) Through intensive ABA interventions, these children had "learned to learn" and were fully "generalizing" their skills. Let it suffice to say that even today, there is no intervention other than intensive 1:1 ABA which is scientifically proven to be able to achieve that kind of result. This has major implications for the IDEA statute and its "least restrictive environment" commandment to educate children with disabilities with non-disabled children to the "maximum extent appropriate." *[1]

In 1993, Dr. Lovaas and his colleagues at UCLA, including Drs. John McEachin and Tristram Smith, published a follow-up ABA study, also funded in part by the NIH (Appendix 2). The purpose of the follow-up study was to track the progress of the children in the 1987 study who had successfully entered mainstream educational settings. With the exception of a single child who had transitioned back into a special education

[1] In the 1987 study (Appendix 1), there was a control group of children receiving only 10 hours per week of the ABA intervention. The study reports that the children in the "10 hours" per week control group fared ***no*** better than the children in the control group which was receiving ***zero*** hours per week of the ABA intervention. Clearly, when it comes to the implementation of ABA therapy, "something" is ***not*** better than nothing. To the extent that ABA therapy can be viewed as a "jump start" for children with autism, a sufficiently intensive "charge" is required. For a child with an ear infection, one would not dream of shortchanging the child on the doctor's prescription to take amoxycillin three times a day for ten days. Yet, that is unfortunately what many school districts will do in regards to the provision of ABA therapy. Sadly, many school districts which offer "some" ABA therapy will offer such therapy at or even ***below*** the "10 hours of ABA per week" levels already proven to be ***ineffective*** and worthless in the 1987 ABA study. (Appendix 1) Some states have convened blue-ribbon panels of scientists and educators to frame "best practice guidelines" for autism interventions. New York State, for example, recently issued a three-volume set of "early intervention" recommendations which include the recommendation that for the child with even the mildest presentment of autism, intervention should start with a "minimum" of 20 hours of ABA per week. The same recommendations caution that adjustments of up to a total of 40 hours per week may be necessary, depending on the individual needs of the child.

setting, the results reported in the 1987 study were real and lasting some six years after the fact.*[2]

In 1999, the Surgeon General issued an extensive report on the state of mental health in the United States (Appendix 3) which focused on autism as a "severe, chronic, developmental disorder." The Surgeon General cited Dr. Lovaas' 1987 ABA study with unequivocal approval, as follows:

> Only in the past decade have studies shown positive outcomes for very young children with autism. Given the severity of the impairment, high intensity of service needs, and costs (both human and financial), there has been an ongoing search for effective treatment.
>
> ***
>
> Thirty years of research demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication learning, and appropriate social behavior. A well-designed study of a psychosocial intervention was carried out by Lovaas and colleagues (Lovaas, 1987; McEachin, et al. 1993)[description of results of study omitted] Up to this point, a number of other research groups have provided at least a partial replication*[3] of the Lovaas model (see Rogers, 1998).

(Appendix 3) The Surgeon General's Report was was based on "thirty years of research" which included the 1987 ABA study and the 1993 follow-up study.

The publication of the 1993 follow-up ABA study (Appendix 2), coupled with the publication of the book "Let Me Hear Your Voice"*[4] in the very same year created a groundswell of public demand for ABA therapy interventions. This public demand for ABA also happened to coincide with increased reported incidence of autistic spectrum disorders. The overall impact was that school districts across the nation which had little, if any, experience with ABA found themselves under increasing pressure to implement such programs. Rather than look to ABA as a promising, if not demonstrably proven and

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[2]There is no claim made in the 1987 or 1993 ABA studies that ABA offers a "cure" for autism. Helen Keller remained deaf and blind, yet she was able, with an earlier and more rudimentary brand of 1:1 intervention (the ever-present Annie Sullivan) to functionally "overcome" her disabilities. I have represented a number of children originally diagnosed with autism who either have been "declassified" or are now being considered for declassification as they no longer meet the criteria for a diagnosis of autism as set forth in the Diagnostic and Statistical Manual ("DSM"). Each and every one of these children had the benefit of an intensive 1:1 ABA program during the pre-school years.

[3] There are now ABA replication sites in Wisconsin, Norway, and California, among other locations.

[4] The 1993 book, "Let Me Hear Your Voice," offers an inspirational, first-person account of a mother whose two children were able to overcome their autism primarily via ABA interventions.

cost-effective*[5]intervention, many school districts "stonewalled" and refused to consider the implementation of ***any*** ABA. They did this by challenging the 1987 and 1993 studies and holding Dr. Lovaas' work up to a level of scrutiny which was unprecedented, and which was inconsistent with the manner in which these same school districts continued to utilize highly questionable interventions and approaches (e.g. Facilitated Communication) which did not enjoy scientific support and which have never been proven to be efficacious.*[6] In other situations, local educational agencies would agree to provide "some" ABA, but often at or below the "10 hours per week" intervention threshold already found to be wholly ***ineffective*** in the 1987 ABA study.*[7]

Over the last decade, by all appearances, a veritable cottage industry has sprung up for the purpose of helping school districts to avoid, if not evade, their statutory obligations under the IDEA statute. With the permission of the Committee, I will now present evidence of specific examples of abuse. The following documented examples of abuse represent only the tip of the iceberg, and will give the Committee a compelling window of insight into what some "local educational agencies" are capable of, and what hurdles and obstacles parents must often face as they attempt to secure an appropriate education for their children.

Example No. 1 (Policy Limiting ABA Intervention Hours)

Submitted as Appendix 5 is an internal memorandum sent by the Director of Westchester County, New York's Early Intervention Unit to Westchester County's

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[5] Appendix 4 presents an article authored by three prominent scientists in the field, later published in a respected peer-review journal, which demonstrates that while the cost of an effective ABA intervention is "frontloaded" and certainly not inexpensive, the alternative "cost" of not providing an effective intervention to the affected individual may easily amount to ***millions*** of dollars over the cost of a lifetime. Let it suffice to say that school districts which are focused primarily on meeting "this year's budget" will not be looking at the cost issue with the requisite "long view."

[6] School districts often will take the position that they are entitled to "choose methodology." This presupposes, however, that there exists a ***genuine*** choice to be made between different "competing" methodologies, much as one might have a choice between Aspirin and Ibuprofen as competing pain relievers. To the extent that school districts are required to consider the "full continuum" of placement and service options, it is disingenuous when a school district always makes a "choice" which fails to include ABA, and which always results in and "defaults" to the perpetuation of stale interventions which do not enjoy scientific support, and which do not have a proven track record of helping significant numbers of children achieve success in typical, mainstream educational settings. The fact that school districts need only provide a "Chevrolet" does not provide school districts with a license to offer children with disabilities educational "transportation" which will not pass inspection. Similarly, in light of the 1987 and 1993 ABA studies, and the 1999 Report of the Surgeon General blessing Dr. Lovaas' seminal 1987 study as a "well designed study," school districts which continue to this day to refer to ABA an an "experimental" or "controversial" intervention are akin to tobacco company executives who, more than 30 years after the Surgeon General declared smoking to be dangerous and life-threatening, continued to take the position, even under oath before Congress, that a causal link between smoking and cancer had never been "scientifically proven." The politics of "denial" apparently have not changed that much since the time of Copernicus.

[7] An Individualized Educational Plan is required to be reasonably "calculated" to produce a meaningful educational benefit. In light of the results of the 1987 ABA study, an ABA intervention plan consisting of only ten hours of ABA per week, or less, would be reasonably "calculated" to do only one thing; that is, ***fail***.

Senior Deputy Attorney. The internal memorandum, which has been redacted to protect the family's privacy, concerns a two-year-old child diagnosed with autism whose parents had requested an intensive ABA program as the anchor of the child's educational program. Whereas the child's parents had requested a thirty-hour per week ABA program, Westchester County offered the child only 8 hours per week of ABA. The memorandum was generated by reason of the family's understandable resistance to accepting only 8 hours per week of ABA therapy. Page 2 of Westchester County's internal memorandum speaks for itself as to the County's internal "concerns":

> 1) Parent is savvy legally and will most likely pursue due process
> 2) Currently, we have been following a ***policy*** which limits E.I. [early intervention] ABA services to ten hours a week
> 3) Since he is a lawyer and will be representing himself or be part of a legal team, we are concerned that anything said could be held against us.....

Since when should it ever be of "concern" to a public official that a parent of a child with a disability is "savvy?" Similarly, to the extent that the IDEA statute requires the local educational agency to "tailor" educational services to the individual needs of the child, how does a local educational agency dare to establish "policies" which, on their face, will limit and thus ***prevent*** the local educational agency from fully individualizing educational services? Finally, when public officials who are charged with protecting children with disabilities express the "concern" that "anything said could be held against us," it is the public which should be very concerned.*[8]

Example No. 2 (Institutionalized Blueprint For "Avoiding" Parents' Requests for ABA)

Submitted as Appendix 6 is a seminar brochure disseminated by the Missouri Association of School Administrators, the Missouri United School Insurance Council (which ostensibly insures school districts in Missouri) and the Missouri law firm of Peper, Martin, Jensen, Maichel and Hetlage. The seminar, entitled "Special Education and The Law," states that its purpose is to provide "a ***private*** briefing designed for school board members, central office administrators, special education directors [etc.]...." This particular briefing apparently was given at four separate locations. When one reads the

[8] Sometimes, I will receive "smoking gun" documents anonymously (and unsolicited) from school district employees who want to be able to sleep at night, but who also wish to continue in their employment without reprisals. This attorney-client communication, however, was sent *directly* to the child's parents as part of Westchester County's response to a request made by the child's parents under New York's Freedom of Information Law! Otherwise, this memorandum never would have seen the light of day. Parenthetically, I would point out that the child in question prevailed at his due process hearing, and ultimately was awarded a 35-40 hour per week ABA program. However, even **after** this compelling internal memorandum surfaced and was admitted into evidence on the third day of a due process hearing, the child's parents still had to endure another week of hearing dates.

"Program Agenda" appearing on page 2, it is apparent why the seminar was made a "private" briefing which was going to be held without the attendance of any parents or other persons who might be advocating for the child's interests. Page 2 of the Program Agenda notes that the 2:20-2:55 session is entitled:

> "Special Education for Early Childhood Autistic Students—How to ***Avoid*** Parent Demands For Lovaas/TEACH Methodologies"*[9]

Thus, the stated purpose of the "private" seminar is ***not*** how a school district should offer children with autism quality educational programs which will address and meet their unique and individual needs, but merely what strategies and artifices may be employed so that the school district can "avoid" having to provide any child with an intensive, effective ABA program. Page three of the seminar brochure (Appendix 6) recites the increase in ABA litigation and the fact that "parents frequently prevail." It also recites that "litigation with respect to [ABA, etc.] is much more time consuming and expensive than general due process litigation and almost always requires a minimum of one expert witness for the district." Perhaps the most alarming portion of the seminar brochure appears at page 12 under the brazen heading "**HOW TO AVOID LIABILITY IN LOVAAS CASES**." That section of the brochure offers the strategy "If parents request LOVAAS, ***listen*** to their concerns and adopt ***some*** of the methodological techniques in the school program." The recommendation being made is that a school district should feign having an interest in the parents' request for ABA and then create the ***appearance*** of an ABA program without actually doing so.*[10] Another "hot tip" offered by the seminar brochure is that the school district should "have someone on the IEP team who is knowledgeable about autism." (Appendix 6, p.12)

Example No. 3 ("How To Avoid Parents' Demands For Lovaas" In Operation)

The foregoing "private briefing" ("HOW TO AVOID PARENTS' DEMANDS FOR LOVAAS") is not merely theoretical poison—it continues to impact negatively with respect to school districts across the country which are considering parent requests for the implementation of ABA interventions. Appendix 7 is an October 4, 2000 transcript excerpt from a case in Hamilton County, Tennessee in which I represented the child, and

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[9] Although the seminar brochure appears to equate ABA and TEACCH, these approaches are quite different, with different stated objectives. Whereas the objective of ABA is to attempt to make itself obsolete, TEACCH is a "low maintenance" approach which has no such objective or expectation. As the Surgeon General's report (Appendix 3) reflects, there is no scientific data involving ***controls*** for the TEACCH intervention, notwithstanding its use for the last 25 years. Moreover, whereas many due process proceedings are initiated each year to secure funding or reimbursement for ***ABA*** programs, I have not yet seen a situation where a parent ever sued a school district in order to get their child into a TEACCH program. Although the mandate of the IDEA statute is an "individualized" approach, TEACCH has a virtual "lock" in some states such as North Carolina, the birthplace of the TEACCH model, where the State Legislature actually has reserved a special "line item" in the budget for TEACCH's continued funding. Once again, this kind of approach ***precludes*** any chance that a child's educational program will be individually tailored to his or her unique needs.

[10] Just as decaffeinated coffee may taste like, look like and smell like the genuine article, a school district can easily create an educational program which may ***appear*** appropriate, but which may be missing the one "ingredient" which is necessary to educationally "wake up" the child.

which spanned approximately 30 days of hearing. Hamilton County's lead school psychologist admitted that she ***had*** read and considered "How To Avoid Parents' Demands For Lovaas" in connection with the research which she did on the Internet. Predictably, this same school psychologist, who does assessments, was not able to give an answer as to whether either of Hamilton County's principal special education administrators ever had said anything "positive" about ABA. (Appendix 7, p. 4909) The record disclosed substantial additional documentation in Hamilton County's files which was demonstrably anti-ABA.

During the pendency of the Hamilton County, Tennessee due process hearing, which the child's parents had opened to the public, an article appeared in the Chatanoogan (Appendix 8) which offers a compelling window of insight as to the mindset of Hamilton County and its counsel in its steadfast opposition to ABA interventions. The Chatanoogan article quotes Hamilton County's attorney as saying that even with numerous ***additional*** hearing sessions then remaining, more than $175,000 had already been spent in defending the impartial hearing.*[11] Although my billable ***rate*** is higher than Hamilton County's counsel, my own time charges on the matter were substantially less. In any event, Hamilton County's counsel is then quoted in the Chatanoogan article as saying that:

- Members of Hamilton County's Exceptional Education Department "are devoting enormous effort to this case;"
- The case "is extremely important" in that it may set a precedent on the issue of the schools providing home-based help; and
- "We believe that there are several other potential requests for funding of multi-year home-based education similar to the demands in this case."

To the extent that the Chatanoogan accurately quoted Hamilton County's counsel, the foregoing statements would indicate that Hamilton County's defense of the due process hearing has precious little to do with the unique and individual needs of the child in question, and everything to do with concerns over "precedent" and Hamilton County's fear that ***other*** families in the county may also request ABA intervention programs. This may help to explain why the family involved was compelled to endure approximately 30 hearing dates, possibly setting a new world's record in the annals of due process.*[12]

Example No. 4 (T.H. v. Palatine, Illinois)

T.H. v. Palatine, Illinois, a reported federal court decision, is another example of a school district's misadventures in endlessly litigating a request for ABA interventions.

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[12] Hamilton County's counsel even attempted to block my admission pro hac vice, on the grounds that the Court did not have the authority to grant my application. The Court respectfully disagreed in an extensive opinion.

The newspaper article appearing as Appendix 9 reflects that after losing at the initial hearing stage and the first appeals stage, the Palatine, Illinois School District went on to press an appeal to the federal district court. The district court characterized Palatine's offer of educational services as "absurd" and ordered Palatine to reimburse T.H.'s parents for the cost of his intensive ABA intervention program. Incredibly, as the article reflects, this was a case in which the child's parents were willing to settle for $17,000 at the outset. Ultimately, the matter wound up costing the Palatine School District several hundred thousand dollars between what the district court ordered paid to T.H.'s family and to T.H.'s attorneys, including my law firm. The Palatine case offers a textbook example of "what not to do."

Example No. 5 (How To Avoid Parents' Demands For Lovaas ***Revisited***)

After I became aware of the presentation "How To Avoid Parents' Demands For Lovaas," I wrote to the conference sponsors to communicate how offended I was that anyone would be so brazen to put on a conference of this type. I also notified the State Education Department in Missouri of this conduct. After making the foregoing complaints, I never again saw a conference brochure quite this brazen. What I continue to see, however, are conferences and conference brochures which have been "sanitized" both in tone and content but which communicate the very ***same*** anti-ABA message.

Appendix 10, for example, is a "workshop" brochure put out by LRP, through its "Conference Division," which is entitled "Building A Blueprint For ***Defensible*** Autism Programs." The workshop was noticed to be given in the Fall of 1999 in Maryland, New Jersey, California, Ohio, Missouri and North Carolina. Much like "How To Avoid Parent Demands For Lovaas," the latest LRP brochure starts off with inflammatory fear tactics such as "School districts have been inundated with parental requests for funding for in home educational programs and other therapies claiming to "cure" or "recover" autistic children. Such programming or therapy commonly costs more than $60,000 per year and is usually requested during the child's preschool years. Educators are being faced with these requests, often supported by the recommendations of physicians, psychologists and other professionals..." The workshop brochure thus actually attempts to portray as a "negative" the fact that so many professionals are recommending ABA interventions!

The bullet points under the Heading "WHAT YOU DON'T KNOW COULD COST YOU!" are most instructive. The workshop promises to disclose a "trump card" for school districts to use in ABA litigation. The brochure also promises that Melinda Maloney Baird, Esq., as the workshop's principal presenter, "will provide a 'blueprint' for winning based on the patterns that have emerged in autism litigation and her own experience in representing school agencies." *[13]

[13] In November, 2000, Ms. Baird apparently made a presentation in Tennessee entitled "The New Reauthorization—Back into Hell?" At a recent presentation which Ms. Baird made in Louisville,

I respectfully urge that the focus of workshops paid for by taxpayer dollars should be creating efficacious educational programs, not to learn clever legal strategies "for winning" or creating programs which may appear to be ***legally*** (as opposed to educationally) "defensible."

Example No. 6 (School District Reneging on Its Own "Vote" In Favor of ABA Program)

Appendix 11 is a report from the New York Law Journal concerning a school district located on the Canadian border (Sackets Harbor) which, in September of 1998, held a meeting to develop an Individualized Educational Plan ("IEP") for a preschooler diagnosed with autism. As the article reports, the school district and its attorney ***initiated*** a "vote" of the Committee on Preschool Education ("CPSE") to consider the parents' request to implement an intensive ABA intervention program for their son. After the school district conducted its polling, those who had cast votes in favor of implementing an intensive ABA intervention program ***prevailed*** over those who had cast votes against such a program. The school district then reneged, claiming that the Department of Education had issued interpretations recommending against taking a vote. Essentially, the parents discovered that they were the victims of a "heads I win, tails you lose" proposition.

At the initial hearing, and even after an intervening appeal, the reviewing courts held that the school district was duty-bound to honor the results of the CPSE vote which the school district had itself initiated. Unbeknownst to the child and his family at the time, the school district's counsel ***continued*** to advise its school district clients, in writing (Appendix 12), that "a vote should be taken" and that "...this process should at least not subject the Chairperson or the District to potential legal liability in making recommendations regarding a disabled student."

On the school district's second appeal (the third court proceeding), the New York Supreme Court held that the school district was estopped by its own conduct from challenging the results of the vote taken at the CPSE meeting back in September of 1998. Incredibly, the Sackets Harbor School District is prosecuting yet ***another*** appeal (i.e. a fourth legal proceeding), without complying with the directives of the first three courts which have held that the school district must reimburse the child's parents for the cost of the ABA intervention program which was approved by the vote of the CPSE back in September of 1998. Families with limited resources hardly are in a position to withstand this kind of onslaught.

Kentucky, I am advised by my client, who attended Ms. Baird's presentation, that Ms. Baird made pointed reference to my Hamilton County, Tennessee due process hearing as "The Autism Case From Hell." I am compelled to agree with Ms. Baird on this narrow point. However, I respectfully submit that while Ms. Baird's pandering message of fiscal fear may be seductive to certain school district administrators who may be prepared to balance their budgets on the backs of children with disabilities, her numerous presentations across the country are quite inflammatory and continue to create needless conflict between parents and school districts. School districts would be far better served bringing in professionals in the field who are in a position to train staff and develop effective educational programs.

Example No. 7 (Manufacturing of "Parental Unreasonableness" By School Districts)

In the years following the Supreme Court's decision in Burlington School Committee v. Mass. Dept. of Educ., EHLR 556:389 (1985), courts were called upon to rule on claims asserted by school districts that parents had acted in bad faith or had failed to cooperate. IDEA regulations at 34 C.F.R. Sec. 300.403(d) give a hearing officer the discretion to deny or reduce an award to a child "upon a judicial finding of unreasonableness with respect to actions taken by the parents." Unfortunately, I have seen some school districts abuse these regulations in an attempt to build the possibility of an "offset" into an otherwise weak case where the child is anticipated to be the prevailing party.

By way of example, in one of my IDEA due process matters, several witnesses for a school district testified to an elaborate attempt by parents at an IEP meeting to deliberately conceal from the school district information concerning the child's previous medical history. At least three school district witnesses told the exact same story of the parents "hiding" medical information about the child; in particular, the name of a doctor who had issued a report. The only problem with such testimony was that it was not true. Moreover, the school district and its witnesses who swore to tell the truth knew or certainly had to know that such testimony was not true because there were ***multiple*** letters sent to the district, which the district admittedly received, in which the child's parents had specifically requested the IEP meeting to discuss the ***very*** information which the district had claimed was being concealed. There also was an audiotape of the IEP meeting, which reflects that there ***was*** mention at the IEP meeting of the very doctor whose name allegedly was "hidden" from the school district.

At the very same due process hearing, a key school district witness flatly denied under oath that there was any district "policy" that parents could not receive written evaluations in ***advance*** of IEP meetings. This key school district witness apparently had "forgotten," however, that she had left a recorded message on the parents' answering machine in which she specifically excused her failure to provide the family with evaluations in advance of an upcoming IEP meeting by stating that as per the district administrator, it ***was*** the district's "policy" not to release evaluations in advance of IEP meetings! The child's parents had the presence of mind to save the recorded message, and it was played in open court. In view of what we considered to be compelling evidence of perjury, under the Code of Professional Responsibility, we concluded that we had no choice but to refer the above matter to the United States Attorney's Office for further investigation.*[14]

Overall, the IDEA statute is a great law and many school districts are attempting in good faith to comply with IDEA. However, this Committee should know that quite a few school districts across the country are deliberately thwarting Congress' intent. Some

[14] Since this matter could conceivably result in criminal proceedings, I have chosen to identify this situation generically.

school districts are, in essence, thumbing their noses at children with autistic spectrum disorders and other disabilities. I am grateful that this Committee is taking the time to look into this problem. On my own behalf, as well as on behalf of the many children and families I work with, thank you.

Respectfully submitted,

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Experience: *Mayerson & Associates - March 2000* – Founded practice concentrating primarily in advancing the educational and other related rights of children and adolescents with autistic spectrum disorders. Represent clients in IDEA and related litigation in approximately two dozen states.

Graubard, Mollen & Miller – July 1983 – February 2000 (partner since 1987)
Experience included approximately 25 trials (most as lead counsel), more than 400 depositions, and appellate practice in areas such as partnership, contract, construction, banking, sexual harassment and other employment litigation, lender liability, insurance coverage, hazardous waste, copyright infringement, securities, art authentication and provenance, and IDEA litigation.

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Behavioral Treatment and Normal Educational and Intellectual Functioning in Young Autistic Children

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Autism is a serious psychological disorder with onset in early childhood. Autistic children show minimal emotional attachment, absent or abnormal speech, retarded IQ, ritualistic behaviors, aggression, and self-injury. The prognosis is very poor, and medical therapies have not proven effective. This article reports the results of behavior modification treatment for two groups of similarly constituted, young autistic children. Follow-up data from an intensive, long-term experimental treatment group (n = 19) showed that 47% achieved normal intellectual and educational functioning, with normal-range IQ scores and successful first grade performance in public schools. Another 40% were mildly retarded and assigned to special classes for the language delayed, and only 10% were profoundly retarded and assigned to classes for the autistic/retarded. In contrast, only 2% of the control-group children (n = 40) achieved normal educational and intellectual functioning; 45% were mildly retarded and placed in language-delayed classes, and 53% were severely retarded and placed in autistic/retarded classes.

Kanner (1943) defined autistic children as children who exhibit (a) serious failure to develop relationships with other people before 30 months of age, (b) problems in development of normal language, (c) ritualistic and obsessional behaviors ("insistence on sameness"), and (d) potential for normal intelligence. A more complete behavioral definition has been provided elsewhere (Lovaas, Koegel, Simmons, & Long, 1973). The etiology of autism is not known, and the outcome is very poor. In a follow-up study on young autistic children, Rutter (1970) reported that only 1.5% of his group (n = 63) had achieved normal functioning. About 35% showed fair or good adjustment, usually required some degree of supervision, experienced some difficulties with people, had no personal friends, and showed minor oddities of behavior. The majority (more than 60%) remained severely handicapped and were living in hospitals for mentally retarded or psychotic individuals or in other protective settings. Initial IQ scores appeared stable over time. Other studies (Brown, 1969; DeMyer et al., 1973; Eisenberg, 1956; Freeman, Ritvo, Needleman, & Yokota, 1985; Havelkova, 1968) report similar data. Higher scores on IQ tests, communicative speech, and appropriate play are considered to be prognostic of better outcome (Lotter, 1967).

Medically and psychodynamically oriented therapies have not proven effective in altering outcome (DeMyer, Hingtgen, & Jackson, 1981). No abnormal environmental etiology has been identified within the children's families (Lotter, 1967). At present, the most promising treatment for autistic persons is behavior modification as derived from modern learning theory (DeMyer et al., 1981). Empirical results from behavioral intervention with autistic children have been both positive and negative. On the positive side, behavioral treatment can build complex behaviors, such as language, and can help to suppress pathological behaviors, such as aggression and self-stimulatory behavior. Clients vary widely in the amount of gains obtained but show treatment gains in proportion to the time devoted to treatment. On the negative side, treatment gains have been specific to the particular environment in which the client was treated, substantial relapse has been observed at follow-up, and no client has been reported as recovered (Lovaas et al., 1973).

The present article reports a behavioral-intervention project (begun in 1970) that sought to maximize behavioral treatment gains by treating autistic children during most of their waking hours for many years. Treatment included all significant persons in all significant environments. Furthermore, the project focused on very young autistic children (below the age of 4 years) because it was assumed that younger children would be less likely to discriminate between environments and therefore more likely to generalize and to maintain their treatment gains. Finally, it was assumed that it would be easier to successfully mainstream a very young autistic child into preschool than it would be to mainstream an older autistic child into primary school.

It may be helpful to hypothesize an outcome of the present study from a developmental or learning point of view. One may assume that normal children learn from their everyday environ-

This study was supported by Grant MH-11440 from the National Institute of Mental Health. Aspects of this study were presented at the 1982 convention of the American Psychological Association, Washington, DC, by Andrea Ackerman, Paula Firestone, Gayle Goldstein, Ronald Leaf, John McEachin, and the author. The author expresses his deep appreciation to the many undergraduate students at the University of California, Los Angeles, who served as student therapists on the project, to the many graduate students who served as clinic supervisors, and to the many parents who trusted their children to our care. Special thanks to Laura Schreibman and Robert Koegel, who collaborated in the early stages of this research project. Donald Baer, Bruce Baker, Bradley Bucher, Arthur Woodward, and Haikang Shen provided statistical advice and help in manuscript preparation. B. J. Freeman's help in arranging access to Control Group 2 data is also appreciated.

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App. #1

ments most of their waking hours. Autistic children, conversely, do not learn from similar environments. We hypothesized that construction of a special, intense, and comprehensive learning environment for very young autistic children would allow some of them to catch up with their normal peers by first grade.

Method

Subjects

Subjects were enrolled for treatment if they met three criteria: (a) independent diagnosis of autism from a medical doctor or a licensed PhD psychologist, (b) chronological age (CA) less than 40 months if mute and less than 46 months if echolalic, and (c) prorated mental age (PMA) of 11 months or more at a CA of 30 months. The last criterion excluded 15% of the referrals.

The clinical diagnosis of autism emphasized emotional detachment, extreme interpersonal isolation, little if any toy or peer play, language disturbance (mutism or echolalia), excessive rituals, and onset in infancy. The diagnosis was based on a structured psychiatric interview with parents, on observations of the child's free-play behaviors, on psychological testing of intelligence, and on access to pediatric examinations. Over the 15 years of the project, the exact wording of the diagnosis changed slightly in compliance with changes in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM–III; American Psychiatric Association, 1980). During the last years, the diagnosis was made in compliance with DSM–III criteria (p. 87). In almost all cases, the diagnosis of autism had been made prior to family contact with the project. Except for one case each in the experimental group and Control Group 1, all cases were diagnosed by staff of the Department of Child Psychiatry, University of California, Los Angeles (UCLA) School of Medicine. Members of that staff have contributed to the writing of the DSM–III and to the diagnosis of autism adopted by the National Society for Children and Adults with Autism. If the diagnosis of autism was not made, the case was referred elsewhere. In other words, the project did not select its cases. More than 90% of the subjects received two or more independent diagnoses, and agreement on the diagnosis of autism was 100%. Similarly high agreement was not reached for subjects who scored within the profoundly retarded range on intellectual functioning (PMA < 11 months); these subjects were excluded from the study.

Treatment Conditions

Subjects were assigned to one of two groups: an intensive-treatment experimental group (n = 19) that received more than 40 hours of one-to-one treatment per week, or the minimal-treatment Control Group 1 (n = 19) that received 10 hours or less of one-to-one treatment per week. Control Group 1 was used to gain further information about the rate of spontaneous improvement in very young autistic children, especially those selected by the same agency that provided the diagnostic work-up for the intensive-treatment experimental group. Both treatment groups received treatment for 2 or more years. Strict random assignment (e.g., based on a coin flip) to these groups could not be used due to parent protest and ethical considerations. Instead, subjects were assigned to the experimental group unless there was an insufficient number of staff members available to render treatment (an assessment made prior to contact with the family). Two subjects were assigned to Control Group 1 because they lived further away from UCLA than a 1-hr drive, which made sufficient staffing unavailable to those clients. Because fluctuations in staff availability were not associated in any way with client characteristics, it was assumed that this assignment would produce unbiased groups. A large number of pretreatment measures were collected to test this assumption. Subjects did not change group assignment. Except for two families who left the experimental group within the first 6 months (this group began with 21 subjects), all families stayed with their groups from beginning to end.

Assessments

Pretreatment mental age (MA) scores were based on the following scales (in order of the frequency of their use): the Bayley Scales of Infant Development (Bayley, 1955), the Cattell Infant Intelligence Scale (Cattell, 1960), the Stanford-Binet Intelligence Scale (Thorndike, 1972), and the Gesell Infant Development Scale (Gesell, 1949). The first three scales were administered to 90% of the subjects, and relative usage of these scales was similar in each group. Testing was carried out by graduate students in psychology who worked under the supervision of clinical psychologists at UCLA or licensed PhD psychologists at other agencies. The examiner chose the test that would best accommodate each subject's developmental level, and this decision was reached independently of the project staff. Five subjects were judged to be untestable (3 in the experimental group and 2 in Control Group 1). Instead, the Vineland Social Maturity Scale (Doll, 1953) was used to estimate their MAs (with the mother as informant). To adjust for variations in MA scores as a function of the subject's CA at the time of test administration, PMA scores were calculated for a CA at 30 months (MA/CA × 30).

Behavioral observations were based on videotaped recordings of the subject's free-play behavior in a playroom equipped with several simple early-childhood toys. These videotaped recordings were subsequently scored for amount of (a) *self-stimulatory behaviors*, defined as prolonged ritualistic, repetitive, and stereotyped behavior such as body-rocking, prolonged gazing at lights, excessive hand-flapping, twirling the body as a top, spinning or lining of objects, and licking or smelling of objects or wall surfaces; (b) *appropriate play behaviors*, defined as those limiting the use of toys in the playroom to their intended purposes, such as pushing the truck on the floor, pushing buttons on the toy cash register, putting a record on the record player, and banging with the toy hammer; and (c) *recognizable words*, defined to include any recognizable word, independent of whether the subject used it in a meaningful context or for communicative purposes. One observer who was naive about subjects' group placement scored all tapes after being trained to agree with two experienced observers (using different training tapes from similar subjects). Interobserver reliability was scored on 20% of the tapes (randomly selected) and was computed for each category of behavior for each subject by dividing the sum of observer agreements by the sum of agreements and disagreements. These scores were then summed and averaged across subjects. The mean agreement (based both on occurrences and nonoccurrences) was 91% for self-stimulatory behavior, 85% for appropriate play behavior, and 100% for recognizable words. A more detailed description of these behavioral recordings has been provided elsewhere (Lovaas et al., 1973).

A 1-hr parent interview about the subjects' earlier history provided some diagnostic and descriptive information. Subjects received a score of 1 for each of the following variables parents reported: no recognizable words; no toy play (failed to use toys for their intended function); lack of emotional attachment (failed to respond to parents' affection); apparent sensory deficit (parents had suspected their child to be blind or deaf because the child exhibited no or minimal eye contact and showed an unusually high pain threshold); no peer play (subject did not show interactive play with peers); self-stimulatory behavior; tantrums (aggression toward family members or self); and no toilet training. These 8 measures from parents' intake interviews were summed to provide a sum pathology score. The intake interview also provided information about abnormal speech (0 = normal and meaningful language, however limited; 1 = echolalic language used meaningfully [e.g., to express needs]; 2 = echolalia; and 3 = mute); age of walking; number of siblings in the family; socioeconomic status of the father; sex; and neurological examinations (including EEGs and CAT scans) that resulted in findings of pathology. Finally, CA at first diagnosis and at the beginning of the

present treatment were recorded. This yielded a total of 20 pretreatment measures, 8 of which were collapsed into 1 measure (sum pathology).

A brief clinical description of the experimental group at intake follows (identical to that for Control Group 1): Only 2 of the 19 subjects obtained scores within the normal range of intellectual functioning; 7 scored in the moderately retarded range, and 10 scored in the severely retarded range. No subject evidenced pretend or imaginary play, only 2 evidenced *complex* (several different or heterogeneous behaviors that together formed one activity) play, and the remaining subjects showed *simple* (the same elementary but appropriate response made repeatedly) play. One subject showed minimal appropriate speech, 7 were echolalic, and 11 were mute. According to the literature that describes the developmental delays of autistic children in general, the autistic subjects in the present study constituted an average (or below average) sample of such children.

Posttreatment measures were recorded as follows: Between the ages of 6 and 7 years (when a subject would ordinarily have completed first grade), information about the subjects' first-grade placement was sought and validated; about the same time, an IQ score was obtained. Testing was carried out by examiners who were naive about the subjects' group placement. Different scales were administered to accommodate different developmental levels. For example, a subject with a regular educational placement received a Wechsler Intelligence Scale for Children-Revised (WISC-R; Wechsler, 1974) or a Stanford-Binet Intelligence Scale (Thorndike, 1972), whereas a subject in an autistic/retarded class received a nonverbal test like the Merrill-Palmer Pre-School Performance Test (Stutsman, 1948). In all instances of subjects having achieved a normal IQ score, the testing was eventually replicated by other examiners. The scales (in order of the frequency of usage) included the WISC-R (Wechsler, 1974), the Stanford-Binet (Thorndike, 1972), the Peabody Picture Vocabulary Test (Dunn, 1981), the Wechsler Pre-School Scale (Wechsler, 1967), the Bayley Scales of Infant Development (Bayley, 1955), the Cattell Infant Intelligence Scale (Cattell, 1960), and the Leiter International Performance Scale (Leiter, 1959). Subjects received a score of 3 for *normal functioning* if they received a score on the WISC-R or Stanford-Binet in the normal range, completed first grade in a normal class in a school for normal children, and were advanced to the second grade by the teacher. Subjects received a score of 2 if they were placed in first-grade in a smaller *aphasia* (language delayed, language handicapped, or learning disabled) class. Placement in the aphasia class implied a higher level of functioning than placement in classes for the autistic/retarded, but the diagnosis of autism was almost always retained. A score of 1 was given if the first-grade placement was in a class for the autistic/retarded and if the child's IQ score fell within the severely retarded range.

Treatment Procedure

Each subject in the experimental group was assigned several well trained student therapists who worked (part-time) with the subject in the subject's home, school, and community for an average of 40 hr per week for 2 or more years. The parents worked as part of the treatment team throughout the intervention; they were extensively trained in the treatment procedures so that treatment could take place for almost all of the subjects' waking hours, 365 days a year. A detailed presentation of the treatment procedure has been presented in a teaching manual (Lovaas et al., 1980). The conceptual basis of the treatment was reinforcement (operant) theory; treatment relied heavily on discrimination-learning data and methods. Various behavioral deficiencies were targeted, and separate programs were designed to accelerate development for each behavior. High rates of aggressive and self-stimulatory behaviors were reduced by being ignored; by the use of time-out; by the shaping of alternate, more socially acceptable forms of behavior; and (as a last resort) by the delivery of a loud "no" or a slap on the thigh contingent upon the presence of the undesirable behavior. Contingent physical aversives were not used in the control group because inadequate staffing in that group did not allow for adequate teaching of alternate, socially appropriate behaviors.

During the first year, treatment goals consisted of reducing self-stimulatory and aggressive behaviors, building compliance to elementary verbal requests, teaching imitation, establishing the beginnings of appropriate toy play, and promoting the extension of the treatment into the family. The second year of treatment emphasized teaching expressive and early abstract language and interactive play with peers. Treatment was also extended into the community to teach children to function within a preschool group. The third year emphasized the teaching of appropriate and varied expression of emotions; preacademic tasks like reading, writing, and arithmetic; and *observational learning* (learning by observing other children learn). Subjects were enrolled only in those preschools where the teacher helped to carry out the treatment program. Considerable effort was exercised to mainstream subjects in a normal (average and public) preschool placement and to avoid initial placement in special education classes with the detrimental effects of exposure to other autistic children. This occasionally entailed withholding the subject's diagnosis of autism. If the child became known as autistic (or as "a very difficult child") during the first year in preschool, the child was encouraged to enroll in another, unfamiliar school (to start fresh). After preschool, placement in public education classes was determined by school personnel. All children who successfully completed normal kindergarten successfully completed first grade and subsequent normal grades. Children who were observed to be experiencing educational and psychological problems received their school placement through Individualized Educational Plan (IEP) staffings (attended by educators and psychologists) in accordance with the Education For All Handicapped Children Act of 1975.

All subjects who went on to a normal first grade were reduced in treatment from the 40 hr per week characteristic of the first 2 years to 10 hr or less per week during kindergarten. After a subject had started first grade, the project maintained a minimal (at most) consultant relationship with some families. In two cases, this consultation and the subsequent correction of problem behaviors were judged to be essential in maintaining treatment gains. Subjects who did not recover in the experimental group received 40 hr or more per week of one-to-one treatment for more than 6 years (more than 14,000 hr of one-to-one treatment), with some improvement shown each year but with only 1 subject recovering.

Subjects in Control Group 1 received the same kind of treatment as those in the experimental group but with less intensity (less than 10 hr of one-to-one treatment per week) and without systematic physical aversives. In addition, these subjects received a variety of treatments from other sources in the community such as those provided by small special education classes.

Control Group 2 consisted of 21 subjects selected from a larger group (N = 62) of young autistic children studied by Freeman et al. (1985). These subjects came from the same agency that diagnosed 95% of our other subjects. Data from Control Group 2 helped to guard against the possibility that subjects who had been referred to us for treatment constituted a subgroup with particularly favorable or unfavorable outcomes. To provide a group of subjects similar to those in the experimental group and Control Group 1, subjects for Control Group 2 were selected if they were 42 months old or younger when first tested, had IQ scores above 40 at intake, and had follow-up testing at 6 years of age. These criteria resulted in the selection of 21 subjects. Subjects in Control Group 2 were treated like Control Group 1 subjects but were not treated by the Young Autism Project described here.

Results

Pretreatment Comparisons

Eight pretreatment variables from the experimental group and Control Group 1 (CA at first diagnosis, CA at onset of treat-

Table 1
Means and F Ratios From Comparisons Between Groups on Intake Variables

Group	Diagnosis CA	Treatment CA	PMA	Recognizable words	Toy play	Self-stimulation	Sum pathology	Abnormal speech
Experimental	32.0	34.6	18.8	.42	28.2	12.1	6.9	2.6
Control 1	35.3	40.9	17.1	.58	20.2	19.6	6.4	2.2
F^a	1.58	4.02*	1.49	.92	2.76	3.37	.82	.36

Note. CA = chronological age; PMA = prorated mental age. Experimental group, $n = 19$; Control Group 1, $n = 19$.
[a] $df = 1, 36$.
* $p < .05$.

ment, PMA, sum pathology, abnormal speech, self-stimulatory behavior, appropriate toy play, and recognizable words) were subjected to a multivariate analysis of variance (MANOVA; Brecht & Woodward, 1984). The means and F ratios from this analysis are presented in Table 1. As can be seen, there were no significant differences between the groups except for CA at onset of our treatment ($p < .05$). Control subjects were 6 months older on the average than experimental subjects (mean CAs of 35 months vs. 41 months, respectively). These differences probably reflect the delay of control subjects in their initiation into the treatment project because of staff shortages; analysis will show that differential CAs are not significantly related to outcome. To ascertain whether another test would reveal a statistically significant difference between the groups on toy play, descriptions of the subjects' toy play (taken from the videotaped recordings) were typed on cards and rated for their developmental level by psychology students who were naive about the purpose of the ratings and subject group assignment. The ratings were reliable among students ($r = .79$, $p < .001$), and an F test showed no significant difference in developmental levels of toy play between the two groups.

The respective means from the experimental group and Control Group 1 on the eight variables from the parent interview were .89 and .74 for sensory deficit, .63 and .42 for adult rejection, .58 and .47 for no recognizable words, .53 and .63 for no toy play, 1.0 and 1.0 for no peer play, .95 and .89 for body self-stimulation, .89 and .79 for tantrums, and .68 and .63 for no toilet training. The experimental group and Control Group 1 were also similar in onset of walking (6 vs. 8 early walkers; 1 vs. 2 late walkers), number of siblings in the family (1.26 in each group), socioeconomic status of the father (Level 49 vs. Level 54 according to 1950 Bureau of the Census standards), boys to girls (16:3 vs. 11:8); and number of subjects referred for neurological examinations (10 vs. 15) who showed signs of damage (0 vs. 1). The numbers of favorable versus unfavorable prognostic signs (directions of differences) on the pretreatment variables divide themselves equally between the groups. In short, the two groups appear to have been comparable at intake.

Follow-Up Data

Subjects' PMA at intake, follow-up educational placement, and IQ scores were subjected to a MANOVA that contrasted the experimental group with Control Groups 1 and 2. At intake, there were no significant differences between the experimental group and the control groups. At follow-up, the experimental group was significantly higher than the control groups on educational placement ($p < .001$) and IQ ($p < .01$). The two control groups did not differ significantly at intake or at follow-up. In short, data from Control Group 2 replicate those from Control Group 1 and further validate the effectiveness of our experimental treatment program. Data are given in Table 2 that show the group means from pretreatment PMA and posttreatment educational placement and IQ scores. The table also shows the F ratios and significance levels of the three group comparisons.

In descriptive terms, the 19-subject experimental group shows 9 children (47%) who successfully passed through normal first grade in a public school and obtained an average or above average score on IQ tests ($M = 107$, range = 94–120). Eight subjects (42%) passed first grade in aphasia classes and obtained a mean IQ score within the mildly retarded range of intellectual functioning ($M = 70$, range = 56–95). Only two children (10%) were placed in classes for autistic/retarded children and scored in the profoundly retarded range (IQ < 30).

There were substantial increases in the subjects' levels of intellectual functioning after treatment. The experimental group subjects gained on the average of 30 IQ points over Control Group 1 subjects. Thus the number of subjects who scored within the normal range of intellectual functioning increased from 2 to 12, whereas the number of subjects within the moderate-to-severe range of intellectual retardation dropped from 10 to 3. As of 1986, the achievements of experimental group sub-

Table 2
Means and F Ratios for Measures at Pretreatment and Posttreatment

Group	Intake PMA	Follow-up EDP	Follow-up IQ
	Means		
Experimental	18.8	2.37	83.3
Control 1	17.1	1.42	52.2
Control 2	17.6	1.57	57.5
	F ratios[a]		
Experimental × Control 1	1.47	23.0***	14.4**
Experimental × Control 2	0.77	17.6***	10.4*
Control 1 × Control 2	0.14	0.63	0.45

Note. PMA = prorated mental age; EDP = educational placement. Experimental group, $n = 19$; Control Group 1, $n = 19$; Control Group 2, $n = 21$.
[a] $df = 1, 56$.
* $p < .01$. *** $p < .001$.

Table 3
Educational Placement and Mean and Range of IQ at Follow-Up

Group	Recovered	Aphasic	Autistic/Retarded
Experimental			
N	9	8	2
M IQ	107	70	30
Range	94–120	56–95	—[a]
Control Group 1			
N	0	8	11
M IQ	—	74	36
Range	—	30–102	20–73
Control Group 2			
N	1	10	10
M IQ	99	67	44
Range	—	49–81	35–54

Note. Dashes indicate no score or no entry.
[a] Both children received the same score.

jects have remained stable. Only 2 subjects have been reclassified: 1 subject (now 18 years old) was moved from an aphasia to a normal classroom after the sixth grade; 1 subject (now 13 years old) was moved from an aphasia to an autistic/retarded class placement.

The MA and IQ scores of the two control groups remained virtually unchanged between intake and follow-up, consistent with findings from other studies (Freeman et al., 1985; Rutter, 1970). The stability of the IQ scores of the young autistic children, as reported in the Freeman et al. study, is particularly relevant for the present study because it reduces the possibility of spontaneous recovery effects. In descriptive terms, the combined follow-up data from the control groups show that their subjects fared poorly: Only 1 subject (2%) achieved normal functioning as evidenced by normal first-grade placement and an IQ of 99 on the WISC-R; 18 subjects (45%) were in aphasia classes (mean IQ = 70, range = 30–101); and 21 subjects (53%) were in classes for the autistic/retarded (mean IQ = 40, range = 20–73). Table 3 provides a convenient descriptive summary of the main follow-up data from the three groups.

One final control procedure subjected 4 subjects in the experimental group (Ackerman, 1980) and 4 subjects in Control Group 1 (McEachin & Leaf, 1984) to a treatment intervention in which one component of treatment (the loud "no" and occasional slap on the thigh contingent on self-stimulatory, aggressive, and noncompliant behavior) was at first withheld and then introduced experimentally. A within-subjects replication design was used across subjects, situations, and behaviors, with baseline observations varying from 3 weeks to 2 years after treatment had started (using contingent positive reinforcement only). During baseline, when the contingent-aversive component was absent, small and unstable reductions were observed in the large amount of inappropriate behaviors, and similar small and unstable increases were observed in appropriate behaviors such as play and language. These changes were insufficient to allow for the subjects' successful mainstreaming. Introduction of contingent aversives resulted in a sudden and stable reduction in the inappropriate behaviors and a sudden and stable increase in appropriate behaviors. This experimental intervention helps to establish two points: First, at least one component in the treatment program functioned to produce change, which helps to reduce the effect of placebo variables. Second, this treatment component affected both the experimental and control groups in a similar manner, supporting the assumption that the two groups contained similar subjects.

Analyses of variance were carried out on the eight pretreatment variables to determine which variables, if any, were significantly related to outcome (gauged by educational placement and IQ) in the experimental group and Control Group 1. Prorated mental age was significantly ($p < .03$) related to outcome in both groups, a finding that is consistent with reports from other investigators (DeMyer et al., 1981). In addition, abnormal speech was significantly ($p < .01$) related to outcome in Control Group 1. Chronological age at onset of our treatment was not related to outcome, which is important because the two groups differed significantly on this variable at intake (by 6 months). The failure of CA to relate to outcome may be based on the very young age of all subjects at onset of treatment.

Conceivably, a linear combination of pretreatment variables could have predicted outcome in the experimental group. Using a discriminant analysis (Ray, 1982) with the eight variables used in the first multivariate analysis, it was possible to predict perfectly the 9 subjects who did achieve normal functioning, and no subject was predicted to achieve this outcome who did not. In this analysis, PMA was the only variable that was significantly related to outcome. Finally, when this prediction equation was applied to Control Group 1 subjects, 8 were predicted to achieve normal functioning with intensive treatment: this further verifies the similarity between the experimental group and Control Group 1 prior to treatment.

Discussion

This article reports the results of intensive behavioral treatment for young autistic children. Pretreatment measures revealed no significant differences between the intensively treated experimental group and the minimally treated control groups. At follow-up, experimental group subjects did significantly better than control group subjects. For example, 47% of the experimental group achieved normal intellectual and educational functioning in contrast to only 2% of the control group subjects.

The study incorporated certain methodological features designed to increase confidence in the effectiveness of the experimental group treatment:

1. Pretreatment differences between the experimental and control groups were minimized in four ways. First, the assignment of subjects to groups was as random as was ethically possible. The assignment apparently produced unbiased groups as evidenced by similar scores on the 20 pretreatment measures and by the prediction that an equal number of Control Group 1 and experimental group subjects would have achieved normal functioning had the former subjects received intensive treatment. Second, the experimental group was not biased by receiving subjects with a favorable diagnosis or biased IQ testing because both diagnosis and IQ tests were constant across groups. Third, the referral process did not favor the project cases because there were no significant differences between Control Groups 1 and 2 at intake or follow-up, even though Control Group 2 subjects were referred to others by the same agency.

Fourth, subjects stayed within their groups, which preserved the original (unbiased) group assignment.

2. A favorable outcome could have been caused not by the experimental treatment but by the attitudes and expectations of the staff. There are two findings that contradict this possibility of treatment agency (placebo) effects. First, because Control Group 2 subjects had no contact with the project, and because there was no difference between Control Groups 1 and 2 at follow-up, placebo effects appear implausible. Second, the within-subjects study showed that at least one treatment component contributed to the favorable outcome in the intensive treatment (experimental) group.

3. It may be argued that the treatment worked because the subjects were not truly autistic. This is counterindicated by the high reliability of the independent diagnosis and by the outcome data from the control groups, which are consistent with those reported by other investigators (Brown, 1969; DeMeyer et al., 1973; Eisenberg, 1956; Freeman et al., 1985; Havelkova, 1968; Rutter, 1970) for groups of young autistic children diagnosed by a variety of other agencies.

4. The spontaneous recovery rate among very young autistic children is unknown, and without a control group the favorable outcome in the experimental group could have been attributed to spontaneous recovery. However, the poor outcome in the similarly constituted Control Groups 1 and 2 would seem to eliminate spontaneous recovery as a contributing factor to the favorable outcome in the experimental group. The stability of the IQ test scores in the young autistic children examined by Freeman et al. (1985) attests once again to the chronicity of autistic behaviors and serves to further negate the effects of spontaneous recovery.

5. Posttreatment data showed that the effects of treatment (a) were substantial and easily detected, (b) were apparent on comprehensive, objective, and socially meaningful variables (IQ and school placement), and (c) were consistent with a very large body of prior research on the application of learning theory to the treatment and education of developmentally disabled persons and with the very extensive (100-year-old) history of psychology laboratory work on learning processes in man and animals. In short, the favorable outcome reported for the intensive-treatment experimental group can in all likelihood be attributed to treatment.

A number of measurement problems remain to be solved. For example, play, communicative speech, and IQ scores define the characteristics of autistic children and are considered predictors of outcome. Yet the measurement of these variables is no easy task. Consider play. First, play undoubtedly varies with the kinds of toys provided. Second, it is difficult to distinguish low levels of toy play (simple and repetitive play associated with young, normal children) from high levels of self-stimulatory behavior (a psychotic attribute associated with autistic children). Such problems introduce variability that needs immediate attention before research can proceed in a meaningful manner.

The term *normal functioning* has been used to describe children who successfully passed normal first grade and achieved an average IQ on the WISC–R. But questions can be asked about whether these children truly recovered from autism. On the one hand, educational placement is a particularly valuable measure of progress because it is sensitive to both educational accomplishments and social-emotional functions. Also, continual promotion from grade to grade is made not by one part teacher but by several teachers. School personnel describe children as indistinguishable from their normal friends. On the other hand, certain residual deficits may remain in the normal functioning group that cannot be detected by teachers and parents and can only be isolated on closer psychological assessment, particularly as these children grow older. Answers to such questions will soon be forthcoming in a more comprehensive follow-up (McEachin, 1987).

Several questions about treatment remain. It is unlikely that a therapist or investigator could replicate our treatment program for the experimental group without prior extensive theoretical and supervised practical experience in one-to-one behavioral treatment with developmentally disabled clients as described here and without demonstrated effectiveness in teaching complex behavioral repertoires as in imitative behavior and abstract language. In the within-subjects studies that were reported, contingent aversives were isolated as one significant variable. It is therefore unlikely that treatment effects could be replicated without this component. Many treatment variables are left unexplored, such as the effect of normal peers. Furthermore, the successful mainstreaming of a 2–4-year-old into a normal preschool group is much easier than the mainstreaming of an older autistic child into the primary grades. This last point underscores the importance of early intervention and places limits on the generalization of our data to older autistic children.

Historically, psychodynamic theory has maintained a strong influence on research and treatment with autistic children, offering some hope for recovery through experiential manipulations. By the mid-1960s, an increasing number of studies reported that psychodynamic practitioners were unable to deliver on that promise (Rimland, 1964). One reaction to those failures was an emphasis on organic theories of autism that offered little or no hope for major improvements through psychological and educational interventions. In a comprehensive review of research on autism, DeMyer et al. (1981) concluded that "[in the past] psychotic children were believed to be *potentially* capable of normal functioning in virtually all areas of development . . . during the decade of the 1970s it was the rare investigator who even gave lip-service to such previously held notions . . . infantile autism is a type of developmental disorder accompanied by severe and, to a large extent, permanent intellectual/behavioral deficits" (p. 432).

The following points can now be made. First, at least two distinctively different groups emerged from the follow-up data in the experimental group. Perhaps this finding implies different etiologies. If so, future theories of autism will have to identify these groups of children. Second, on the basis of testing to date, the recovered children show no permanent intellectual or behavioral deficits and their language appears normal, contrary to the position that many have postulated (Rutter, 1974; Churchill, 1978) but consistent with Kanner's (1943) position that autistic children possess potentially normal or superior intelligence. Third, at intake, all subjects evidenced deficiencies across a wide range of behaviors, and during treatment they showed a broad improvement across all observed behaviors. The kind of (hypothesized) neural damage that mediates a particular kind of behavior, such as language (Rutter, 1974), is not consistent with these data.

Although serious problems remain for exactly defining autism or identifying its etiology, one encouraging conclusion can be stated: Given a group of children who show the kinds of behavioral deficits and excesses evident in our pretreatment measures, such children will continue to manifest similar severe psychological handicaps later in life unless subjected to intensive behavioral treatment that can indeed significantly alter that outcome.

These data promise a major reduction in the emotional hardships of families with autistic children. The treatment procedures described here may also prove equally effective with other childhood disorders, such as childhood schizophrenia. Certain important, practical implications in these findings may also be noted. The treatment schedule of subjects who achieved normal functioning could be reduced from 40 hr per week to infrequent visits even after the first 2 years of treatment. The assignment of one full-time special-education teacher for 2 years would cost an estimated $40,000, in contrast to the nearly $2 million incurred (in direct costs alone) by each client requiring life-long institutionalization.

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Long-Term Outcome for Children With Autism Who Received Early Intensive Behavioral Treatment

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After a very intensive behavioral intervention, an experimental group of 19 preschool-age children with autism achieved less restrictive school placements and higher IQs than did a control group of 19 similar children by age 7 (Lovaas, 1987). The present study followed-up this finding by assessing subjects at a mean age of 11.5 years. Results showed that the experimental group preserved its gains over the control group. The 9 experimental subjects who had achieved the best outcomes at age 7 received particularly extensive evaluations indicating that 8 of them were indistinguishable from average children on tests of intelligence and adaptive behavior. Thus, behavioral treatment may produce long-lasting and significant gains for many young children with autism.

Infantile autism is a condition marked by severe impairment in intellectual, social, and emotional functioning. Its onset occurs in infancy, and the prognosis appears to be extremely poor (Lotter, 1978). For example, in the longest prospective follow-up study with a sound methodological design, Rutter (1970) found that only 1 of 64 subjects with autism (fewer than 2%) could be considered free of clinically significant problems by adulthood, as evidenced by holding a job, living independently, and maintaining an active and age-appropriate social life. The remaining subjects showed numerous dysfunctions, such as marked oddities in behavior, social isolation, and florid psychopathology. The majority of subjects required supervised living conditions.

Professionals have attempted a wide variety of interventions in an effort to help children with autism. For many years, no scientific evidence showed that any of these interventions brightened the children's long-term prognosis (DeMyer et al., 1981). How-

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ever, since the 1960s, one of these interventions, behavioral treatment, has appeared promising. Behavioral treatment has been found to increase adaptive behaviors such as language and social skills, while decreasing disruptive behaviors such as aggression (DeMyer, Hingtgen, & Jackson, 1981; Newsom & Rincover, 1989; Rutter, 1985). Furthermore, behavioral treatment has been continuously refined and improved as a result of ongoing research efforts at a number of sites (Lovaas & Smith, 1988).

Some recent evidence has indicated that behavioral treatment has developed to the point that it can produce substantial improvements in the overall functioning of young children with autism (Simeonnson, Olley, & Rosenthal, 1987). Lovaas (1987) provided approximately 40 hours per week of one-on-one behavioral treatment for a period of 2 years or more to an experimental group of 19 children with autism who were under 4 years of age. This intervention also included parent training and mainstreaming into regular preschool environments. When re-evaluated at a mean age of 7 years, subjects in the experimental group had gained an average of 20 IQ points and had made major advances in educational achievement. Nine of the 19 subjects completed first grade in regular (nonspecial education) classes entirely on their own and had IQs that increased to the average range. By contrast, two control groups totalling 40 children, also diagnosed as autistic and comparable to the experimental group at intake, did not fare nearly as well. Only one of the control subjects (2.5%) attained normal levels of intellectual and educational functioning.

These data suggest that behavioral treatment is effective. However, the durability of treatment gains is uncertain. In one prior major study, Lovaas, Koegel, Simmons, and Long (1973) found that children with autism regressed following the termination of treatment. Other studies have shown that children with autism may display increased difficulties when they enter adolescence (Kanner, 1971; Waterhouse & Fein, 1984). Also, as was stated in the first follow-up (Lovaas, 1987), "Certain residual deficits may remain in the normal-functioning group that cannot be detected by teachers and parents and can only be isolated on closer psychological assessment, particularly as these children grow older" (p. 8). This possibility points to the need for a more detailed assessment and for continued follow-ups of the group over time.

The present investigation contained two parts: In the first part we examined whether several years after the evaluation at age 7, the experimental group in Lovaas's (1987) study had maintained its treatment gains. Subjects in the experimental group and one of the control groups completed standardized tests of intellectual and adaptive functioning. The groups were then contrasted with each other, and their current performance was compared to their performance on previous assessments. The second part of the investigation focused on those subjects who had achieved the best outcome at the end of first grade in the Lovaas (1987) study (i.e., the 9 subjects who were classified as normal functioning out of the 19 in the experimental group). We examined the extent to which these best-outcome subjects could be considered free of autistic symptomatology. A test battery was constructed to assess a variety of possible deficits: for example, idiosyncratic thought patterns, mannerisms, and interests; lack of close relationships with family and friends; difficulty in getting along with people; relative weaknesses in certain areas of cognitive functioning, such as abstract reasoning; not working up to ability in school; flatness of affect; absence or peculiarity in sense of humor. Possible strengths to be identified included normal intellectual functioning, good relationships with family members, ability to function independently, appropriate use of leisure time, and adequate socialization with peers. Numerous methodological precautions were taken to ensure objectivity of the follow-up examination.

Method

Subjects and Background

Characteristics of the subjects and their treatment have been described elsewhere (Lovaas, 1987) and will only be summarized here. The initial treatment study contained 38 children who, at the time of intake, were very young (less than 40 months if mute, less than 46 months if echolalic) and had received a diagnosis of autism from a licensed clinical psychologist or psychiatrist not involved in the study. These 38 subjects were divided into an experimental group and a control group. The assignment to groups was made on the basis of staff availability. At the beginning of each academic quarter, treatment teams were formed. The clinic director and staff members then determined whether any opening existed for intensive treatment. If so, the next referral received would enter the experimental group; otherwise, the subject entered the control group. The experimental group contained 19 children who received 40 or more hours per week of one-to-one behavioral treatment for 2 or more years. The control group was comprised of 19 children who received a much less intensive intervention (10 hours a week or less of one-to-one behavioral treatment in addition to a variety of treatments provided by community agencies, such as parent training or special education classes). The initial study also included a second control group, consisting of 21 children with autism who were followed over time by a nearby agency but who were never referred for this study. However, these 21 subjects were not available for the present investigation. On standardized measures of intelligence, the second control group did not differ from either the experimental group or the first control group at intake, nor did it differ from the first control group when evaluated again when the subjects were 7 years old. These findings suggest that, as measured by standardized tests, (a) the children with autism who were referred to us for treatment were comparable to children with autism seen elsewhere and (b) the minimal treatment provided to the first control group did not alter intellectual functioning.

Statistical analysis of an extensive range of pretreatment measures confirmed that the experimental group and control group were comparable at intake and closely matched on such important variables as IQ and severity of disturbance. The mean chronological age (CA) at diagnosis for subjects in the experimental group was 32 months. Their mean IQ was 53 (range 30 to 82; all IQs are given as deviation scores). The mean CA of subjects in the control group was 35 months; their mean IQ was 46 (range 30 to 80). Most of the subjects were mute, all had gross deficiencies in receptive language, none played with peers or showed age-appropriate toy play, all were emotionally withdrawn, most had severe tantrums, and all showed extensive ritualistic and stereotyped (self-stimulatory) behaviors. Thus, they appeared to be a representative sample of children with autism (Lovaas, Smith, & McEachin, 1989). A more complete presentation of the intake data was reported by Lovaas (1987).

The children in the experimental group and control group received their respective treatments from trained student therapists who worked in the child's home. The parents also worked with their child, and they received extensive instruction and supervision on appropriate treatment techniques. Whenever possible, the children were integrated into regular preschools. The treatment focused primarily on developing language, increasing social behavior, and promoting cooperative play with peers along with independent and appropriate toy play. Concurrently, substantial efforts were directed at decreasing excessive rituals, tantrums, and aggressive behavior. (For a more detailed description of the intervention program, see the treatment manual [Lovaas et al., 1980] and instructional videotapes that supplement the manual [Lovaas & Leaf, 1981].)

At the time of the present follow-up (1984–1985), the mean CA of the experimen-

tal group children was 13 years (range = 9 to 19 years). All children who had achieved normal functioning by the age of 7 years had ended treatment by that point. (*Normal functioning* was operationally defined as scoring within the normal range on standardized intelligence tests and successfully completing first grade in a regular, nonspecial education class entirely on one's own.) On the other hand, some of the children who had not achieved normal functioning at 7 years of age had, at the request of their parents, remained in treatment. The length of time that experimental subjects had been out of treatment ranged from 0 to 12 years (mean = 5), with the normal-functioning children having been out for 3 to 9 years (mean = 5).

The mean age of subjects in the control group was 10 years (range 6 to 14). The length of time that these children had been out of treatment ranged from 0 to 9 years (mean = 3). Thus, experimental subjects tended to be older and had been out of treatment longer than had control subjects. This difference in age occurred because the first referrals for the study were all assigned to the experimental group due to the fact that referrals came slowly (7 in the first 3.5 years) and therapists were available to treat all of them. (As noted earlier, subjects were assigned to the experimental group if therapists were available to treat them; otherwise, they entered the control group.)

Statistical analyses were conducted to test whether a bias resulted from the tendency for the first referrals to go into the experimental group. For example, it is conceivable that the first referrals could have been higher functioning at intake or could have had a better prognosis than subsequent referrals. If so, the subject assignment procedure could have favored the experimental group. To assess this possibility, we correlated the order of referral with intake IQ and with IQ at the first follow-up (age 7 years). Pearson correlations were computed across both groups and within each group. These analyses indicated that the order in which subjects were referred was not associated with intake IQ or outcome IQ. Consequently, although the tendency for the first referrals to enter the experimental group created a potential bias, the data indicate that this was unlikely.

Procedure

The assessment procedure included ascertaining school placement and administering three standardized tests. Information on school placement was obtained from subjects' parents, who classified them as being in either a regular or a special education class (e.g., a class for children with autism or mental retardation, language delays, multihandicaps, or learning disabilities). The three standardized tests were as follows:

1. *Intelligence test.* The Wechsler Intelligence Scale for Children-Revised (Wechsler, 1974) was administered when subjects were able to provide verbal responses. This included all 9 best-outcome experimental subjects plus 8 of the remaining 10 experimental subjects and 6 of the 19 control subjects. For subjects who were not able to provide verbal responses, the Leiter International Performance Scale (Leiter, 1959) and the Peabody Picture Vocabulary Test-Revised (Dunn, 1981) were administered. All of these tests have been widely used for the assessment of intellectual functioning in children with autism (Short & Marcus, 1986).

2. *The Vineland Adaptive Behavior Scales* (Sparrow, Balla, & Cicchetti, 1984). The Vineland is a structured interview administered to parents assessing the extent to which their child exhibits behaviors that are needed to cope effectively with the everyday environment.

3. *The Personality Inventory for Children* (Wirt, Lachar, Klinedinst, & Seat, 1977). This measure is a 600-item true–false questionnaire filled out by parents that assesses the extent to which their children show various forms of psychological disturbance (e.g., anxiety, depression, hyperactivity, and psychotic behavior).

These three tests were intended to provide a comprehensive evaluation of intellectual, social, and emotional functioning. All of the tests have been standardized on average populations. Hence, they provide an objective basis for comparing subjects to children without handicaps across the various areas that they assess.

Data were obtained on all subjects except one girl in the control group, who was known to be institutionalized and functioning very poorly. The 9 best-outcome subjects (those who had been classified as normal functioning at age 7) received particularly extensive evaluations, as outlined later. Of the 28 remaining subjects, 17 were evaluated by staff members in our treatment program, and 11 received evaluations from outside agencies such as schools or psychology clinics. (In some cases, the outside agencies did not administer all of the measures in this battery.)

Evaluation of Best-Outcome Subjects. To ensure objectivity in the evaluation of the best-outcome subjects, we arranged for blind administration and scoring of all tests for these subjects as follows. A psychologist not associated with the study recruited advanced graduate students in clinical psychology to administer the tests. The examiners were not familiar with the history of the children, and the psychologist told them simply that the testing was part of a research study on assessment of children. The psychologist advised them that the nature of the study necessitated providing only certain standard background information: age, school placement and grade, and parent's name and phone number. To increase the heterogeneity of the sample and to control for any examiner bias, each examiner also tested one or more subjects who were matched in age to the experimental subjects and had no history of behavioral disturbance. The examiners were randomly assigned an approximately equal number of subjects for testing in the experimental group and the comparison group. Two experimental subjects were not living in the local area. Therefore, for each of them, the psychologist recruited a tester from the subject's hometown area as well as an age-matched control subject, and data were collected as just described. In addition, the child's examiner filled out a clinical rating scale following a structured interview that covered a list of standard topics, including friendships, family relations, and school and community activities. The interview was designed both for eliciting content and for sampling interpersonal style. The rating scale consisted of 22 items, each scored 0 (best clinical status) to 3 (marked deviance) points. The items were designed to include likely areas of difficulty for children with autism of average intelligence (e.g., compulsive or ritualistic behavior, empathy for and interest in others, a sense of humor) as well as areas of potential difficulty for the general child population (e.g., depressed mood, anxiety, hyperactivity). (The complete scale and a copy of instructions for the clinical interview can be obtained by writing to the third author).

Results

Experimental Versus Control Group

This first section examines the overall effects of treatment through comparison of the follow-up data from the 19 subjects who received the intensive (experimental) treatment to the data from those who received the minimal (control) treatment. Data were obtained from all subjects on school placement and from all but one subject in the control group on IQ. On the Vineland, scores were obtained for 18 of 19 experimental subjects and 15 of 19 control subjects. The lowest availability of follow-up scores was on the Personality Inventory for Children, with scores for 15 experimental subjects and 12 control subjects.

The subjects in the control group who had Personality Inventory for Children scores did not appear to differ from subjects who were missing these scores, as compared on

t tests for differences in intake IQ, IQ at 7 years old, or IQ in the present study.

As noted earlier, 17 of the 29 subjects who were not in the best-outcome group were evaluated by Project staff members, 11 were evaluated by outside agencies, and 1 was not evaluated. To check whether Project staff members were biased in their evaluations or in their selection of which subjects to evaluate, we used *t* tests to compare subjects they evaluated to those evaluated by outside agencies on intake IQ, IQ at age 7 years, and IQ in the present study. No significant differences between subjects evaluated by Project staff members and those evaluated by outside agencies were found.

School Placement. In the experimental group, 1 of the 9 subjects from the best-outcome group who had attended a regular class at age 7 (J. L.) was now in a special education class. However, 1 of the other 10 subjects had gone from a special education class to a regular class and was enrolled in a junior college at the time of this follow-up. The remaining experimental subjects had not changed their classification. Overall, then, the proportion of experimental subjects in regular classes did not change from the age 7 evaluation (9 of 19, or 47%). In the control group, none of the 19 children were in a regular class, as had been true at the age 7 evaluation. The difference in classroom placement between the experimental group and the control group was statistically significant, χ^2 (1, N = 38) = 19.05, $p < .05$.

Intellectual Functioning. The test scores for the experimental group and control group on intellectual functioning, adaptive and maladaptive behaviors, and personality functioning are summarized in Table 1. As can be seen in the table, the experimental group at follow-up had a significantly higher mean IQ than did the control group. This difference was significant, $t(35) = 2.97$, $p < .01$. Eleven subjects (58%) in the experimental group obtained Full-Scale IQs of at least 80; only 3 subjects (17%) in the control group did as well. The scores were similar to those obtained by the experimental group and control group at age 7 (mean IQs of 83 and 52, respectively), indicating that the experimental group had maintained its gains in intellectual functioning between age 7 and the time of the current evaluation.

Table 1
Mean Scores and *SD*s by Group and Measure at Follow-Up

	Group			
	Experimental		Control	
Measure	Mean	*SD*	Mean	*SD*
IQ	84.5	32.4	54.9	29.1
Vineland[a]				
Communication	5.1	28.4	51.9	26.7
Daily Living Skills	73.1	26.9	45.9	25.4
Socialization	75.5	26.8	49.7	19.9
Adaptive Behavior Composite	71.6	26.8	45.7	21.3
Maladaptive Behavior	10.6	8.2	17.1	7.2
PIC[b] Scales				
Mean elevation	61.8	10.2	64.8	8.1
Scales > 70	4.0	3.9	6.2	2.8

[a]Vineland Adaptive Behavior Scale. [b]Personality Inventory for Children.

Adaptive and Maladaptive Behavior. On the Vineland, the mean overall or Composite score was 72 in the experimental group and 48 in the control group. (The average score for the general population on this test is 100, with a standard deviation [*SD*] of 15.) On the three subscales—Communication, Daily Living, and Socialization—each score closely paralleled the Composite score. The interaction between the groups and the subscales was not significant, indicating that across the three subscales, the experimental group consistently scored higher than did the control group. As can be seen in Table 1, Maladaptive Behavior was significantly higher in the control group, $t(31) = 2.39$, $p < .05$. The mean score for the control group was in the clinically significant range whereas that of the experimental group was not. (Scores of 13 and above are considered to be indicative of clinically significant levels of maladaptive behavior at ages 6 to 9 years; 12 or above, at 12 to 13 years; and 10 or above, at 14 years and older.) Thus, the findings indicate that the experimental group showed more adaptive behaviors and fewer maladaptive behav-

iors than did the control group.

Personality Functioning. Scores for the experimental group and control group did not differ on overall scale elevation, with mean *t* scores of 62 and 65, respectively. (On this test, the mean *t* score for the general population is approximately 50 [*SD* = 10].) *T* scores above 60 are considered indicative of possible or mild deviance, whereas *t* scores above 70 are viewed as suggesting a clinically significant problem, namely, one that may require professional attention. There was a significant interaction between the groups and the individual scales on this test, $F(15, 390) = 2.36$, $p < .01$. Results of the Tukey test indicated that the most reliable difference between groups occurred on the Psychosis scale, on which the experimental subjects had a mean of 78 and the control subjects had a mean of 104, $F(1, 26) = 8.53$, $p < .01$. Seven subjects in the experimental group scored in the clinically preferred range (below 70), whereas no subjects in the control group scored that low. Only one other scale showed a significant difference, Somatic Concerns, $F(1, 26) = 4.60$, $p < .05$. The control subjects tended to display a below average level of somatic complaints (mean of 45 as compared to 54 for the experimental subjects).

Best-Outcome Versus Nonclinical Comparison Group

A *t* test indicated no significant difference in age between the best-outcome group and the comparison group of children without a history of clinically significant behavioral disturbance. Subjects in the best-outcome group had a mean age of 12.42 years (range 10.0 to 16.25) versus 12.92 years (range 9.0 to 15.17) for the nonclinical comparison group. Scores on the WISC-R and clinical rating scale were obtained for all subjects; 1 experimental subject and 2 nonclinical comparison subjects were missing Vineland scores, and 2 experimental subjects and 1 nonclinical comparison subject were missing Personality Inventory for Children scores. Both the Vineland and Personality Inventory for Children were completed by parents. In cases where these scores were not obtained, the parents had declined to participate.

On the measures that provide standardized scores, the functioning of the best-outcome subjects was measured most precisely by comparing the best-outcome group against the test norms. Therefore, this analysis is of primary interest. Data for the nonclinical comparison group are mainly useful in confirming that the assessment procedures were valid and in providing a contrast group for the one measure without norms, the Clinical Rating Scale. For the nonclinical comparison group, it will suffice to summarize the results as follows: On the WISC-R this group had mean IQs of 116 Verbal, 118 Performance, and 119 Full-Scale. On the Vineland the group obtained mean standard scores of 102 Communication, 100 Daily Living Skills, 102 Socialization, and 101 Composite. The mean scale score on the Personality Inventory for Children was 49. Thus, the nonclinical comparison group displayed above-average or average functioning across all areas that were assessed.

The next section is focused on the functioning of the best-outcome group on IQ, adaptive and maladaptive behavior, and personality measures and contrasts the best-outcome subjects with the comparison subjects on the Clinical Rating Scale.

Intellectual Functioning. Table 2 presents the IQ data for each subject in the best-outcome group and the mean scores for the group. This table shows that, as a whole, the 9 best-outcome subjects performed well on the WISC-R. Their IQs placed them in the high end of the normal range, about two thirds of an *SD* above the mean. Their Full-Scale IQs ranged from 99 to 136.

Subjects' scores were evenly distributed across a range from 80 to 125 on Verbal IQ and from 88 to 138 on Performance IQ. The subjects averaged 3 points higher on Performance IQ than Verbal IQ. Two of them (J. L. and A. G.) had at least a 20-point difference

Table 2
WISC-R Scores of the Best-Outcome Subjects

	Verbal					Performance					WISC-R IQ		
Subject	Infrm	Simil	Arith	Vocab	Compr	PicC	PicA	BlkD	ObjA	Cod	VIQ	PIQ	Full
R.S.	12	12	13	9	11	10	9	13	12	11	106	106	106
M.C.	17	19	11	14	10	12	16	19	19	11	125	138	136
M.M.	14	13	10	14	11	12	11	11	11	8	114	102	109
L.B.	12	16	11	13	15	7	12	17	17	19	119	131	128
J.L.	6	9	7	4	8	18	11	16	14	7	80	123	100
D.E.	9	17	8	10	15	13	9	12	9	17	98	114	105
A.G.	7	14	12	11	13	9	4	8	11	10	108	88	99
B.W.	12	11	10	10	9	7	10	9	11	10	102	95	99
B.R.	11	14	11	13	16	12	10	12	11	10	118	106	114
Mean	11.1	13.9	10.3	10.9	12	11.1	10.2	13	12.8	11.4	108	111	111

Note. Infrm = Information, Simil = Similarities, Arith = Arithmetic, Vocab = Vocabulary, Compr = Comprehension, PicC = Picture Completion, PicA = Picture Arrangement, BlkD = Block Design, ObjA = Object Assembly, Cod = Coding, VIQ = Verbal IQ, PIQ = Performance IQ, and Full = Full-Scale IQ.

between Verbal and Performance IQ.

On each subtest of the WISC-R, the mean for the general population is 10 (*SD* = 3). It can be seen from Table 2 that the best-outcome subjects scored highest on Similarities, Block Design, and Object Assembly. They scored lowest on Picture Arrangement and Arithmetic. Thus, the subjects consistently scored at or above average.

Adaptive and Maladaptive Behavior. Table 3 presents the data for the best-outcome group on the Vineland Adaptive Behavior Scales. It can be seen that the best-outcome group scored about average on the Composite Scale and on the subscales for Communication, Daily Living, and Socialization. However, Table 3 shows that some of the best-outcome subjects had marginal scores, including J. L., B. W., and M. M. Even so, all of the best-outcome subjects had Composite scores within the normal range.

As can be seen in Table 3, on the Maladaptive Behavior Scale (Parts I and II), the mean score for the best-outcome group indicated that, on average, these subjects did not display clinically significant levels of maladaptive behavior. Three of them scored in the clinically significant range versus one subject in the nonclinical comparison group, which had a mean of 7.7 on this scale.

Personality Functioning. The results of the Personality Inventory for Children are summarized in Table 4. The best-outcome subjects obtained valid profiles on the Personality Inventory for Children, as measured by the three validity scales (Lie, Frequency, and Defensiveness). As can be seen from the table, the subjects scored in the normal range across all scales. They tended to score highest on Intellectual-Screening, Psychosis, and Frequency. Intellectual-Screening assesses slow intellectual development, and Psychosis and Frequency assess unusual or strange behaviors. Only Intellectual-Screening was above the normal range, and this scale is affected by subjects' early history. For example, the scale contains statements such as "My child first talked before he (she) was two years old," which would be false for the best-outcome subjects regardless of their current level of functioning.

As Table 4 indicates, 4 best-outcome subjects had a single scale elevated beyond

Table 3
Scores on the Vineland Adaptive Behavior Scale for the Best-Outcome Subjects

	Adaptive behavior				Maladaptive
Subject	Com	DLS	Soc	Comp	behavior
R.S.	83	98	102	92	6
M.C.	119	93	86	98	16
M.M.	119	79	114	105	2
L.B.	107	108	112	108	4
J.L.	77	103	94	88	13
D.E.	93	81	82	80	15
A.G.	101	97	99	98	5
B.W.	83	74	105	83	9
B.R.	—	—	—	—	—
Mean	98	92	99	94	8.8

Note. Com = Communication, DLS = Daily Living Skills, Soc = Socialization, Comp = Adaptive Behavior Composite.

Table 4
T Scores on the Personality Inventory for Children for the Best-Outcome Subjects

	T score																	
Subject	Mean	<70	L	F	Def	Adj	Ach	I-S	Dvl	Som	Dep	Fam	Dlq	Wdr	Anx	Psy	Hyp	Soc
R.S.	56	1	49	54	43	61	53	75	49	44	69	47	46	69	60	65	46	64
M.C.	52	1	48	63	37	43	39	54	38	64	55	54	46	65	51	75	40	55
M.M.	49	0	42	54	43	50	42	64	46	58	48	55	46	47	53	46	54	36
L.B.	51	1	60	50	49	49	37	70	39	55	49	48	51	45	60	51	49	51
J.L.	70	9	42	84	37	85	77	94	65	78	86	65	61	69	78	76	52	72
D.E.	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—
A.G.	51	0	38	45	49	57	48	39	53	51	49	69	40	55	55	55	49	63
B.W.	54	1	45	63	50	59	64	48	55	47	44	57	90	44	45	46	62	44
B.R.	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—
Mean	55	2	46	56	44	58	51	64	49	57	57	56	54	56	57	59	50	55

Note. Mean = mean elevation across all scales. L = Lie scale, F = Frequency, Def = Defensiveness, Adj = Adjustment, Ach = Achievement, I-S = Intellectual-Screening, Dvl = Development, Som = Somatic Concern, Dep = Depression, Fam = Family Relations, Dlq = Delinquency, Wdr = Withdrawal, Anx = Anxiety, Psy = Psychosis, Hyp = Hyperactivity, Soc = Social Skills.

the clinically significant range and a 5th (J. L.) had nine scales elevated, including the highest scores in the best-outcome group on Intellectual-Screening, Psychosis, and Frequency. Thus, this subject appeared to account for much of the elevation in scores on these scales. By comparison, there were 3 subjects in the nonclinical comparison group with at least one scale elevated.

Clinical Rating Scale. On this scale, 8 of the best-outcome subjects scored between 0 and 10, and the 9th (J. L.) scored 42. The mean was 8.8, with a standard deviation of 12.9. The nonclinical comparison subjects all scored between 0 and 5 (mean = 1.7, SD = 2.1). Because these SDs are unequal, we used a nonparametric statistic, a Mann-Whitney U test, revealing a significant difference between groups, $U = 19$, $p < .05$. Thus, the best-outcome subjects displayed more deviance than did the comparison subjects, but most of the deviance appeared to come from one subject, J. L.

Discussion

This study is a later and more extensive follow-up of two groups of young subjects with autism who were previously studied by Lovaas (1987): (a) an experimental group (n = 19) that had received very intensive behavioral treatment and (b) a control group (n = 19) that had received minimal behavioral treatment. In the present study we have reported data on these children at a mean age of 13 years for subjects in the experimental group and 10 years for those in the control group. The data were obtained from a comprehensive assessment battery.

The main findings from the test battery were as follows: First, subjects in the experimental group had maintained their level of intellectual functioning between their previous assessment at age 7 and the present evaluation at a mean age of 13, as measured by standardized intelligence tests. Their mean IQ was about 30 points higher than that of control subjects. Second, experimental subjects also displayed significantly higher levels of functioning than did control subjects on measures of adaptive behavior and personality. Third, in a particularly rigorous evaluation of the 9 subjects in the experimental group who had been classified as best-outcome (normal-functioning) in the earlier study (Lovaas, 1987), the test results consistently indicated that the subjects exhibited average intelligence and average levels of adaptive functioning. Some deviance from average was found on the personality test and the clinical ratings. However, this deviance appeared to derive from the extreme scores of one subject, J. L. (see Table 2, 3, and 4). This subject also had been removed from nonspecial education classes and placed in a class for children with language delays, and he obtained relatively

low scores (about 80) on the Verbal section of the intelligence test and the Communication section of the measure of adaptive behavior. Thus, he no longer appeared to be normal-functioning. However, the remaining 8 subjects who had previously been classified as normal-functioning demonstrated average IQ, with intellectual performance evenly distributed across subtests, were able to hold their own in regular classes, did not show signs of emotional disturbance, and demonstrated adequate development of adaptive and social skills within the normal range. In addition, subjective clinical impressions of blind examiners did not discriminate them from children with no history of behavioral disturbance. These 8 subjects (42% of the experimental group) may be judged to have made major and enduring gains and may be described as "normal-functioning." By contrast, none of the control group subjects achieved such a favorable outcome, consistent with the poor prognosis for children with autism reported by other investigators (Freeman, Ritvo, Needleman, & Yokota, 1985).

In order to evaluate this outcome, we must pay close attention to whether or not our methodology was sound. The adequacy of our methodology is crucial because the outcome in the present study represents a major improvement over outcomes obtained in previous experimental studies on the treatment of children with autism (Rutter, 1985). The only reports of comparable outcomes have come from uncontrolled case studies (e.g., Bettelheim, 1967), and subsequent investigations have indicated that these case studies grossly overestimated the outcomes obtainable with the treatment that was provided. Similarly, reports of major gains in other populations, such as large IQ increases in children from impoverished backgrounds, also have been based on highly questionable evidence (Kamin, 1974; Spitz, 1986). Such reports have the potential to cause a great deal of harm by misleading consumers and professionals.

A detailed description of all the methodological safeguards that should be built into a treatment study is beyond the scope of the present report (see Kazdin, 1980; Kendall & Norton-Ford, 1982; Spitz, 1986). However, we note that we incorporated a large number of methodological safeguards in both the original study (Lovaas, 1987) and the present investigation:

1. The experimental group and the control group received equivalent assessment batteries at intake and were found to be very similar on a multitude of important variables. Moreover, the number of control group subjects who were predicted to achieve normal functioning, had they received intensive treatment, was approximately equal to the number of experimental subjects who actually did achieve normal functioning with intensive treatment (Lovaas & Smith, 1988). Thus, the subject assignment procedure yielded groups that were comparable prior to treatment. This provided a strong indication that the superior functioning of the experimental group after treatment was a result of the treatment itself rather than a biased procedure for assigning subjects to the experimental group.

2. All subjects remained in the groups to which they were assigned at intake. Only 2 subjects dropped out, and they were not replaced. Therefore, the original composition of the groups was essentially preserved.

3. All subjects were independently diagnosed as autistic by PhD or MD clinicians, and there was high agreement on the diagnosis between the independent clinicians. This provided evidence that subjects met criteria for a diagnosis of autism.

4. Prior to treatment, these subjects appeared to be comparable to those diagnosed as having autism in other research investigations. Evidence for this comes from the second control group that was incorporated into the initial treatment study. This group was evaluated by another research team (independent of ours), had similar IQs at intake based on the same measures of intelligence that we used, yet showed similar outcome data to those reported by other investigators. Additional evidence can be

derived from the similarity of our intake data to data reported by other investigators (Lovaas et al., 1989). For example, although Schopler and his associates (Schopler, Short, & Mesibov, 1989) suggested that our sample had a higher mean IQ than did other samples of children with autism, their own data do not appear to differ from ours (Lord & Schopler, 1989). Thus, there is evidence that our subjects were a typical group of preschool-age children with autism rather than a select group of high-level children with autism who would have been expected to achieve normal functioning with little or no treatment.

5. The first control group, which received up to 10 hours a week of one-to-one behavioral treatment, did not differ at posttreatment from the second control group, which received no treatment from us. Both groups achieved substantially less favorable outcomes than did the experimental group. Because all groups were similar at pretreatment, this result confirms that our subjects had problems that responded only to intensive treatment rather than problems such as being noncompliant or holding back (masking an underlying, essentially average intellectual functioning that would respond to smaller-scale interventions).

6. Subjects' families ranged from high to low socioeconomic status, and, on average, they did not differ from the general population (Lovaas, 1987). Thus, although our treatment required extensive family participation, a diverse group of families was apparently able to meet this requirement.

7. The treatment has been described in detail (Lovaas et al., 1980; Lovaas & Leaf, 1981), and the effectiveness of many components of the treatment has been demonstrated experimentally by a large number of investigators over the past 30 years (cf. Newsom & Rincover, 1989). Hence, our treatment may be replicable, a point that is discussed in greater detail later.

8. The results of the present follow-up, which extended several years beyond discharge from treatment for most subjects, are an encouraging sign that treatment gains have been maintained for an extended period of time.

9. A wide range of measures was administered, avoiding overreliance on intelligence tests, which have limitations if used in isolation (e.g., bias resulting from teaching to the test, selecting a test that would yield especially favorable results, failing to assess other aspects of functioning such as social competence or school performance) (Spitz, 1986; Zigler & Trickett, 1978).

10. The use at follow-up of a normal comparison group, standardized testing, and blind rating allowed for an objective, detailed, and quantifiable assessment of treatment effectiveness. A particularly rigorous assessment was given to those subjects who showed the most improvement.

Taken together, these safeguards provide considerable assurance that the favorable outcome of the experimental subjects can be attributed to the treatment they received rather than to extraneous factors such as improvement that would have occurred regardless of treatment, biased procedures for selecting subjects or assigning them to groups, or narrow or inappropriate assessment batteries.

Despite the numerous precautions that we have taken, several concerns may be raised about the validity of the results. Perhaps the most important is that the assignment to the experimental or control group was made on the basis of therapist availability rather than a more arbitrary procedure such as alternating referrals (assigning the first referral to the experimental group, the second to the control group, the third to the experimental group, and so forth). However, it seems unlikely that the assignment was biased in view of the pretreatment data we have presented on the similarity between the experimental and control groups. On the other hand, we do not know as yet whether there exists a pretreatment variable that does predict outcome but was not among the 19 we chose, yet could have discriminated between groups. In an earlier publication (Lovaas et al., 1989), we responded in some

detail to the concern about subject assignment as well as other possible problems associated with the original study. There are certain additional questions that may be raised by this follow-up investigation:

1. The experimental group was older than the control group at the time of this follow-up evaluation. We explained this finding earlier and noted that data analyses indicated that it was unlikely that this age difference reflected a bias in subject assignments.

2. The follow-up assessments for 17 of the lower functioning subjects in this study were conducted by staff members from our Project, who could have biased the test results. However, as noted previously, a check revealed no evidence of such a bias.

3. The Clinical Rating Scale, based on an interview with subjects who had been classified as normal-functioning in the original study, has no norms or data on reliability and validity. However, we regard the interview simply as an extra check on whether the examiners detected residual signs of autism or other behavior problems that were somehow overlooked in the three other (well-standardized) measures in the study and their 30 subscales. We do not regard the interview as an instrument that by itself yields conclusive results. No other interview that suited our purposes currently exists. In future investigations, we plan to use an interview that Michael Rutter and his associates are now developing for the purpose of detecting of residual signs of autism in individuals with average intelligence.

4. As in most long-term follow-up studies, we had some missing data. However, there is no evidence that the missing data would have changed the overall results.

5. In our analysis of the best-outcome group, we noted that the group averages deviated from "normal" on one subscale of the Personality Inventory for Children and on the Clinical Rating Scale. We then attributed this deviance to the extreme scores of one subject rather than to general problems within this group. We recognize that group averages are seldom interpreted this way. However, as statisticians and methodologists have pointed out (e.g., Barlow & Hersen, 1984), there are many times when group averages represent the performance of few or no subjects within the group. This was one of those times, as is clearly shown by the data on individual subjects (Tables 2, 3, and 4). Deviance was found almost exclusively in one subject, not evenly distributed across all subjects, and we have presented the results accordingly.

The most important void for research to fill at this time is replication by independent investigators who employ sound methodologies. Given the objective assessment instruments that we used and the detailed description that we have provided of the treatment (Lovaas et al., 1980), such a replication should be possible. However, the treatment is complex and to replicate it properly, an investigator probably needs to possess (a) a strong foundation in learning theory research; (b) a detailed knowledge of the treatment manual we used; (c) a supervised practicum of at least 6 months in one-to-one work with clients who have developmental delays, emphasizing discrimination learning and building complex language; and (d) a commitment to provide 40 hours of one-to-one treatment to client per week, 50 weeks per year, for at least 2 years. Our best-outcome subjects all required a minimum of 2 years of intensive treatment to achieve average levels of functioning (another indication that those subjects had pervasive disabilities and were not merely non-compliant).

A second void to fill concerns the majority of children who did not benefit to the point of achieving normal functioning with intensive treatment. Perhaps an earlier start in treatment would have been all that was needed to obtain favorable outcomes with many of these children. More pessimistically, perhaps such children require new and different interventions that have yet to be discovered and implemented. In any case, it is essential to develop more appropriate

services for these children.

Finally, a rather speculative but promising area for research is to determine the extent to which early intervention alters neurological structures in young children with autism. Autism is almost certainly the result of deficits in such neurological structures (Rutter & Schopler, 1987). However, laboratory studies on animals have shown that alterations in neurological structure are quite possible as a result of changes in the environment in the first years of life (Sirevaag & Greenough, 1988), and there is reason to believe that alterations are also possible in young children. For example, children under 3 years of age overproduce neurons, dendrites, axons, and synapses. Huttenlocher (1984) hypothesized that, with appropriate stimulation from the environment, this overproduction might allow infants and preschoolers to compensate for neurological anomalies much more completely than do older children. Caution is needed in generalizing from these findings on average children to early intervention with children with autism, particularly because the exact nature of the neurological anomalies of children with autism is unclear at present (e.g., Rutter & Schopler, 1987). Nevertheless, the findings suggest that intensive early intervention could compensate for neurological anomalies in such children. Finding evidence for such compensation would help explain why the treatment in this study was effective. More generally, it might contribute to an understanding of brain–behavior relations in young children.

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Internet Mental Health

Autistic Disorder

Description

- American Description
- European Description
- Autism - U.S. Surgeon General NEW

Treatment

- Autism - NIMH

Research

- Research

(see pages 6-7)

Stories of Recovery & Personal Experiences

- Come Back Jack - The Parish Family's experience with their autistic son, Jack

Booklets

- The Child with Autism - AACAP
- Childhood Disorders Booklets

Magazine Articles

- Autism - A Confusing Childhood Disorder - Mayo Clinic Health Oasis, May 10, 1999 [External Link]
- Childhood Disorders Articles

Internet Links to Childhood Disorders Sites

- Autistic Disorder Sites

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App. #3

Chapter 3
Children and Mental Health

Normal Development

- Theories of Development
- Social and Language Development
- Temperament
- Developmental Psychopathology

Overview of Risk Factors and Prevention

- Risk Factors
- Prevention

Overview of Mental Disorders in Children

- General Categories of Mental Disorders of Children
- Assessment and Diagnosis
- Evaluation Process
- Treatment Strategies

Attention-Deficit/Hyperactivity Disorder

- Treatment

Depression and Suicide in Children and Adolescents

Other Mental Disorders in Children and Adolescents

Anxiety Disorders

The combined prevalence of the group of disorders known as anxiety disorders is higher than that of virtually all other mental disorders of childhood and adolescence (Costello et al., 1996). The 1-year prevalence in children ages 9 to 17 is 13 percent (Table 3-1). This section furnishes brief overviews of several anxiety disorders: separation anxiety disorder, generalized anxiety disorder, social phobia, and obsessive-compulsive disorder. Treatments for all but the latter are grouped together below.

Separation Anxiety Disorder
Although separation anxieties are normal among infants and toddlers, they are not appropriate for older children or adolescents and may represent symptoms of separation anxiety disorder. To reach the diagnostic threshold for this disorder, the anxiety or fear must cause distress or affect social, academic, or job functioning and must last at least 1 month (DSM-IV). Children with separation anxiety may cling to their parent and have difficulty falling asleep by themselves at night. When separated, they may fear that their parent will be involved in an accident or taken ill, or in some other way be "lost" to the child forever. Their need to stay close to their parent or home may make it difficult for them to attend school or camp, stay at friends' houses, or be in a room by themselves. Fear of separation can lead to dizziness, nausea, or palpitations (DSM-IV).

Separation anxiety is often associated with symptoms of depression, such as sadness, withdrawal, apathy, or difficulty in concentrating, and such children often fear that they or a family member might die. Young children experience nightmares or fears at bedtime.

About 4 percent of children and young adolescents suffer from separation anxiety

- Conditions Associated With Depression
- Prevalence
- Course and Natural History
- Causes
- Consequences
- Treatment

Other Mental Disorders in Children and Adolescents

- Anxiety Disorders
- Autism
- Disruptive Disorders
- Substance Use Disorders in Adolescents
- Eating Disorders

Services Interventions

- Treatment Interventions
- Newer Community-Based Interventions
- Crisis Services

Service Delivery

- Service Utilization
- Service Systems and Financing
- Culturally Appropriate Social Support Services
- Support and Assistance for Families
- Integrated System Model
- Effectiveness of Systems of Care

disorder (DSM-IV). Among those who seek treatment, separation anxiety disorder is equally distributed between boys and girls. In survey samples, the disorder is more common in girls (DSM-IV). The disorder may be overdiagnosed in children and teenagers who live in dangerous neighborhoods and have reasonable fears of leaving home.

The remission rate with separation anxiety disorder is high. However, there are periods where the illness is more severe and other times when it remits. Sometimes the condition lasts many years or is a precursor to panic disorder with agoraphobia. Older individuals with separation anxiety disorder may have difficulty moving or getting married and may, in turn, worry about separation from their own children and partner.

The cause of separation anxiety disorder is not known, although some risk factors have been identified. Affected children tend to come from families that are very close-knit. The disorder might develop after a stress such as death or illness in the family or a move. Trauma, especially physical or sexual assault, might bring on the disorder (Goenjian et al., 1995). The disorder sometimes runs in families, but the precise role of genetic and environmental factors has not been established. The etiology of anxiety disorders is more thoroughly discussed in Chapter 4.

Generalized Anxiety Disorder

Children with generalized anxiety disorder (or overanxious disorder of childhood) worry excessively about all manner of upcoming events and occurrences. They worry unduly about their academic performance or sporting activities, about being on time, or even about natural disasters such as earthquakes. The worry persists even when the child is not being judged and has always performed well in the past. Because of their anxiety, children may be overly conforming, perfectionist, or unsure of themselves. They tend to redo tasks if there are any imperfections. They tend to seek approval and need constant reassurance about their performance and their anxieties (DSM-IV). The 1-year prevalence rate for all generalized anxiety disorder sufferers of all ages is approximately 3 percent. The lifetime prevalence rate is about 5 percent (DSM-IV).

About half of all adults seeking treatment for

- Summary: Effectiveness of Systems of Care

Conclusions

References

this disorder report that it began in childhood or adolescence, but the proportion of children with this disorder who retain the problem into adulthood is unknown. The remission rate is not thought to be as high as that of separation anxiety disorder.

Social Phobia

Children with social phobia (also called social anxiety disorder) have a persistent fear of being embarrassed in social situations, during a performance, or if they have to speak in class or in public, get into conversation with others, or eat, drink, or write in public. Feelings of anxiety in these situations produce physical reactions: palpitations, tremors, sweating, diarrhea, blushing, muscle tension, etc. Sometimes a full-blown panic attack ensues; sometimes the reaction is much more mild. Adolescents and adults are able to recognize that their fear is unreasonable or excessive, although this recognition does not prevent the fear. Children, however, might not recognize that their reaction is excessive, although they may be afraid that others will notice their anxiety and consider them odd or babyish.

Young children do not articulate their fears, but may cry, have tantrums, freeze, cling, appear extremely timid in strange social settings, shrink from contact with others, stay on the side during social events, and try to stay close to familiar adults. They may fall behind in school, avoid school completely, or avoid social activities among children their age. The avoidance of the fearful situations or worry preceding the feared event may last for weeks and interferes with the individual's daily routine, social life, job, or school. They may find it impossible to speak in social situations or in the presence of unfamiliar people (for review of social phobia, see DSM-IV; Black et al., 1997).

Social phobia is common, the lifetime prevalence ranging from 3 to 13 percent, depending on how great the fear is and on how many different situations induce the anxiety (DSM-IV; Black et al., 1997). In survey studies, the majority of those with the disorder were found to be female (DSM-IV). Often the illness is lifelong, although it may become less severe or completely remit. Life events may reassure the individual or exacerbate the anxiety and disorder.

Treatment of Anxiety
Although anxiety disorders are the most common disorder of youth, there is relatively little research on the efficacy of psychotherapy (Kendall et al., 1997). For childhood phobias, contingency management[10] was the only intervention deemed to be *well-established*, according to an evaluation by Ollendick and King (1998), which applied the American Psychological Association Task Force criteria (noted earlier). Several psychotherapies are *probably efficacious* for treating phobias: systematic desensitization[11] ; modeling, based on research by Bandura and colleagues, which capitalizes on an observational learning technique (Bandura, 1971; see also Chapter 2); and several cognitive-behavioral therapy (CBT) approaches

(Ollendick & King, 1998).
CBT, as pioneered by Kendall and colleagues (Kendall et al., 1992; Kendall, 1994), is deemed by the American Psychological Association Task Force as *probably efficacious*. It has four major components: recognizing anxious feelings, clarifying cognitions in anxiety-provoking situations,[12] developing a plan for coping, and evaluating the success of coping strategies. A more recent study in Australia added a parent component to CBT, which enhanced reduction in post-treatment anxiety disorder significantly compared with CBT alone (Barrett et al., 1996). However, none of the interventions identified above as *well-established* or *probably efficacious* has, for the most part, been tested in real-world settings.

In addition, psychodynamic treatment to address underlying fears and worries can be helpful, and behavior therapy may reduce the child's fear of separation or of going to school; however, the experimental support for these approaches is limited.

Preliminary research suggests that selective serotonin reuptake inhibitors may provide effective treatment of separation anxiety disorder and other anxiety disorders of childhood and adolescence. Two large-scale randomized controlled trials are currently being undertaken (Greenhill, 1998a, 1998b). Neither tricyclic antidepressants nor benzodiazepines have been shown to be more effective than placebo in children (Klein et al., 1992; Bernstein et al., 1998).

Obsessive-Compulsive Disorder
Obsessive-compulsive disorder (OCD), which is classified in DSM-IV as an anxiety disorder, is characterized by recurrent, time-consuming obsessive or compulsive behaviors that cause distress and/or impairment. The obsessions may be repetitive intrusive images, thoughts, or impulses. Often the compulsive behaviors, such as hand-washing or cleaning rituals, are an attempt to displace the obsessive thoughts (DSM-IV). Estimates of prevalence range from 0.2 to 0.8 percent in children, and up to 2% of adolescents (Flament et al., 1998).

There is a strong familial component to OCD, and there is evidence from twin studies of both genetic susceptibility and environmental influences. If one twin has OCD, the other twin is more likely to have OCD if the children are identical twins rather than fraternal twin pairs. OCD is increased among first-degree relatives of children with OCD, particularly among fathers (Lenane et al., 1990). It does not appear that the child is simply imitating the relative's behavior, because children who develop OCD tend to have symptoms different from those of relatives with the disease (Leonard et al., 1997). Many adults with either childhood- or adolescent-onset of OCD show evidence of abnormalities in a neural network known as the orbitofrontal-striatal area (Rauch & Savage, 1997; Grachev et al., 1998).

Recent research suggests that some children with OCD develop the condition after experiencing one type of streptococcal infection (Swedo et al., 1995). This condition is referred to by the acronym PANDAS, which stands for Pediatric Autoimmune Neuro-psychiatric Disorders Associated with Streptococcal infections. Its hallmark is a sudden and abrupt exacerbation of OCD symptoms after a strep infection. This form of OCD occurs when the immune system generates antibodies to the streptococcal bacteria, and the antibodies cross-react with the basal ganglia[13] of a susceptible child, provoking OCD (Garvey et al., 1998). In other words, the cause of this form of OCD appears to be antibodies directed against the infection mistakenly attacking a region of the brain and setting off an inflammatory reaction.

The selective serotonin reuptake inhibitors appear effective in ameliorating the symptoms

of OCD in children, although more clinical trials have been done with adults than with children. Several randomized, controlled trials revealed SSRIs to be effective in treating children and adolescents with OCD (Flament et al., 1985; DeVeaugh-Geiss et al., 1992; Riddle et al., 1992, 1998). The appropriate duration of treatment is still being studied. Side effects are not inconsequential: dry mouth, somnolence, dizziness, fatigue, tremors, and constipation occur at fairly high rates. Cognitive- behavioral treatments also have been used to treat OCD (March et al., 1997), but the evidence is not yet conclusive.

Autism

Autism, the most common of the pervasive developmental disorders (with a prevalence of 10 to 12 children per 10,000 [Bryson & Smith, 1998]), is characterized by severely compromised ability to engage in, and by a lack of interest in, social interactions. It has roots in both structural brain abnormalities and genetic predispositions, according to family studies and studies of brain anatomy. The search for genes that predispose to autism is considered an extremely high research priority for the National Institute of Mental Health (NIMH, 1998). Although the reported association between autism and obstetrical hazard may be due to genetic factors (Bailey et al., 1995), there is evidence that several different causes of toxic or infectious damage to the central nervous system during early development also may contribute to autism. Autism has been reported in children with fetal alcohol syndrome (Aronson et al., 1997), in children who were infected with rubella during pregnancy (Chess et al., 1978), and in children whose mothers took a variety of medications that are known to damage the fetus (Williams & Hersh, 1997).

Cognitive deficits in social perception likely result from abnormalities in neural circuitry. Children with autism have been studied with several imaging techniques, but no strongly consistent findings have emerged, although abnormalities in the cerebellum and limbic system (Rapin & Katzman, 1998) and larger brains (Piven, 1997) have been reported. In one small study (Zilbovicius et al., 1995), evidence of delayed maturation of the frontal cortex was found. The evidence for genetic influences include a much greater concordance in identical than in fraternal twins (Cook,

1998).

Treatment

Because autism is a severe, chronic developmental disorder, which results in significant lifelong disability, the goal of treatment is to promote the child's social and language development and minimize behaviors that interfere with the child's functioning and learning. Intensive, sustained special education programs and behavior therapy early in life can increase the ability of the child with autism to acquire language and ability to learn. Special education programs in highly structured environments appear to help the child acquire self-care, social, and job skills. Only in the past decade have studies shown positive outcomes for very young children with autism. Given the severity of the impairment, high intensity of service needs, and costs (both human and financial), there has been an ongoing search for effective treatment.

Thirty years of research demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior. A well-designed study of a psychosocial intervention was carried out by Lovaas and colleagues (Lovaas, 1987; McEachin et al., 1993). Nineteen children with autism were treated intensively with behavior therapy for 2 years and compared with two control groups. Followup of the experimental group in first grade, in late childhood, and in adolescence found that nearly half the experimental group but almost none of the children in the matched control group were able to participate in regular schooling. Up to this point, a number of other research groups have provided at least a partial replication of the Lovaas model (see Rogers, 1998).

Several uncontrolled studies of comprehensive center-based programs have been conducted, focusing on language development and other developmental skills. A comprehensive model, Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH), demonstrated short-term gains for preschoolers with autism who received daily TEACCH home-teaching sessions, compared with a matched control group (Ozonoff & Cathcart, 1998). A review of other comprehensive, center-based programs has been conducted, focusing on elements

considered critical to school-based programs, including minimum hours of service and necessary curricular components (Dawson & Osterling, 1997).

The antipsychotic drug, haloperidol, has been shown to be superior to placebo in the treatment of autism (Perry et al., 1989; Locascio et al., 1991), although a significant number of children develop dyskinesias as a side effect (Campbell et al., 1997). Two of the SSRIs, clomipramine (Gordon et al., 1993) and fluoxetine (McDougle et al., 1996), have been tested, with positive results, except in young autistic children, in whom clomipramine was not found to be therapeutic, and who experienced untoward side effects (Sanchez et al., 1996). Of note, preliminary studies of some of the newer antipsychotic drugs suggest that they may have fewer side effects than conventional antipsychotics such as haloperidol, but controlled studies are needed before firm conclusions can be drawn about any possible advantages in safety and efficacy over traditional agents.

Disruptive Disorders

Disruptive disorders, such as oppositional defiant disorder and conduct disorder, are characterized by antisocial behavior and, as such, seem to be a collection of behaviors rather than a coherent pattern of mental dysfunction. These behaviors are also frequently found in children who suffer from attention-deficit/hyper-activity disorder, another disruptive disorder, which is discussed separately in this chapter. Children who develop the more serious conduct disorders often show signs of these disorders at an earlier age. Although it is common for a very young children to snatch something they want from another child, this kind of behavior may herald a more generally aggressive behavior and be the first sign of an emerging oppositional defiant or conduct disorder if it occurs by the ages of 4 or 5 and later. However, not every oppositional defiant child develops conduct disorder, and the difficult behaviors associated with these conditions often remit.

Oppositional defiant disorder (ODD) is diagnosed when a child displays a persistent or consistent pattern of defiance, disobedience, and hostility toward various authority figures including parents, teachers, and other adults.

ODD is characterized by such problem behaviors as persistent fighting and arguing, being touchy or easily annoyed, and deliberately annoying or being spiteful or vindictive to other people. Children with ODD may repeatedly lose their temper, argue with adults, deliberately refuse to comply with requests or rules of adults, blame others for their own mistakes, and be repeatedly angry and resentful. Stubbornness and testing of limits are common. These behaviors cause significant difficulties with family and friends and at school or work (DSM-IV; Weiner, 1997). Oppositional defiant disorder is sometimes a precursor of conduct disorder (DSM-IV).

In different studies, estimates of the prevalence of ODD have ranged from 1 to 6 percent, depending on the population sample and the way the disorder was evaluated, but not depending on diagnostic criteria. Rates are lower when impairment criteria are more strict and when information is obtained from teachers and parents rather than from the children alone (Shaffer et al., 1996a). Before puberty, the condition is more common in boys, but after puberty the rates in both genders are equal.

In preschool boys, high reactivity, difficulty being soothed, and high motor activity may indicate risk for the disorder. Marital discord, disrupted child care with a succession of different caregivers, and inconsistent, unsupervised child-rearing may contribute to the condition.

Children or adolescents with *conduct disorder* behave aggressively by fighting, bullying, intimidating, physically assaulting, sexually coercing, and/or being cruel to people or animals. Vandalism with deliberate destruction of property, for example, setting fires or smashing windows, is common, as are theft; truancy; and early tobacco, alcohol, and substance use and abuse; and precocious sexual activity. Girls with a conduct disorder are prone to running away from home and may become involved in prostitution. The behavior interferes with performance at school or work, so that individuals with this disorder rarely perform at the level predicted by their IQ or age. Their relationships with peers and adults are often poor. They have higher injury rates and are prone to school expulsion and problems with the law. Sexually transmitted diseases are common. If they have been removed from

home, they may have difficulty staying in an adoptive or foster family or group home, and this may further complicate their development. Rates of depression, suicidal thoughts, suicide attempts, and suicide itself are all higher in children diagnosed with a conduct disorder (Shaffer et al., 1996b).

The prevalence of conduct disorder in 9- to 17-year-olds in the community varies from 1 to 4 percent, depending on how the disorder is defined (Shaffer et al., 1996a). Children with an early onset of the disorder, i.e., onset before age 10, are predominantly male. The disorder appears to be more common in cities than in rural areas (DSM-IV). Those with early onset have a worse prognosis and are at higher risk for adult antisocial personality disorder (DSM-IV; Rutter & Giller, 1984; Hendren & Mullen, 1997). Between a quarter and a half of highly antisocial children become antisocial adults.

The etiology of conduct disorder is not fully known. Studies of twins and adopted children suggest that conduct disorder has both biological (including genetic) and psychosocial components (Hendren & Mullen, 1997). Social risk factors for conduct disorder include early maternal rejection, separation from parents with no adequate alternative caregiver available, early institutionalization, family neglect, abuse or violence, parents' psychiatric illness, parental marital discord, large family size, crowding, and poverty (Loeber & Stouthamer-Loeber, 1986). These factors are thought to lead to a lack of attachment to the parents or to the family unit and eventually to lack of regard for the rules and rewards of society (Sampson & Laub, 1993). Physical risk factors for conduct disorder include neurological damage caused by birth complications or low birthweight, attention-deficit/hyperactivity disorder, fearlessness and stimulation-seeking behavior, learning impairments, autonomic underarousal, and insensitivity to physical pain and punishment. A child with both social deprivation and any of these neurological conditions is most susceptible to conduct disorder (Raine et al., 1998).

et al., 1995). Studies have shown a correlation between the behavior and attributes of 3-year-olds and the aggressive behavior of these children at ages 11 to 13 (Raine et al., 1998). Measurements of aggressive behaviors have been shown to be stable over time (Sampson & Laub, 1993). Training parents of high-risk children how to deal with the children's demands may help. Parents may need to be taught to reinforce appropriate behaviors and not harshly punish transgressing ones, and encouraged to find ways to increase the strength of the emotional ties between parent and child. Working with high-risk children on social interaction and providing academic help to reduce rates of school failure can help prevent some of the negative educational consequences of conduct disorder (Johnson & Breckenridge, 1982).

Treatment

Several psychosocial interventions can effectively reduce antisocial behavior in disruptive disorders. A recent review of psychosocial treatments for children and adolescents identified 82 studies conducted between 1966 and 1995 involving 5,272 youth (Brestan & Eyberg, 1998). The criterion for inclusion was that the child was in treatment for conduct problem behavior, based on displaying a symptom of conduct disorder or oppositional defiant disorder, rather than on a DSM diagnosis of either, although children did meet DSM criteria for one of these conditions in about one-third of the studies.

By applying criteria established by the American Psychological Association Task Force (see earlier) to the 82 studies, two treatments met criteria for *well- established* treatment and 10 for *probably efficacious* treatment. Two *well-established* treatments, both directed at training parents, succeeded in reducing problem behaviors. The two treatments were a parent training program based on the manual *Living With Children* (Bernal et al., 1980) and a videotape modeling parent training (Spaccarelli et al., 1992). The first teaches parents to reward desirable behaviors and ignore or punish deviant behaviors, based on principles of operant conditioning. The second provides a series of videotapes covering parent-training

encouraging because of the potential to intervene effectively with youth at high risk of poor outcomes. A new and promising approach for the treatment of conduct disorder is multisystemic therapy, an intensive home- and family-focused treatment that is described under Home-Based Services.

Despite strong enthusiasm for improving care for conduct-disordered youth, there are important groups of children, specifically girls and ethnic minority populations, who were not sufficiently represented in these studies to ensure that the identified treatments work for them. Other issues raised by Brestan and Eyberg (1998) are cost-effectiveness, the sufficiency of a given intervention, effectiveness over time, and the prevention of relapse.

No drugs have been demonstrated to be consistently effective in treating conduct disorder, although four drugs have been tested. Lithium and methylphenidate have been found (one double-blind placebo trial each) to reduce aggressiveness effectively in children with conduct disorder (Campbell et al., 1995; Klein et al., 1997b), but in two subsequent studies with the same design, the positive findings for lithium could not be reproduced (Rifkin et al., 1989; Klein, 1991). In one of the latter studies, methylphenidate was superior to lithium and placebo. A third drug, carbamazepine, was found in a pilot study to be effective, but multiple side effects were also reported (Kafantaris et al., 1992). The fourth drug, clonidine, was explored in an open trial, in which 15 of 17 patients showed a significant decrease in aggressive behavior, but there were also significant side effects that would require monitoring of cardiovascular and blood pressure parameters (Kemph et al., 1993).

Substance Use Disorders in Adolescents

Since the early 1990s there has been a "sharp resurgence" in the misuse of alcohol and other drugs by adolescents (Johnston et al., 1996). A recent review, focusing particularly on substance abuse and dependence, synthesizes research findings of the past decade (Weinberg et al., 1998). The authors review epidemiology, course, etiology, treatment, and prevention and discuss comorbidity with other mental disorders in adolescents. All of these issues are important

to public health, but none is more relevant to this report than the co-occurrence of alcohol and other substance use disorders with other mental disorders in adolescents.

According to the National Comorbidity Study, 41 to 65 percent of individuals with a lifetime substance abuse disorder also have a lifetime history of at least one mental disorder, and about 51 percent of those with one or more lifetime mental disorders also have a lifetime history of at least one substance use disorder (Kessler et al., 1996). The rates are highest in the 15- to 24-year-old age group (Kessler et al., 1994). The cross-sectional data on association do not permit any conclusion about causality or clinical prediction (Kessler et al., 1996), but an appealing theory suggests that a subgroup of the population abuses drugs in an effort to self-medicate for the co-occurring mental disorder. Little is actually known about the role of mental disorders in increasing the risk of children and adolescents for misuse of alcohol and other drugs. Stress appears to play a role in both the process of addiction and the development of many of the comorbid conditions.

The review by Weinberg and colleagues (1998) provides more detail on epidemiology and assessment of alcohol and other drug use in adolescents and describes several effective treatment approaches for these problems. A meta-analysis and literature review (Stanton & Shadish, 1997) concluded that family-oriented therapies were superior to other treatment approaches and enhanced the effectiveness of other treatments. Multisystemic family therapy, discussed elsewhere in this chapter, is effective in reducing alcohol and other substance use and other severe behavioral problems among adolescents (Pickrel & Henggeler, 1996).

Eating Disorders

Eating disorders are serious, sometimes life-threatening, conditions that tend to be chronic (Herzog et al., 1999). They usually arise in adolescence and disproportionately affect females. About 3 percent of young women have one of the three main eating disorders: anorexia nervosa, bulimia nervosa, or binge-eating disorder (Becker et al., 1999). Binge-eating disorder is a newly recognized condition featuring episodic uncontrolled consumption, without compensatory activities, such as

vomiting or laxative abuse, to avert weight gain (Devlin, 1996). Bulimia, in contrast, is marked by both binge eating and by compensatory activities. Anorexia nervosa is characterized by low body weight (< 85 percent of expected weight), intense fear of weight gain, and an inaccurate perception of body weight or shape (DSM-IV). Its mean age of onset is 17 years (DSM-IV).

The causes of eating disorders are not known with precision but are thought to be a combination of genetic, neurochemical, psychodevelopmental, and sociocultural factors (Becker et al., 1999; Kaye et al., 1999). Comorbid mental disorders are exceedingly common, but interrelationships are poorly understood. Comorbid disorders include affective disorders (especially depression), anxiety disorders, substance abuse, and personality disorders (Herzog et al., 1996). Anorexia nervosa has the most severe consequence, with a mortality rate of 0.56 percent per year (or 5.6 percent per decade) (Sullivan, 1995), a rate higher than that of almost all other mental disorders (Herzog et al., 1996). Mortality is from starvation, suicide, or electrolyte imbalance (DSM-IV). The mortality rate from anorexia nervosa is 12 times higher than that for other young women in the population (Sullivan, 1995).

Treatment of eating disorders entails psychotherapy and pharmacotherapy, either alone or in combination. Treatment of comorbid mental disorders also is important, as is treatment of medical complications. There are some controlled studies of the efficacy of specific treatments for *adults* with bulimia and binge-eating disorder (Devlin, 1996), but fewer for anorexia nervosa (Kaye et al., 1999). Controlled studies in adolescents are rare for any eating disorder (Steiner and Lock, 1998). Pharmacological studies in young *adult* women found conflicting evidence of benefit from antidepressants for anorexia and some reduction in the frequency of binge eating and purging with tricyclic antidepressants

especially because a sizable proportion of those with eating disorders have limited response to treatment (Kaye et al., 1999).

[10] Contingency management attempts to alter behavior by manipulating its consequences through the behavioral principles of shaping, positive reinforcement, and extinction.

[11] A technique that trains people to "unlearn" fears by presentation of fearful stimuli along with nonfearful stimuli.

[12] This refers to understanding how cognitions are being distorted.

[13] Basal ganglia are groups of neurons responsible for motor and impulse control, attention, and regulation of mood and behavior.

Back to Top

Home | Contents | Previous | Next

Financial Cost and Benefits of Intensive Early Intervention for Young Children with Autism - Pennsylvania Model Achieving Cost Savings

BRIEFING

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Executive Summary

Clinical and educational research and public policy reviews that have emerged in the past several years now make it possible to estimate the cost-benefits of intensive early intervention with infants, toddlers and preschoolers with autism or pervasive developmental disorders (PDD). It is now known that the attainment of intellectual, social, and behavioral functioning within the normal range can be achieved for a signficant proportion of children with autism or PDD when they are served in settings, situations, and learning environments that use principles of applied behavior analysis for teaching. Educational costs and other representative costs from Pennsylvania, including costs for public resources other than those from the educational and adult developmental disabilities services sectors, were used in a cost-benefit analysis. This briefing document presents estimates of cost-benefit assuming average participation for three years between the ages of 2 years old to school entry in such services. The analysis indicates cost-aversion or cost-avoidance, the extent to which cost savings are realized by providing early intervention. Positive dollar values indicate savings.

Autism is a disorder of brain development arising before age 3. Autism has a severe impact upon the development and use of social and communication skills, and is also characterized by stereotyped behavior and highly restricted interests or activities. Children with autism tend to leave school as young adults with these conditions still present. They require lifelong care, services, and supervision. Spontaneous recovery and highly successful rehabilitation through regular educational processes are very rare.

During the past decade research began to demonstrate that significant proportions of children with autism or PDD who participated in intensive early intervention based on the principles of applied behavior analysis achieved normal or near-normal functioning. Applied behavior analysis is a natural science approach to solving socially important problems of behavior, such asbuilding appropriate cognitive, communication, and social skills in children with autism and PDD. Although there have been some criticisms of this research on some philosophical grounds, these philosophical grounds have not generated research results that indicate achievement of normal or near-normal functioning for these children.

The availability of these instructional technologies and approaches has changed the picture and outlook for cost-benefit and cost-aversion analysis of early intervention for these children, particularly in terms of averting education-long and life-long costs for special services. The cost - benefit model applied in this briefing assumes a range of effects of early intervention for these children that will result in some attending regular education, some special education, and some intensive special education.

Fifteen assumptions, reflecting research findings, program evaluation experience, and cost analysis considerations, underpin the cost-benefit analysis and are presented in the main body of the briefing. A brief annotated reference list of research findings and related reviews is also appended. Seven schedules and two appendices provide background information and layouts of findings. The analysis specifies an annual cost for these services of about $33,000, but extrapolations to $50,000

are feasible and noted.

In general, rounded terms for the purposes of summary, for children with autism or PDD who participate in competently delivered intensive early behavioral intervention:

- Cost savings from ages 3-22 years at $33,000 initial annual cost range from $185,000 to $205,000 without inflation and from $275,000 to $300,000 with inflation.

- Cost savings from ages 3-45 years at $33,000 initial annual cost range from $560,000 to $875,000 without inflation and from $1,050,000 to $1,650,000 with inflation.

- Differences in initial costs of $33,000 and $50,000 per year for intensive early behavioral intervention have a modest impact (about $51,000 higher expenditures per child for three years) on savings, but are outweighed by the extent of the savings noted above, even with respect to savings for ages 3-22 years without inflation.

- In terms of most likely levels of savings; based on a rate of normal functioning achieved of from 30% to 40% of children with autism or PDD, with inflation the projected savings would be $285,000 to $295,00 to age 22 and $1,200,000 to $1,350,000 to age 45.

- In terms of most likely levels of savings compared to controls in the UCLA study; based on a rate of normal functioning achieved of from 30% to 40% of children with autism or PDD, with inflation the projected savings would be $61,798 to $68,606 to age 22 and $668,678 to $823,920 to age 45.

Contents

	Page
Overview	4
Background	
Contemporary Research	
Controversy and Criticisms	
Prior Cost-Benefit Analysis	
Varying Effects for Different Children	
Need for Cost-Benefit Analysis	
Assumptions in the Present Analysis	7
Findings in the Present Analysis	9
Annotated Bibliography	11
Descriptions of Schedules and Appendices	13
Summary Tables Identifying Costs and Benefits	
Schedule 1: Present (1996) Costs for Services and Income Estimates	15
Schedule 2: Most Probable Level of Recovery or Essential Mainstreaming = 30% - 40%	16
Schedule 3: Costs to Age 22 Years	17
Schedule 4: Costs from Age 22 to Age 45 Years	18
Schedule 5: Financial Cost-Benefit of Early Intervention - Ages 3-45 Years and Summary of Benefit Levels (Relative Cost) Ages 3-45 Years	19
Schedule 6: Service Financial Benefits at Different Levels of Effectiveness, Age 3 to 22 Years, Per 100 Children Served	20
Schedule 7: Service Financial Benefits at Different Levels of Effectiveness, Age 3 to 45 Years, Per 100 Children Served	21
Schedule 8: Service Financial Benefits at Different Levels of Effectiveness, Age 3 to 22 Years, Per 100 Children Served - Pennsylvania Model vs. UCLA Controls	22
Schedule 9: Service Financial Benefits at Different Levels of Effectiveness, Age 3 to 45 Years, Per 100 Children Served - Pennsylvania Model vs. UCLA Controls	23
Appendix A: Financial Information: Per Recipient Expenditure Estimates	24
Appendix B: Values of Primary Estimates: Age 3 to 45 Years	25

Overview

Background

First identified in the 1940s, autism is a disorder of brain development arising before age three, and often identified by that age or shortly thereafter. Autism has a severe impact upon the development and use of social and communication skills, and is also characterized by stereotyped behavior (e.g., rituals or repetitive behaviors) and highly restricted interests or activities. It has generally been found that between 60% to 75% of all children with autism also have some degree of mental retardation. The relationship between autism and mental retardation is not well understood, because some children with autism have intellectual abilities within the normal--and in a small number of cases, the superior--range. However, research clearly indicates that children with both autism and mental retardation tend to leave school as young adults with these conditions still present. They require lifelong care, services, and supervision. Spontaneous recovery and highly successful rehabilitation through regular educational processes are very rare.

Nationally, however, educational services for children with autism are among the most intensively staffed and expensive forms of special education available under provisions of the Individuals with Disabilities Education Act. The picture is similar for children diagnosed with pervasive developmental disorder (PDD), which has many characteristics in common with autism.

Contemporary Research

During the past decade research began to demonstrate that significant proportions of children with autism or PDD who participated in intensive early intervention based on the principles of applied behavior analysis achieved normal or near-normal functioning. Applied behavior analysis[1] is a natural science approach to solving socially important problems of behavior, such a building appropriate cognitive, communication, and social skills in children with autism and PDD. Here, also, we include both early intervention and preschool services, which are sometimes provided under the auspices of different public agencies in the states under the umbrella term of early intervention. Follow-up research by one group of investigators found that the benefits of early intensive behavioral intervention persisted into adolescence and young adulthood. The most comprehensive research was published by Ivar Lovaas and colleagues at UCLA, but studies by other independent investigators confirmed that it is possible for many children with autism or PDD to achieve normal functioning through early intensive intervention of this type. Of great importance is the fact that many children in the study samples whose skills did not reach normal levels nonetheless made significant, functional gains in core areas, such as everyday living and communication skills. A small proportion (about 10%,

[1]Applied behavior analysis entails the specific and comprehensive use of principles of human learning, i.e., operant psychology or learning theory, in order to enhance the development, abilities, and self-direction skills of children and adults with disabilities. In the treatment of autism, various applied behavior analytic approaches may be referred to colloquially as discrete trial training, direct instruction, Lovaas therapy, or behavior modification.

across several studies) appeared to continue to need intensive intervention beyond the early childhood years. Research is ongoing to better identify the specific instructional and programmatic practices that enhance outcomes in these children.

Controversy and Criticisms

The research findings just summarized have been controversial, in that they date only from the mid-to-late 1980s and these findings have been the specific focus of research on autism and PDD conducted in only a few locations. For researchers, replication of the original findings has been a major concern and is the focus of ongoing efforts, as noted above. Moreover, these findings have emerged at a time when leaders of some philosophical movements in special education have begun to advocate for apparently incompatible educational practices of unproven efficacy, under the rubrics of total inclusion and "developmental appropriateness." Criticisms of early intensive behavioral intervention by some of these advocates have focused on alleged side effects, such as adverse social consequences. These criticisms are not grounded in sound research or established facts. They are erroneous interpretations of behavioral intervention, reflect incomplete or distorted understanding of behavioral procedures, or are otherwise suppositional and groundless. Among many leading clinicians and researchers concerned with effective intervention for autism and PDD, the question is not whether children with autism or PDD can achieve substantially improved functioning, but what practices lead to the best outcomes for these children.

Prior Cost-Benefit Analysis

Although critics of early behavioral intervention for autism and PDD stress philosophical concerns, from a public policy standpoint, the scientifically validated achievement of normal functioning by many children with autism or PDD has profound implications for analyses of the relative costs and benefits of early intervention for these children. Until recently, benefits could be estimated solely in terms of savings that might be associated with decreased, but still persisting, dependency in later childhood and into adulthood. Considering the high cost of specialized educational services for children with autism or PDD compared to regular education or other forms of special education, potential benefits were confined to relative savings at different levels of care during adulthood. Savings reflected comparison of total educational and adult services costs with and without specialized education. Because no basis existed for projecting these cost differentials, the cost-benefit of early intervention services remained unidentified.

Varying Effects for Different Children

With the emergence of research documenting substantial improvements for large proportions of children with autism or PDD following early intensive behavioral intervention, and confirmatory studies showing that the effects can be long-term, it has become possible to project costs and utilization more specifically. Such projections are aided by the compilation of costs for adult services in the developmental disabilities service sector by contemporary researchers, data that were not previously available. Thus, costs and benefits may be projected with reasonable confidence in terms

of:

(1) children who achieve normal functioning, participate in regular education with little or no support, and are vocationally productive as adults;

(2) children who derive sufficient benefit from early intensive intervention that they are then able to participate in nonintensive special education, and evidence persisting but reduced dependency in adulthood; and

(3) children who achieve meaningful functional improvements but still require specialized and intensive educational and adult services.

In the present analyses, costs from the Commonwealth of Pennsylvania are used to develop overall cost comparisons in the calculation of cost-benefit.

Need for Cost-Benefit Analysis

As expenditures for social welfare, public health, and specialized human services have increased dramatically over the past two decades, there has been an increasing impetus for understanding the costs and consequences (i.e., benefits) of the investment of public resources and funding in specific progams and services. Welfare reform, Medicaid reform through such initiatives as managed care and home and community-based services waivers, and scrutiny of the rising costs of Part H early intervention services, preschool services, and related expenditures are all manifestations of the need to contain costs and direct resources in the most efficient and effective ways possible. In the area of intensive early intervention as a whole, including services for young children with autism or PDD, there has been mounting concern regarding cost-benefit. This concern has arisen because of the wide variations in costs for seemingly similar services available through local contractors. There are additional concerns are that possible economies may be lost when substitute financing mechanisms (for example, Medicaid fee-for-service) are used in lieu of system-wide cost-related rates within the educational or other specialized public service sector.

This briefing presents a cost-benefit analysis of early intensive behavioral intervention for autism or PDD based on the three groups of children that were previously identified: Those whose skills improve to within the normal range, those who make large gains but continue to require some special services, and those who will probably require long-term intensive help.

The analysis compares the costs and benefits of services for children with autism or PDD who receive intensive early intervention relative to those of children without disabilities in general, to children who continue to require special education, and those of other children with autism who do not receive effective intervention or who otherwise continue to require intensive supports. The analysis provides a projection of cost-aversion, that is, the costs avoided through provision of intensive early behavioral intevention services. These costs are stated as positive dollar amounts. A number of assumptions required to structure the analysis are detailed below.

Assumptions in the Present Analysis

1. Current research does not identify characteristics of children with autism or PDD that predict their response to early intensive intervention (e.g., initial I.Q. is not a good predictor) during the years before school entry, funded as either early intervention or preschool services. Thus, benefit must be gauged upon outcomes as identified in the literature.

2. The proportion of children who achieve normal functioning in all areas is probably somewhat lower than the proportion reported so far in the behavioral research literature (i.e., just under 50%) because (1) in very young children, when severe or profound mental retardation is present, a conclusive diagnosis of autism or PDD may not be made, and (2) other local or nonspecific factors probably affect whether children are diagnosed or, especially, referred for early intensive behavioral intervention.

3. In any group of children with autism or PDD who receive competently delivered early intensive behavioral intervention, between 20% and 60% will achieve normal functioning. Ten percent (10%) will continue to require intensive special education and intensive adult services, and the remainder will evidence benefit sufficient to reduce the intensity of educational and adult services requirements.

4. For these reasons, cost-benefit should be couched in terms of marginal benefit, in terms of impact of improvement as well as the attainment of normal functioning. Analyses should encompass comparison of costs for children with autism or PDD who achieve normal functioning with costs for serving children without disabilities, and with costs for serving children with autism or PDD who make large gains but do not move into the normal range. The latter group should also be compared with children who make minimal gains.

5. Without early intensive behavioral intervention the majority of children with autism or PDD will manifest enduring dependency on adult developmental disabilities services. This is consistent with the literature on child, adolescent, and young adult development for people with autism or PDD.

6. The costs of intensive behavior analytic center-based services for children with autism or PDD (including those with a home-based, parent-directed component) may not be comparable or equivalent, on average, with the costs of intensive home-based services, when instruction is comparably intensive, but relative costs and utilization mix are not well-established. The mix of costs for intensive early intervention services is represented here as an average which is assumed to be a represenative average for use of both center-based and home-based services.

7. Children with autism or PDD who ultimately develop normal skills are assumed to participate in regular education; those who make large gains but not sufficient for them to participate successfully in regular education are assumed to participate in special education; and children who make minimal gains Are assumed to participate in intensive special education or the equivalent from a cost perspective. Special education alternatives (e.g., intensive special education) are assumed to be

equivalent in cost regardless of whether they are delivered in segregated, partially integrated, related service, and fully inclusive models, based on requisite instructional load requirements for comparable instructional and educational effects. In short, comparable instruction is assumed to cost the same regardless of whether an inclusive approach is used or not.

8. Because no generalizable mortality data exist for people with autism or PDD (owing partially to the advent of the diagnosis in the 1940s and lack of data on several populations), cost-benefit analyses including the adult years are made only to age 45. There is no compelling evidence of marked mortality prior to age 45 years for children surviving to adulthood, and the lifespan of people with autism or PDD may well be similar to that of the general population. Therefore, this cutoff point will tend to underestimate adult income from supported or regular employment, utilization of general public entitlements or benefits during adulthood, utilization costs for adult developmental disabilities services, and costs for utilization of aging services and public retirement or income transfer programs for elders.

9. Present costs are used as indicators of future costs, with recognition that reforms in welfare and public health may either result in decreased per person rates or expenditures, or in substitution of services in the future. To compensate, costs have been trended forward at 3% per annum, except for SSI/ADC(AFDC) or the equivalent such as TANF, which is trended at 1.5%. These trend factors probably represent an underestimate of inflationary factors. The average cost inflator for health related services from 1986 to 1996 was about 4.5%.

10. SSI/ADC costs are used as a summary cost for all utilization of general public benefits outside of the early intervention, educational, and developmental services sectors (e.g., public housing subsidies, food stamps, child care, temporary assistance, all forms of public assistance, higher education grants, vocational assistance, public transportation, Medicaid card services). Although these are not entered as costs for nondisabled children to age 22 years, they are entered as costs for all children with autism or PDD who achieve normal functioning (three years' cost), and partial or minimal effects (18 years' cost). SSI/ADC is also entered as a cost for 23 years to age 45 years for 25% of nondisabled children and children with autism or PDD who achieve normal functioning, and for 100% for children with autism or PDD who make substantial improvements or who benefit minimally. A lower estimate of 15% would not significantly alter relative costs, engendering only a 4% flex in total income or expense for nondisabled children and children with autism or PDD who achieve normal functioning. However, in light of present welfare reform initiatives, reduction to a 15% estimate might well be warranted in further analysis.

11. The average duration of early intensive behavioral intervention is assumed to be three years, a period that is associated in the literature with apparent better benefits from participation in these services. The existing literature suggests that two years of intervention can result in normal functioning, but in this analysis it is recognized that children may participate in from two to four years of early intervention (between the ages of two years old and school entry) and three years is stipulated to be a representative average duration.

12. Children with autism or PDD who achieve normal functioning are assumed to use family support services during participation in intensive early intervention. Children who make substantial gains and those for whom minimal effects are attained are assumed to use 18 years of family support services, to age 22 years.

During adulthood, those who achieve substantial improvements but not normal functioning are assumed to use 18 years of Medicaid waiver (or equivalent) services and 15 years of supported work services. During adulthood, for adults for whom minimal effects are obtained, 80% are assumed to use waiver services for 20 years, 20% are assumed to use intensive community services for 23 years, and 40% are assumed to use supported work services for 15 years. These utilization patterns are a function of variations in individual service needs and delays between requests for services and service enrollment associated with waiting lists. With the possible exception of adults with whom intervention is minimally effective, the cost mixes used are lower than those that are presently typical for intensive comprehensive community services for adults with autism or PDD (e.g., ICF/MR and ambulatory clinic variants or equivalent levels of care).

13. Supported employment wages are projected as comparable for individuals with autism or PDD who achieve substantial or minimal gains, at 20% of the median household annual income. It should be noted that although this probably overestimates income (and thus offset of service costs) for people with minimal benefits, it nonetheless reflects a single-person income level that remains below current poverty level indicators, and a full-time employment (40-hour week) hourly rate of $3.24 hourly in 1996.

14. This analysis uses costs reported in several sources for the Commonwealth of Pennsylvania. Annual Regular education costs are $7,543 per year in 1996, special education is $12,935, and intensive special education is $28,806 (from Schedule 1). The initial annual cost of early intensive behavioral intervention is set at $32,820. To calculate the cost-benefit of this intervention set at a higher level of $50,000, readers may simply subtract $53,100 from inflated benefit totals and subtract $51,540 from uninflated benefit totals.

15. Finally, in composite, the service costs and inflators used will tend to underestimate cost slightly relative to current expenditure patterns, whereas the earnings projected will tend to overestimate income slightly; providing, overall, a relatively conservative estimate of cost-benefit. All saving shown, however, are net of the expense of providing intensive behavioral early intervention.

Findings in the Present Analysis

At $32,820 initial annual cost, the total cost-benefit savings of intensive applied behavior analysis services per child with autism or PDD for ages 3-22 years averages from $187,399 to $205,305 without inflation and from $273,764 to $300,997 with inflation.

The majority of savings to schools accrue from children who achieve partial benefit rather than normal range functioning, and savings decrease slightly (by about 9%) on average with increased

rates of children achieving normal range functioning. [Note: See Schedule 6]

At $50,000 initial annual cost, the corresponding cost-benefit savings of intensive applied behavior analysis services per child with autism or PDD ages 3-22 years averages from $135,859 to $153,765 without inflation and from $220,664 to $248,897 with inflation.

At $32,820 initial annual cost, the total cost-benefit savings of intensive applied behavior analysis services per child with autism or PDD for ages 3-45 years averages from $561,933 to $874,446 without inflation and from $1,040,806 to $1,661,774 with inflation.

The majority of savings to the developmental disabilities sector accrue from children who achieve normal range of functioning rather than partial benefit, and savings increase substantially (by about 62%) on average with increased rates of children achieving normal range functioning. [Note: See Schedule 7]

At $50,000 initial annual cost, the corresponding cost-benefit savings of intensive applied behavior analysis services per child with autism or PDD ages 3-45 years averages from $510,906 to $822,906 without inflation and from $987,706 to $1,608,674 with inflation.

Assuming a probable rate of normal functioning achieved of from 30% to 40% of children with autism or PDD who receive early intensive behavioral intervention compared to completely ineffective intervention, cost-benefit savings per child served would be from $287,381 to $294,189 with inflation to age 22 and from $1,196,048 to $1,351,290 with inflation to age 45. [Note: See Schedule 2]

Assuming a probable rate of normal functioning achieved of from 30% to 40% of children with autism or PDD who receive early intensive behavioral intervention compared to benefits shown by the UCLA control group in research studies, cost-benefit savings per child served would be from $61,768 to $68,606 with inflation to age 22 and from $668,678 to $823,920 with inflation to age 45. [Note: See Schedules 8 and 9]

Annotated Bibliography

These sources report outcomes or follow-up outcomes from early intensive behavioral intervention for autism or PDD using the principles of applied behavior analysis:

Anderson, S. R., Avery, D. L., DiPietro, E. K., Edwards, G. L., & Christian, W. P. (1987). Intensive home-based early intervention with autistic children. *Education and Treatment of Children, 10,* 352-366.

Birnbrauer, J. S., & Leach, D. J. (1993). The Murdoch Early Intervention Program after 2 years. *Behaviour Change, 10*(2), 63-74.

Lovaas, O. I. (1987). Behavioral treatment and normal intellectual and educational functioning in autistic children. *Journal of Consulting and Clinical Psychology, 55*, 3-9.

McEachin, J. J., Smith, T., & Lovaas, O. I. (1993). Long term outcome for children with autism who received early intensive behavioral treatment. *American Journal on Mental Retardation, 97*, 359-372.

Perry, R., Cohen, I, & DeCarlo, R. (1995). Case study: Deterioration, autism, and recovery in two siblings. *Journal of the American Academy of Child and Adolescent Psychiatry, 34*, 232-237.

Sheinkopf, S. J., & Siegel, B. (in press). Home based behavioral treatment of young autistic children. *Journal of Autism and Developmental Disorders*. (Available upon request to the authors).

This source exemplifies a cost-benefit analysis of early intervention for at-risk children and briefly addresses early intervention for children with identified disabilities:

Barnett, W. S., & Escobar, C. M. (1990). Economic costs and benefits of early intervention. In S. J. Meisels & J. P. Shonkoff (Eds.), *Handbook of early childhood intervention* (pp. 560-582). New York, NY: Cambridge University Press.

This source identifies the primary characteristics of effective intensive early intervention services for children with autism or PDD based upon the existing clinical research literature:

Green, G.(1996). Early behavioral intervention for autism. What does research tell us? In C. Maurice, G. Green, & S. Luce (Eds.), *Behavioral intervention for young children with autism: A manual for parents and professionals* (pp. 29-44). Austin, TX: Pro-Ed.

This source identifies the basis for claims of effective interventionS for autism or PDD other than

those using the principles of applied behavior analysis:

Smith, T. (1996). Are other treatments effective? In C. Maurice, G. Green,& S. C. Luce. (Eds.). *Behavioral intervention for young children with autism: A manual for parents and professionals* (pp. 45-62). Austin, TX: Pro-Ed.

These sources identify the functional and practical skills of adults with autism and their service utilization patterns:

Jacobson, J. W., & Ackerman, L. J. (1990). Differences in adaptive development among persons with autism and mental retardation. *Journal of Autism and Developmental Disorders, 20*, 205-219.

Janicki, M. P., & Jacobson, J. W. (1983). Selected clinical features and service characteristics of autistic adults. *Psychological Reports, 52*,387-390.

This source addresses the issues presented by requirements for appropriate educational practices to address the needs of children with severe or complex disabilities in the context of the movement to full inclusion in educational settings:

Kauffman, J. M., & Hallahan, D. P. (1995). *The illusion of full inclusion: A comprehensive critique of a current special education bandwagon.* Austin, TX: Pro-Ed.

These sources identify research findings from 25 years of research regarding the premise that the use of reinforcement procedures undermines intrinsic motivation to learn and enhance performance, a criticism levied against early intensive behavioral intervention:

Cameron, J., & Pierce, W. D. (1994). Reinforcement, reward and intrinsic motivation. *Review of Educational Research, 64*, 363-423.

Eisenberger, R.,.& Cameron, J. (1996). Detrimental effects of reward: Reality or myth? *American Psychologist, 51*, 1153-1166.

Summary Tables Identifying Costs and Benefits

Schedule 1: Present (1996) Costs for Services and Income Estimates [This schedule presents a listing of the *1996 costs* used in the analysis.]

Schedule 2: Most Probable Level of Normal Range Achieved or Essential Mainstreaming = 30% - 40% [This schedule presents findings of financial benefits at 30% and 40% rates of normal range achieved, separately for ages 3-22 (top of table), and ages 3-45 years (bottom of table). Values are shown, with inflation and in 1996 dollars, per 100 children and per child.]

Schedule 3: Costs to Age 22 Years [This schedule presents findings regarding costs to age 22 years. These include costs for regular education, family support services, SSI/ADC, intensive early intervention, and regular, special, and intensive special education. Costs are attributed according to whether a child is nondisabled, or achieves functioning in the normal range, partial benefit, or minimal benefit from early intensive intervention. Costs are shown separately with inflation and in 1996 dollars.]

Schedule 4: Costs to Age 45 Years [This schedule presents findings regarding costs from age 22 to 45 years. These include costs for family support services, SSI/ADC, Home and Community Based Services (waiver services), or intensive community services, and income from regular or supported work. Costs are attributed according to whether a person is nondisabled, or achieves normal range functioning, partial benefit, or minimal benefit from early intensive intervention. Costs (expenses) and income are shown separately with inflation and in 1996 dollars.]

Schedule 5: Financial Cost-Benefit of Early Intervention - Ages 3-45 Years and Summary of Benefit Levels (Relative Cost) Ages 3-45 Years [This schedule combines net costs for ages 3-22 and 22-45 years from Schedules 3 and 4. These costs are shown separately with inflation and in 1996 dollars. Simple comparisons of costs among groups with differing levels of benefit are presented at the bottom of the schedule.]

Schedule 6: Service Financial Benefits at Different Levels of Effectiveness, Age 3 to 22 Years, Per 100 Children Served [This schedule presents a comparison of financial benefits at different levels or rates of normal range achievement for children ages 3-22 years, achieved by intensive early intervention, ranging from 20% of children achieving normal range functioning (an assumed minimal rate) to 60% of children achieving normal range functioning (a rate somewhat higher than that justified by the current literature). At each level of effectiveness, differing rates of not only normal range achievement, but also partial benefit, are projected. Costs are shown in terms of the aggregate of 100 children served, and averages per person served, with inflation and in 1996 dollars.]

Schedule 7: Service Financial Benefits at Different Levels of Effectiveness, Age 3 to 45 Years, Per 100 Children Served [This schedule presents a comparison of financial benefits at different levels or rates of normal range achievement for people ages 3-45 years, attained through intensive

early intervention, ranging from 20% of children achieving normal range functioning (an assumed minimal rate) to 60% of children achieving normal range functioning (a rate somewhat higher than that justified by the current literature). At each level of effectiveness, differing rates of not only normal range achievement, but also partial benefit, are projected. Costs are shown in terms of the aggregate of 100 children served, and averages per person served, with inflation and in 1996 dollars.]

Schedule 8: Service Financial Benefits at Different Levels of Effectiveness, Age 3 to 22 Years, Per 100 Children Served - Pennsylvania Model vs. UCLA Controls [This schedule presents a comparison of financial benefits at different levels or rates of achievement of normal functioning for people ages 3-22 years, achieved by intensive early intervention, versus benefits from regular early intervention. Costs are shown in terms of the aggregate of 100 children served, and averages per person served, with inflation and in 1996 dollars. Bold numbers denote per child inflated and uninflated savings. The summary table at the bottom of the page depicts cost savings adjusted for differences in three-year costs of early intervention and intensive early intervention.]

Schedule 9: Service Financial Benefits at Different Levels of Effectiveness, Age 3 to 45 Years, Per 100 Children Served - Pennsylvania Model vs. UCLA Controls [This schedule presents a comparison of financial benefits at different levels or rates of achievement of normal functioning for people ages 3-45 years, achieved by intensive early intervention, versus benefits from regular early intervention. Costs are shown in terms of the aggregate of 100 children served, and averages per person served, with inflation and in 1996 dollars. Bold numbers denote per child inflated and uninflated savings. The summary table at the bottom of the page depicts cost savings adjusted for differences in three-year costs of early intervention and intensive early intervention.]

Appendix A: Financial Information: Per Recipient Expenditure Estimates [This appendix presents information regarding the sources used in order to develop the estimates used in the cost analysis.]

Appendix B: Values of Primary Estimates: Age 3 to 45 Years [This appendix presents the trend table for the estimates used in the cost analysis for the period 1992 to 2038.The year 1992 was used as a base year in this table because some available data were current to that year. However, costs reported in the schedules were trended from 1996 values.]

Schedule 1:
Present (1996) Costs for Services and Income Estimates--Pennsylvania Model

This schedule presents a listing of the *1996 costs* used in the analysis.

Present Age of the Child with Autism	3 years
Beginning Calendar Year	1996
Early Intervention Annual Cost	3,284
Family Support Services Annual Cost	1,110
Intensive Early Intervention Annual Cost	32,820
Regular Education Annual Cost	7,543
Special Education Annual Cost	12,935
Intensive Special Education Annual Cost	28,806
Home and Community Based Services (Adult) Annual Cost	31,818
Intensive Community Services (Adult) Annual Cost	46,838
Institutional Services (or equivalent, Adult) Annual Cost	56,775
Supplemental Security Income/Aid to Dependent Children Annual Cost (estimate for all generic public support costs)	5,379
Median Household Annual Income	33,714
Supported Wages Annual Value (a % of median income)	6,743

Schedule 2:
Most Probable Level of Normal Range Achieved or Essential Mainstreaming = 30% - 40%; Pennsylvania Model

This schedule presents findings of financial benefits at 30% and 40% rates at which normal functioning is achieved, separately for ages 3-22 (top of table), and ages 3-45 years (bottom of table). Values are shown, with inflation and in 1996 dollars, per 100 children and per child.

Financial Benefits, Age 3-22 Years: Per 100 Children and Per Child

	Inflated Total	1996$ Total	Inflated /Student	1996$ /Student
At 30%Normal Range				
30Norm Range vs. Partial Effect	8,444,670	5,798,970	281,489	193,299
60 Partial vs. Minimal Effect	20,974,200	14,283,900	349,570	238,065
10 Minimal Effect	0	0	0	0
Net	29,418,870	20,082,870	**294,189**	**200,829**
At 40% Normal Range				
40 Norm Range vs. Partial Effect	11,259,560	7,731,960	281,489	193,299
50 Partial vs. Minimal Effect	17,478,500	11,903,250	349,570	238,065
10 Minimal Effect	0	0	0	0
Net	28,738,060	19,635,210	**287,381**	**196,352**

Note: Compare savings with cost of 13 years of public education at $128,731 inflated and $98,061 in 1996 dollars.

Financial Benefits, Ages 3-45 Years: Per 100 Children and Per Child

	Inflated Total	1996$ Total	Inflated /Student	1996$ /Student
At 30% Normal Range				
30 Norm Range vs. Partial Effect	70,916,700	36,961,050	2,363,890	1,232,035
60 Partial vs. Minimal Effect	46,668,080	27,045,060	811,468	450,751
10 Minimal Effect	0	0		
Net	119,604,780	64,006,110	**1,196,048**	**640,061**
At 40% Normal Range				
40 Norm Range vs. Partial Effect	94,555,600	49,281,400	2,363,890	1,232,035
50 Partial vs. Minimal Effect	40,573,400	22,537,550	811,468	450,751
10 Minimal Effect	0	0		
Net	135,129,000	71,818,950	**1,351,290**	**718,190**

Note: Bold numbers denote per child inflated and uninflated savings.

Schedule 3:
Costs to Age 22 Years - Pennsylvania Model

This schedule presents findings regarding costs to age 22 years. These include costs for regular education, family support services, SSI/ADC, intensive early intervention, and regular, special, and intensive special education. Costs are attributed according to whether a child is *nondisabled, or achieves functioning in the normal range, partial benefit, or minimal benefit* from early intensive intervention. Costs are shown separately with inflation and in 1996 dollars.

Note: Table Shows (Expense) Only	Costs with Inflation	Costs in 1996$
NonDisabled Child		
Thirteen Years of Regular Education	128,731	98,061
Net	(128,731)	(98,061)
Autism- with Normal Range Effects of Early Intervention		
Three Years of Family Support Services	3,433	3,330
Three Years of SSI/ADC	16,380	16,137
Three Years of Intensive Early Intervention	101,445	98,460
Thirteen Years of Regular Education	128,731	98,061
Net	(249,989)	(215,988)
Autism- with Partial Effects of Early Intervention		
Eighteen Years of Family Support Services	27,873	19,980
Eighteen Years of SSI/ADC	117,244	96,822
Three Years of Intensive Early Intervention	101,445	98,460
Fifteen Years of Special Education	284,916	194,025
Net	(531,478)	(409,287)
Autism- with Minimal Effects of Early Intervention		
Eighteen Years of Family Support Services	27,873	19,980
Eighteen Years of SSI/ADC	117,244	96,822
Three Years of Intensive Early Intervention	101,445	98,460
Fifteen Years of Intensive Special Education	634,486	432,090
Net	(881,048)	(647,352)

Schedule 4:
Costs from Age 22 to Age 45 Years -Pennsylvania Model

This schedule presents findings regarding costs from age 22 to 45 years. These include costs for family support services, SSI/ADC, Home and Community Based Services (waiver services), or intensive community services, and income from regular or supported work. Costs are attributed according to whether a person is *nondisabled, or ahieves normal functioning, partial benefit, or minimal benefit* from early intensive intervention. Costs (expenses) and income are shown separately with inflation and in 1996 dollars.

Note: Table Shows Income (Expense)	Costs with Inflation	Costs in 1996$
NonDisabled Child		
Twenty-Three Years of SSI/ADC and All Other Public Benefits (25%)	(49,796)	(32,119)
Twenty-Three Years of Wages and Other Income (75%)	564,369	465,250
Net	514,573	433,131
Autism- with Normal Range Effects of Early Intervention		
Twenty-Three Years of SSI/ADC and All Other Public Benefits (25%)	(49,796)	(32,119)
Twenty-Three Years of Wages and Other Income (75%)	564,369	465,250
Net	514,573	433,131
Autism- with Partial Effects of Early Intervention		
Five Years of Family Support Services	(10,331)	(5,550)
Twenty-Three Years of SSI/ADC	(199,184)	(128,476)
Eighteen Years of Waiver Services	(1,559,872)	(572,724)
Fifteen Years of Supported Work	170,662	101,145
Net	(1,598,725)	(605,605)
Autism- with Minimal Effects of Early Intervention		
Five Years of Family Support Services	(10,331)	(5,550)
Twenty-Three Years of SSI/ADC	(199,184)	(128,476)
Twenty Years of Waiver Services (80%)	(1,349,878)	(509,088)
Twenty-Three Years of Intensive Community Services (20%)	(569,495)	(215,455)
Fifteen Years of Supported Work (40%)	68,265	40,458
Net	(2,060,623)	(818,111)

Schedule 5:
Financial Cost-Benefit of Early Intervention - Pennsylvania Model - Ages 3-45 Years

This schedule combines net costs for ages 3-22 and 22-45 years *from Schedules 3 and 4*. These costs are shown separately with inflation and in 1996 dollars. *Simple comparisons* of costs among groups with differing levels of benefit are presented at the bottom of the schedule.

Note: Table Shows Income (Expense)	With Inflation	Costs in 1996$
NonDisabled Child		
Childhood Costs	(128,731)	(98,061)
Adult Cost or Benefit	514,573	433,131
Net	**385,842**	**335,070**
Autism- with Normal Range Effects of Early Intervention		
Childhood Costs	(249,989)	(215,988)
Adult Cost or Benefit	514,573	433,131
Net	**265,584**	**217,193**
Autism- with Partial Effects of Early Intervention		
Childhood Costs	(531,478)	(409,287)
Adult Cost or Benefit	(1,598,725)	(605,605)
Net	**(2,130,203)**	**(1,014,892)**
Autism- with Minimal Effects of Early Intervention		
Childhood Costs	(881,048)	(647,352)
Adult Cost or Benefit	(2,060,623)	(818,111)
Net	**(2,941,671)**	**(1,465,643)**

Note: Bold numbers denote total income or (expense).

Schedule 6:
Service Financial Benefits at Different Levels of Effectiveness, Age 3 to 22 Years, Per 100 Children Served - Pennsylvania Model

This schedule presents a comparison of financial benefits at different levels or rates of achievement of normal functioning for *children ages 3-22* years, achieved by intensive early intervention, ranging from 20% of children achieving normal functioning (an assumed minimal rate) to 60% of children achieving normal functioning (a rate somewhat higher than that justified by the current literature). At each level of effectiveness, differing rates of not only achievement of normal range functioning, but also partial benefit, are projected. Costs are shown in terms of *the aggregate of 100 children served, and averages per person served,* with inflation and in 1996 dollars. Bold numbers denote per child inflated and uninflated savings.

At 20% Normal Range	Inflated Total	1996$ Total	Inflated /Student	1996$ /Student
20 Norm Range vs. Partial Effect	5,629,780	3,865,980	281,489	193,299
70 Partial vs. Minimal Effect	24,469,900	16,664,550	349,570	238,065
10 Minimal Effect	0	0		
Net	30,099,680	20,530,530	**300,997**	**205,305**
At 30%Normal Range				
30Norm Range vs. Partial Effect	8,444,670	5,798,970	281,489	193,299
60 Partial vs. Minimal Effect	20,974,200	14,283,900	349,570	238,065
10 Minimal Effect	0	0		
Net	29,418,870	20,082,870	**294,189**	**200,829**
At 40% Normal Range				
40 Norm Range vs. Partial Effect	11,259,560	7,731,960	281,489	193,299
50 Partial vs. Minimal Effect	17,478,500	11,903,250	349,570	238,065
10 Minimal Effect	0	0		
Net	28,738,060	19,635,210	**287,381**	**196,352**
At 50% Normal Range				
50 Norm Range vs. Partial Effect	14,074,450	9,664,950	281,489	193,299
40 Partial vs. Minimal Effect	13,982,800	9,544,200	349,570	238,065
10 Minimal Effect	0	0		
Net	28,057,250	19,209,150	**280,572**	**192,092**
At 60% Normal Range				
60 Norm Range vs. Partial Effect	16,889,340	11,597,940	281,489	193,299
30 Partial vs. Minimal Effect	10,481,100	7,141,950	349,570	238,065
10 Minimal Effect	0	0		
Net	27,376,440	18,739,890	**273,764**	**187,399**

Schedule 7:
Service Financial Benefits at Different Levels of Effectiveness, Age 3 to 45 Years, Per 100 Children Served - Pennsylvania Model

This schedule presents a comparison of financial benefits at different levels or rates of achievement of normal functioning for *people ages 3-45 years*, achieved by intensive early intervention, ranging from 20% of children achieving normal range functioning (an assumed minimal rate) to 60% of children achieving normal range functioning (a rate somewhat higher than that justified by the current literature). At each level of effectiveness, differing rates of not only normal range functioning, but also partial benefit, are projected. Costs are shown in terms of *the aggregate of 100 children served, and averages per person served,* with inflation and in 1996 dollars. Bold numbers denote per child inflated and uninflated savings.

	Inflated Total	1996$ Total	Inflated /Student	1996$ /Student
At 20% Normal Range				
20 Norm Range vs. Partial Effect	47,277,800	24,640,700	2,363,890	1,232,035
70 Partial vs. Minimal Effect	56,802,760	31,552,570	811,468	450,751
10 Minimal Effect	0	0		
Net	104,080,560	56,193,270	**1,040,806**	**561,933**
At 30% Normal Range				
30 Norm Range vs. Partial Effect	70,916,700	36,961,050	2,363,890	1,232,035
60 Partial vs. Minimal Effect	46,668,080	27,045,060	811,468	450,751
10 Minimal Effect	0	0		
Net	119,604,780	64,006,110	**1,196,048**	**640,061**
At 40% Normal Range				
40 Norm Range vs. Partial Effect	94,555,600	49,281,400	2,363,890	1,232,035
50 Partial vs. Minimal Effect	40,573,400	22,537,550	811,468	450,751
10 Minimal Effect	0	0		
Net	135,129,000	71,818,950	**1,351,290**	**718,190**
At 50% Normal Range				
50 Norm Range vs. Partial Effect	118,194,500	61,601,750	2,363,890	1,232,035
40 Partial vs. Minimal Effect	32,458,720	18,030,040	811,468	450,751
10 Minimal Effect	0	0		
Net	150,653,220	79,631,790	**1,506,532**	**796,318**
At 60% Normal Range				
60 Norm Range vs. Partial Effect	141,833,400	73,922,100	2,363,890	1,232,035
30 Partial vs. Minimal Effect	24,344,040	12,522,530	811,468	450,751
10 Minimal Effect	0	0		
Net	166,177,440	87,444,630	**1,661,774**	**874,446**

Schedule 8:
Service Financial Benefits at Different Levels of Effectiveness, Age 3 to 22 Years, Per 100 Children Served - Pennsylvania Model vs. UCLA Controls

This schedule presents a comparison of financial benefits at different levels or rates of achievement of normal functioning for people ages 3-22 years, achieved by intensive early intervention, versus benefits from regular early intervention. Costs are shown in terms of the aggregate of 100 children served, and averages per person served, with inflation and in 1996 dollars. Bold numbers denote per child inflated and uninflated savings. The summary table at the bottom of the page depicts cost savings adjusted for differences in three-year costs of early intervention and intensive early intervention.

At 30% Normal Range	Inflated Total	1996$ Total	Inflated /Student	1996$ /Student
30 Norm Range vs. Partial Effect	8,444,670	5,798,970	281,489	193,299
60 Partial vs. Minimum Effect	20,974,200	14,283,900	349,570	238,065
10 Minimal Effect	0	0		
Net	30,099,680	20,530,530	**294,189**	**200,829**
At 40% Normal Range				
40 Norm Range vs. Partial Effect	11,259,560	7,731,960	281,489	193,299
50 Partial vs. Minimum Effect	17,478,500	11,903,250	349,570	238,065
10 Minimal Effect	0	0		
Net	28,738,060	19,635,210	**287,381**	**196,352**
At 50% Normal Range				
50 Norm Range vs. Partial Effect	14,074,450	9,664,950	281,489	193,299
40 Partial vs. Minimum Effect	13,982,800	9,544,200	349,570	238,065
10 Minimal Effect	0	0		
Net	28,057,250	19,209,150	**280,572**	**192,092**
UCLA Controls				
3 Norm Range vs. Partial Effect	844,467	579,897	281,489	193,299
45 Partial vs. Minimum Effect	12,584,520	8,589,780	349,570	238,065
52 Minimal Effect	0	0		
Net	13,428,987	9,169,677	**134,290**	**91,697**

Summary: Savings at Different Levels of Benefit vs. UCLA Controls, Age 3 to 22:

Level of Benefit	Inflated /Student	1996$ /Student
At 30% Normal Range	68,606	17,839
At 40% Normal Range	61,798	13,362
At 50% Normal Range	54,989	9,102

(Taking into account difference between costs of early intervention, for UCLA controls, and intensive early intervention)

Schedule 9

Service Financial Benefits at Different Levels of Effectiveness, Age 3 to 45 Years, Per 100 Children Served - Pennsylvania Model vs. UCLA Controls

This schedule presents a comparison of financial benefits at different levels or rates of achievement of normal functioning for people ages 3-45 years, achieved by intensive early intervention, versus benefits from regular early intervention. Costs are shown in terms of the aggregate of 100 children served, and averages per person served, with inflation and in 1996 dollars. Bold numbers denote per child inflated and uninflated savings. The summary table at the bottom of the page depicts cost savings adjusted for differences in three-year costs of early intervention and intensive early intervention.

	Inflated Total	1996$ Total	Inflated /Student	1996$ /Student
At 30% Normal Range				
30 Norm Range vs. Partial Effect	70,916,700	36,961,050	2,363,890	1,232,035
60 Partial vs. Minimum Effect	46,668,080	27,045,060	811,468	450,751
10 Minimal Effect	0	0		
Net	119,604,780	64,006,110	**1,196,048**	**640,061**
At 40% Normal Range				
40 Norm Range vs. Partial Effect	94,555,600	49,281,400	2,363,890	1,232,035
50 Partial vs. Minimum Effect	40,573,400	22,357,550	811,468	450,751
10 Minimal Effect	0	0		
Net	135,129,000	71,818,950	**1,351,290**	**718,190**
At 50% Normal Range				
50 Norm Range vs. Partial Effect	118,194,500	61,601,750	2,363,890	1,232,035
40 Partial vs. Minimum Effect	32,458,720	18,030,040	811,468	450,751
10 Minimal Effect	0	0		
Net	150,653,220	79,631,790	**1,506,532**	**796,318**
UCLA Controls				
3 Norm Range vs. Partial Effect	7,091,670	3,696,105	2,363,890	1,232,035
45 Partial vs. Minimum Effect	36,516,060	20,283,795	811,468	450,751
52 Minimal Effect	0	0		
Net	43,607,730	23,979,900	**436,077**	**239,799**

Summary: Savings at Different Levels of Benefit vs. UCLA Controls, Age 3 to 45:

Level of Benefit	Inflated /Student	1996$ /Student
At 30% Normal Range	668,678	309,691
At 40% Normal Range	823,920	387,820
At 50% Normal Range	979,162	465,948

(Taking into account difference between costs of early intervention, for UCLA controls, and intensive early intervention)

Appendix A:
Financial Information: Per Recipient Expenditure Estimates - Pennsylvania Model

This appendix presents information regarding the sources used in order to develop the estimates used in the cost analysis.

Sources:

Source for EI, FSS, HCBS, Institutional, and SSI/ADC is Braddock et al. (1995). *State of the states in developmental disabilities.* Washington, DC: American Association on Mental Retardation.

Source for Intensive Community Services is annual expenditures for 6 person or less ICF/MR plus one half of the difference between this amount and the annual institutional expenditure, from Braddock et al. (1995), as above.

Source for Special Education expenditures is average for all special education types from Barnett & Escomar (1990). Economic costs and benefits of early intervention. In Meisels & Shokoff (Eds.), *Handbook of early childhood intervention* (pp. 560-582). New York: Cambridge University Press. Source for Intensive Special Education expenditures is multihandicapped rate, p. 566.

Source for Regular Education expenditures is U.S.D.O.E. (1992). *The condition of education* (NCES 92-096), p. 334.

Source for Intensive Early Intervention is the average cost of 7 model programs reported in Harris & Handleman (1994). *Preschool education programs for children with autism.* Austin, TX: Pro-Ed.

Source for Median Household Income is the 1990 federal census. Supported wages indexed at 20% average of median household income for Pennsylvania.

All amounts are trended at 3%, except SSI/ADC which is trended at 1.5%.

Appendix B:
Values of Primary Estimates: Age 3 to 45 Years - Pennsylvania Model

This appendix presents the trend table for the estimates used in the cost analysis for the period 1992 to 2038.The year 1992 was used as a base year in this table because some available data were current to that year. However, costs reported in the schedules were trended from 1996 values.

Age	Year	EI	FSS	Int EI	Reg Ed	SpecEd	Int SpcEd	HCBS	Int Com	Institutl	SSI	Mdn Inc	Supp Wages
	1992	2918	986	29161	6702	11493	25594	28270	41615	50444	5068	31764	6353
	1993	3006	1016	30035	6903	11838	26362	29118	42863	51957	5144	32241	6448
	1994	3096	1046	30936	7110	12193	27153	29992	44149	53516	5221	32725	6545
	1995	3189	1077	31865	7323	12559	27967	30891	45474	55122	5299	33215	6643
3	1996	3284	1110	32820	7543	12935	28806	31818	46838	56775	5379	33714	6743
4	1997	3383	1143	33805	7769	13324	29670	32773	48243	58478	5460	34219	6844
5	1998	3484	1177	34819	8003	13723	30561	33756	49690	60233	5542	34733	6947
6	1999	3589	1213	35864	8243	14135	31477	34769	51181	62040	5625	35254	7051
7	2000	3696	1249	36940	8490	14559	32422	35812	52717	63901	5709	35782	7156
8	2001	3807	1287	38048	8745	14996	33394	36886	54298	65818	5795	36319	7264
9	2002	3922	1325	39189	9007	15446	34396	37993	55927	67793	5882	36864	7373
10	2003	4039	1365	40365	9277	15909	35428	39132	57605	69826	5970	37417	7483
11	2004	4160	1406	41576	9555	16386	36491	40306	59333	71921	6059	37978	7596
12	2005	4285	1448	42823	9842	16878	37586	41515	61113	74079	6150	38548	7710
13	2006	4414	1491	44108	10137	17384	38713	42761	62946	76301	6243	39126	7825
14	2007	4546	1536	45431	10441	17906	39875	44044	64835	78590	6336	39713	7943
15	2008	4683	1582	46794	10755	18443	41071	45365	66780	80948	6431	40309	8062
16	2009	4823	1630	48198	11077	18996	42303	46726	68783	83376	6528	40913	8183
17	2010	4968	1679	49644	11410	19566	43572	48128	70847	85878	6626	41527	8305
18	2011	5117	1729	51133	11752	20153	44879	49572	72972	88454	6725	42150	8430
19	2012	5270	1781	52667	12105	20758	46226	51059	75161	91107	6826	42782	8556
20	2013	5428	1834	54247	12468	21380	47612	52591	77416	93841	6928	43424	8685
21	2014	5591	1889	55875	12842	22022	49041	54168	79739	96656	7032	44075	8815
22	2015	5759	1946	57551	13227	22682	50512	55793	82131	99556	7138	44736	8947
23	2016	5932	2004	59277	13624	23363	52027	57467	84595	102542	7245	45407	9081
24	2017	6110	2064	61056	14032	24064	53588	59191	87133	105619	7353	46089	9218
25	2018	6293	2126	62887	14453	24786	55196	60967	89747	108787	7464	46780	9356
26	2019	6482	2190	64774	14887	25529	56852	62796	92439	112051	7576	47482	9496
27	2020	6676	2256	66717	15334	26295	58557	64680	95212	115412	7689	48194	9639
28	2021	6876	2324	68719	15794	27084	60314	66620	98068	118875	7805	48917	9783
29	2022	7083	2393	70780	16268	27897	62123	68619	101011	122441	7922	49650	9930
30	2023	7295	2465	72904	16756	28733	63987	70677	104041	126114	8041	50395	10079
31	2024	7514	2539	75091	17258	29595	65907	72798	107162	129897	8161	51151	10230
32	2025	7740	2615	77344	17776	30483	67884	74982	110377	133794	8284	51918	10384
33	2026	7972	2694	79664	18309	31398	69920	77231	113688	137808	8408	52697	10539
34	2027	8211	2774	82054	18859	32340	72018	79548	117099	141942	8534	53488	10698
35	2028	8457	2858	84515	19424	33310	74179	81934	120612	146201	8662	54290	10858
36	2029	8711	2943	87051	20007	34309	76404	84392	124230	150587	8792	55104	11021
37	2030	8972	3032	89662	20607	35338	78696	86924	127957	155104	8924	55931	11186
38	2031	9241	3123	92352	21225	36399	81057	89532	131796	159758	9058	56770	11354
39	2032	9519	3216	95123	21862	37491	83489	92218	135750	164550	9193	57621	11524
40	2033	9804	3313	97977	22518	38615	85993	94984	139822	169487	9331	58486	11697
41	2034	10098	3412	100916	23194	39774	88573	97834	144017	174571	9471	59363	11873
42	2035	10401	3515	103943	23889	40967	91230	100769	148337	179808	9613	60253	12051
43	2036	10713	3620	107062	24606	42196	93967	103792	152787	185203	9758	61157	12231
44	2037	11035	3729	110273	25344	43462	96786	106906	157371	190759	9904	62075	12415
45	2038	11366	3841	113582	26105	44766	99690	110113	162092	196482	10053	63006	12601

Estimates to Age 45 years

Note: Some estimates were based on 1992 data and all estimates are trended forward from that year or, for later estimates, back to that year

(App 5)

DATE: 06-26-96

TO: Lee Elliott, Esq.
Sr. Deputy County Attorney

FROM: Susanne D. Kaplan, Director/SCD

RE: [X] E.I. [ ] 4410
[ ] Mediation [X] Due Process

[name redacted] DOB 03-22-94 — Name of Child/DOB

6-19-96 — Date of Meeting/School District (if Applicable)

The parent/guardian of the above named child may be requesting either mediation/ due process hearing.

PARTIES INVOLVED: Parents of [redacted] and Westchester County ECCU, Susanne D. Kaplan, Director/SCD, Veronica Strawder, Program Coordinator, Meryl Bovard, Program Administrator, Sue Ann Galante, Service Coordinator.

BACKGROUND: At initial IFSP parent expressed desire for a program that included ABA 1:1 at home, based on this child's diagnosis. Sue Ann Galante offered Special Instruction, 3 to 4 days extended visits, and based on availability of specific providers discussed, Occupational Therapy would be provided twice per week if special instructor could be available only 3 times. Speech twice monthly to work with special instructior in developing a consistent approach was also part of plan.

Mother would not sign the IFSP until she went over plan with Mr. [redacted] She would mail back to me and then services could begin once appropriate service providers were located. 6-24-96 Received phone call from [redacted] He was upset with plan. Has read research which supports 40 hours of ABA, and this was not acceptable.

He is a litigator and will take this as far as he needs to fight for more hours, at least 20 hours. He is aware of other court cases where all the parents have won.

[parent's and child's names redacted for privacy reasons]

215

ISSUE/CONCERNS:

1) Parent is savvy legally and will most likely pursue due process

2) Currently we have been following a policy which limits E.I. ABA services to ten hours a week. [redacted]

3) Since he is a lawyer and will be representing himself or be part of a legal team we are concerned that anything said could be held against us. Should or could we forward calls to you?

WCDOH Contact Person/Telephone Number:

Name: _____

Title: _____

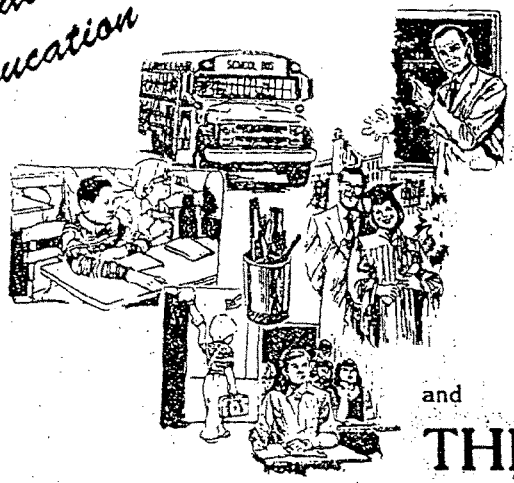
Telephone: _____

SK/mm
Attachments

cc: Patsy Yang Lewis, Deputy Commissioner
Veronica Strawder, Program Coordinator

Annual School Law Seminar

Special Education



and THE LAW

Issues and Trends

A private briefing designed for school board members, central office administrators, special education directors, building administrators and regular educators focusing on special education issues

presented by:
Missouri Association of School Administrators
Missouri United School Insurance Council
and
Peper, Martin, Jensen, Maichel and Hetlage

THURSDAY
March 12, 1998
Adams Mark-Kansas City
Truman Sports Complex
703 East 39th Street
Kansas City, MO
(816) 737-0200

FRIDAY
March 13, 1998
Holiday Inn Westport
1973 Craigshire
St. Louis, MO
(314) 434-0100

THURSDAY
April 2, 1998
Marriott's Tan-Tar-A
Resort & Golf Club
State Road KK
Osage Beach, MO
(573) 348-3131

FRIDAY
April 3, 1998
Holiday Inn-University Plaza
333 John Q. Hammond Pkwy.
Springfield, MO
(417) 864-7333

App 6

PROGRAM AGENDA

12:00 P.M. — 1:00 P.M.
Registration

1:00 P.M. — 1:45 P.M.
A Practical Approach to Identifying and Serving Section 504 Students

1:45 P.M. — 2:20 P.M.
Related Services and Assistive Technology — the New Battlefield in Litigation

2:20 P.M. — 2:55 P.M.
Special Education for Early Childhood Autistic Students — How to Avoid Parent Demands for LOVAAS/TEACH Methodologies

2:55 P.M. — 3:15 P.M.
Refreshment Break

3:15 P.M. — 3:50 P.M.
Reauthorization Update and What the Courts Are Saying

3:50 P.M. — 4:25 P.M.
Students with Behavioral Concerns: From Identification to Behavioral Management

4:25 P.M. — 5:00 P.M.
Question and Answer Session

5:00 P.M. — 6:00 P.M.
Reception

SPECIAL EDUCATION FOR EARLY CHILDHOOD AUTISTIC STUDENTS - HOW TO AVOID PARENT DEMANDS FOR LOVAAS/TEACH METHODOLOGIES

WHAT ARE THESE STRANGE SOUNDING METHODOLOGIES?

A. LOVAAS

1. Lovaas is an educational methodology that is also known as applied behavioral analysis (ABA). It has been described as a very intensive, individual discrete trial method of presenting information to a child. Lovaas is an outgrowth of the operant conditioning methodology and involves the use of a reward to reinforce appropriate behaviors. For example, the LOVAAS trainer must be sure that the student is attending. A question or demand is presented to the student and the instructor attempts to elicit the desired response. If the child presents with the desired response, the child is rewarded with positive reinforcers such as edibles, praise, and music.

2. Lovaas is designed primarily for early childhood special education students with autism, pervasive developmental delay (PDD) or similar disabilities. The methodology is based on the premise that, unlike typically developing children, autistic children do not learn from their environment and require a more intensive learning environment. Proponents insist that the approach is supported by empirical studies and that intensive efforts must be made with autistic children during a "window of opportunity" between the ages of two through six before the autistic behaviors become entrenched.

3. Lovaas is designed to be implemented for 2-3 years at which time the premise is that the child can be integrated in the regular classroom. The stated goal of LOVAAS therapy is to phase the child into regular education by reducing negative behaviors and teaching skills to enable learning in the classroom, such as sitting still, making eye contact, attending to a task, imitating others, and communicating.

4. Proponents of this applied behavioral analysis approach believe that the behavioral deficits exhibited by autistic children may be changed by an intensive focus on changing the individual behavior problems.

5. Lovaas has two goals: reducing behavioral excesses such as tantrums and acting out behaviors; and improving communication deficits.

6. Discrete trials are conducted in a one-on-one setting by trained instructors who may be family, friends or college students. A full 35-40 hour program may require as many as 5-6 trained instructors. Lovaas involves a discrete trial format, which provides opportunities for the child to achieve success in mastering small tasks which are necessary for success in a regular classroom.

7. The discrete trial format begins with simple tasks and imitative activities and then builds to more complex activities that require greater language and more cognition. Students are given repeated opportunities in the form of trials to give the appropriate response, and the appropriate response is reinforced through an individualized reinforcer such as food, toys, smiles, or praise. The program is sequential and requires work with a trained therapist to shape the program to the student's needs and strengths. The choice of program and the pacing of the program is directed by a therapist familiar with the method and the student.

8. The recommended minimum time per week is 30-40 hours.

9. Proponents advocate that the methodology be employed for a 2-3 year time period, from 4-6 hours per day for five to seven days a week without breaks for the full year.

10. An in-home component is almost always recommended with consistency and cooperation between any school and home programs.

11. Critics state that the much-touted results of the program are neither valid nor likely to be duplicated in the general population of students with autism. Critics also attack the method for its lack of scientific vigor. Critics also contend that the programming is too intense, aversive in that it allows no time for play and creates a likelihood of therapist dependence and prompt dependence. Opponents also criticize this approach for teaching splinter skills which cannot be easily generalized and take issue with the proponents' position that it leads to a "cure."

B. TEACCH (Treatment and Education of Autistic and related Communication handicapped Children).

1. TEACCH is a methodology designed to meet the needs of autistic children and children with severe communication deficits or developmental delays. It was developed by Dr. Eric Schopler of the University of North Carolina at Chapel Hill. Dr. Schopler is a critic of the LOVAAS method and believes that the progress under that program has been overstated.

2. TEACCH is to be presented by special education staff within the classroom who have received specific training in TEACCH. Students perform tasks at special workstations, often separated from dividers from the rest of the class. The tasks are often repetitive visual-motor activities and the children operate independently using cues.

3. This approach does not use applied behavioral analysis, but emphasizes a cognitive approach and behavior modification. It focuses on using

meaningful routines without constant adult assistance to encourage independence. It also teaches self-care skills and focuses on managing disruptive behavior. The emphasis on making use of skills that children already possess.

II. ISN'T METHODOLOGY LEFT TO THE DISTRICT'S DISCRETION?

A. As a general rule, methodological decisions are left to the discretion of educators.

B. If a school district, however, fails to offer an appropriate program and/or placement to a student with disabilities, a parent may be able to obtain a specific methodology through due process litigation.

III. WHO PAYS AND WHAT DOES IT COST?

A. If the child is of mandatory school age, the public school district will be required to pay for LOVAAS or TEACCH if the IEP provides for one of these particular methodologies or if it is ordered to provide them through litigation.

B. If the child is eligible for services through the early childhood special education program, the State is required to pay the full cost of the program. *See Rolla 31 Sch. Dist. v. State*, 837 S.W.2d 1 (Mo. banc 1992).

C. A full 35-40 hour LOVAAS program in the home setting may cost as much as $40,000 per year.

IV. INCREASED LITIGATION

A. 1-2 cases per year during early 1990s; 10 in 1995; 30 in 1996. 50+ in 1997.

B. Parents frequently prevail and the district is ordered to provide the specific methodology in the home or in the district.

C. Litigation with respect to these methodologies is much more time consuming and expensive that general due process litigation and almost always requires a minimum of one expert witness for the district.

D. To prevail, a district needs -- among other things -- significant documentation regarding its own program and strategies and documentation that student progress in the district program.

E. Factors common to cases in which parents have prevailed:

1. Significant procedural violations by the district.

with the district to develop an IEP. The district proposed a half-day, four day a week, facility based program with 120 minutes per week of speech/language therapy, OT and a home visit every six weeks and an autism consultation once a month. The parents rejected that placement. The judge determined the district's program was appropriate and designed to offer the student educational benefit. The judge also determined no procedural violations had occurred.

J. *Sioux Falls Sch. Dist. V. Koupal,* 526 N.W.2d 248 (S.D. 1994). Affirmed trial court's rejection of parental challenge to school district's refusal to include specific teacher training in student's IEP. Six year old student diagnosed with severe autism received special education, including instruction through the TEACCH method. The parent requested, through the IEP process, that the student's IEP specify that his classroom teacher would receive at least five days of TEACCH training as a related service prior to the time that she worked with the student. The parties agreed that the student's teachers were otherwise competent in the TEACCH method and that that methodology was appropriate for the student. The court concluded that the IDEA does not include teacher training as a related service and that it could not, therefore, be required in an IEP.

K. ***Flour Bluff Indep. Sch. Dist. (SEA Texas March 5, 1997).*** District proposed IEP for four-year-old student with PDD that called for placement in preschool classroom for children with disabilities six hours per day, speech therapy, OT, assistive technology, classroom modifications, ESY and in-home training. The parents withdrew the child and began an in-home LOVAAS program. The hearing officer determined the proposed IEP was appropriate, but required some modification, including the addition of a 1:1 aide trained in instruction of students with autism. The parents were not entitled to reimbursement for the in-home program except for the summer because the district denied the student FAPE when it failed to provide ESY services.

VII. HOW TO AVOID LIABILITY IN LOVAAS CASES

A. If parents request LOVAAS, listen to their concerns and adopt some of the methodological techniques in the in-school program.

B. Evaluate the child properly and utilize experts in autism.

C. Have someone on the IEP team who is knowledgeable about autism. ← Hot tip!

D. Be proactive.

E. At least investigate the possible of LOVAAS type therapies and see if you can design a program that incorporates some of those strategies.

F. Examine all methodologies -- use a continuum of methodology approach.

1 BEFORE THE TENNESSEE STATE DEPARTMENT OF EDUCATION

2
ZACHARY DEAL,)
3)
Petitioner,)
4)
vs.) No. 99-59
5)
HAMILTON COUNTY DEPARTMENT)
6 OF EDUCATION,)
)
7 Respondent.)

8 6703 Bonny Oaks Street
Chattanooga, Tennessee
9
October 4, 2000
10
TRANSCRIPT OF DUE PROCESS HEARING
11
SEVENTEENTH DAY OF HEARING
12 Pages 4591 through 4832

13 BEFORE: A. JAMES ANDREWS, ESQ.
ADMINISTRATIVE LAW JUDGE
14
APPEARANCES OF COUNSEL:
15
For the Petitioner: Gary S. Mayerson, Esq.
16 (Present when noted herein)
600 Third Avenue, 31st Floor
17 New York, New York 10016

18 Theodore R. Kern, Esq.
602 South Gay Street, Suite 504
19 Knoxville, Tennessee 37902

20 For the Respondent: Gary D. Lander, Esq.
1000 Tallan Building
21 Chattanooga, Tennessee 37402

22 - - -

23 VOLUNTEER REPORTING SERVICE
730 CHERRY STREET, SUITE E
24 POST OFFICE BOX 447
CHATTANOOGA, TENNESSEE 37402
25 (423) 756-0221

App. 7

1 JUDGE ANDREWS: Okay.

2 MR. LANDER: They asked that, and after we'd

3 drawn, the ruin was that both will be filed.

4 JUDGE ANDREWS: That's fine.

5 MR. MAYERSON: Judge, can we get that notebook

6 back? Is that possible?

7 JUDGE ANDREWS: Sure.

8 MR. MAYERSON: Just need it for the case.

9 JUDGE ANDREWS: That's yours. All right. Call

10 your first witness.

11 (Off-the-record discussion.)

12 DONNA PALMER,

13 called as a witness by the respondent, being first duly

14 sworn, was examined and testified as follows:

15 DIRECT EXAMINATION

16 BY MR. LANDER:

17 Q Please state your name.

18 A Donna Palmer.

19 Q Ms. Palmer, where do you live?

20 A 107 North Clift Lane, Chattanooga.

21 Q By whom are you employed?

22 A Hamilton County Department of Education.

23 Q Mrs. Palmer, let me show you what has been

24 marked for identification as Exhibit 512 and ask if you

25 can identify that document.

1 A This is my vita.
2 Q Is it current?
3 A Yes.
4 Q And what is your title currently with the
5 Hamilton County Department of Education?
6 A Lead school psychologist.
7 Q How long have you been a school psychologist for
8 Hamilton County schools? If you want to refer to your
9 vita, that will be fine.
10 A I do. I first began working as a school
11 psychologist in 1979 and then, after another period of
12 time, again in 1991 and it's been continuous since 1991.
13 Q Okay. Your vita reflects your educational
14 background after leaving high school?
15 A Yes.
16 Q Okay. And your bachelor of science degree is in
17 psychology?
18 A Yes.
19 Q And you have -- have you -- you have post
20 baccalaureate work in psychology, you took a master's in
21 special education?
22 A Right.
23 Q Okay. And have you completed -- you didn't take
24 another degree in psychology?
25 A No.

(Cross examination)

1 A Actually, I --

2 MR. LANDER: You don't have to answer.

3 THE WITNESS: Okay.

4 MR. MAYERSON: Just with testing, Judge?

5 JUDGE ANDREWS: Trust me, we're going to have

6 lots of witnesses here that are going to be able to give

7 answers to that question. I can see the future to that

8 extent.

9 Q Okay. You had an article yesterday from Barry

10 Prizant?

11 A Yes.

12 Q Would you agree that he's a -- one of these

13 classic people who's always writing against Lovaas and

14 the ABA studies, he's constantly writing articles

15 critical about ABA?

16 A I don't know that.

17 Q You don't know? Okay. Have you ever read, in

18 this county, a school district publication called How to

19 Avoid Parents' Demands for Lovaas? Have you ever read

20 such a document?

21 A Would you say that again?

22 Q Have you ever read a pamphlet or publication

23 called -- I'm not suggesting it has an actual cover like

24 it was published by a publisher, but it's a document

25 entitled How to Avoid Parents' Demands for Lovaas? Have

1 you ever seen that?
2 A Did you say it was a Hamilton County --
3 Q I'm saying have you ever seen a document from
4 any source called How to Avoid Parents' Demands for
5 Lovaas?
6 A Have I ever seen one from any source? Yes.
7 Q Where did you see it?
8 A Probably on the Internet.
9 Q How did you get to that document, if I may ask?
10 A I use, I use the Internet to do a lot of
11 research.
12 Q Have you ever -- to the extent that you have any
13 questions or concerns about ABA, have you ever heard
14 Irise Chapman or Jane Dixon say anything positive about
15 ABA, ever?
16 A I don't, I really just don't have an answer to
17 that.
18 Q Okay, all right. Now, am I correct that to the
19 extent that you ever saw Zachary in the flesh, it was for
20 about five minutes?
21 A That's probably about right, yeah.
22 Q To the extent that you had any questions or
23 concerns about ABA, did you ever communicate those to the
24 parents, ever?
25 A No.

These individuals are the Chief Special Educ. Administrators in Hamilton County.

the CHATTANOOGAN.COM

Latest Local News - February 1, 2001

Legal Expenses Over $175,000 In Autistic Child Case

Posted: Thursday, July 06, 2000

An attorney for the Hamilton County Schools said over $175,000 has already been spent in defending a case in which parents of an autistic child want home-based programming for the child.

Attorney Gary Lander said the case "is extremely important" in that it may set a precedent on the issue of the schools providing home-based help.

He said, "We believe there are several other potential requests for funding of multi-year home-based education similar to the demands in this case."

An administrative law judge has been hearing the case - having held 10 days of hearings already. There are additional sessions set for July 10-14, and the parents have not yet completed their case.

The parents have been instructed to finish their side by July 11.

Mr. Lander said the county schools would not be able to put on its case in the remaining three days so there will need to be additional sessions later in the summer.

App. #8

He said the case was complicated when the parents "demanded a meeting to plan for the readmission of their son to public school in the fall, which we agreed to do upon the agreement of the parents that we conduct a new assessment of their son which is ongoing."

A full assessment team is to meet on the case on July 25.

Mr. Lander said members of the exceptional education department "are devoting enormous effort to this case."

He said his firm's charges on the autism litigation from Sept. 1, 1999, to the end of May are $161,889.50. He said work through June would be another $12,000.

Mr. Lander said there are some $5,700 out of pocket expenses related to the autism case.

He said his firm (Chambliss, Bahner and Stophel) was charging $31,285 for general counsel matters (not involving litigation) for the past year. He said that was down from $42,799.

Mr. Lander asked an increase in his hourly rate to $195 per hour. He was at $150 per hour when he started handling special education cases in 1993.

Robert A. Smith, deputy superintendent, recommended approving the Lander proposal "based on the outstanding work" he and his firm had done.

E-mail this article to a friend

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PUBLICATIONS — 127th Year No. 328 Tuesday, September 7, 1999 8 Sect

NO. 189 P.2/4

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Legal battle may open doors for autistic

Judge makes Dist. 15 pay for student's needs

By Michelle Martin
Daily Herald Staff Writer

Nine toddlers sit with their parents in a circle.

A teacher asks each to identify themselves in a photograph, and the children, all with some form of disability, eagerly participate.

But not Tommy Harrington. The 2½-year-old sits away from the group, curled in a blue beanbag chair.

His mother and a teacher's aide try to keep the blond boy calm by soothing and holding him. But within minutes, his frustration erupts, as he kicks and screams to get out of the chair and away from the room.

His mother helps hold him down, she later says, because the teacher said it would help him learn.

A little more than two years later, Tommy finished a year of regular preschool, which he attended with an aide. By the end of the year, Tommy was the singing and dancing star of the class, doing the "Locomotion" around the room and taking home an award for his "Sunshine Smile."

"It helped us all enjoy the singing and the dancing even more," his mother, Lora Harrington, read from the certificate.

The difference, Lora Harrington is convinced, has been two years of specialized attention she arranged for Tommy. With the help of an autism expert, Tommy has had 30 to 40 hours each week of intensive, individualized therapy in his home.

The cost of the therapy was about $30,000 a year. Lora and Steven Harrington started by paying the bills themselves, borrowing from family members to make ends meet.

But in a recent court ruling, which may change how public schools react to autistic children in their care, a federal court has ordered Palatine Township Elementary District 15 to repay the family for all those costs — about $60,000 for two years — as well as attorneys' fees and future payments for Tommy's ongoing individualized education.

The family's battle has been watched closely, by school districts and parents of autistic children

See AUTISM on Page 13

Lora and Steven Harrington, and their children Tommy, 5, have spent more than two years w Palatine Township Elementary District 15 to p therapy for Tommy, who has autism.

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Top

Daily Herald Tuesday, September 7, 1999 SUBURBS

AUTISM: District 15, family of boy have worked out plan

Continued from Page 1

alike.

Experts disagree on what direct effect it will have, since federal Judge James B. Moran specified the ruling does not bind other school districts to the same level of service.

But the decision shows how changing interpretations of federal law are raising the bar on what school districts are expected to provide for special education students, particularly those with autism.

"What this ruling says is that the needs of these kids come first," said Dr. Bennett Leventhal, the chairman of the pediatric psychiatry department at the University of Chicago. "A lot of schools have prescribed formulas: if you have this disorder, you get these services. I'm sure they would argue that's not what they do, but that's the reality."

The law requires every special education student to have an individualized plan, agreed to by the school district and the parents, designed to meet that child's needs.

Lora Harrington did not think the plan District 15 proposed for her son took his needs into account.

Two years, two state hearings and a federal court hearing later, Judge Moran agreed with her. In the end, District 15 or its insurer could have to pay up to $300,000 for the therapy and attorney fees, nearly five times what it would have cost to pay for the program from the beginning.

Edward Rafferty, the assistant superintendent for special services in neighboring Schaumburg Township Elementary District 54, points out the ruling does not apply to his district. But in his next breath, he acknowledges it made him take another look at what his district provides for autistic children.

"We're raising the bar legally, but we're also raising the bar in knowledge," Rafferty said.

According to National Institute of Mental Health, between 15 and 20 children out of 10,000 display autistic behaviors. The most severely disabled are profoundly retarded, do not speak and appear to live in their own worlds.

Others display average or above average intelligence, but have difficulty communicating, controlling their impulses and coping with new situations. Most have difficulty relating to other people.

Recently, scientists have labeled more and more children autistic, although they debate whether the actual number of children who have the disability has risen.

A 1994 change in federal law [illegible]

had many children in the preschool with autism, and many, many of them went on to do very well."

Some children with autism attend regular classes in District 15, as in many other school districts across the country. Those who can go to school without special help are considered "recovered."

That's what Lora Harrington wants for Tommy.

"I know my son will never be the President of the United States," she said. "But I want him to be able to have a job."

She didn't believe District 15's plan would help him do that, even though Mittelheuser told her other students had succeeded.

Programs like the one District 15 proposed do help some children with autism, Leventhal said. But when he was one of seven experts who testified at a state hearing in the Harrington case, he said such a program would only hurt Tommy's ability to behave appropriately.

Rafferty said children with autism have such a wide range of abilities the diagnosis of autism — that one word — really says nothing about how schools should teach them.

"We have students in self-contained classrooms, and we have students functioning in regular classes," Rafferty said.

District 54, the largest elementary district in the state, has special education teachers that do applied behavior analysis, as well as training others to do it. But the district has never provided a 40-hour-a-week, 52-week-a-year, one-on-one program for a student, he said.

"I can't even begin to imagine what that would cost," he said, noting that public school requirements might drive the cost higher than the $30,000 the Harringtons spent.

The federal special education law does not mention money, except to say special education should be free. But money lies at the bottom of most debates about special education.

This year, the state of Illinois expects to spend $868.8 million, about 17 percent of the state's total education budget, reimbursing school districts for special education. That doesn't cover all the special education services districts provide, said Tom Hernandez, a spokesman for the state school board.

District 15 plans to spend about $12.4 million on special education this year, more than 10 percent of its budget. Education for autistic and physically disabled students will cost the district an average of more than $13,000 each.

Since the state does not reim-

Neighbor charg

By Robert Sanchez
Daily Herald Staff Writer

A simple speeding ticket on a New Mexico highway led to the capture of a 31-year-old Westmont man suspected of murdering his neighbor over the weekend.

Authorities on Monday charged Scott Faulkner, of 102 Indian Trail Drive, with first-degree murder in Saturday morning's stabbing death of Rosé Ross, 95, of Westmont.

Faulkner was formally charged one day after New Mexico State Police nabbed him for speeding in his mother's car about 8 a.m. Sunday morning.

"Everything worked this case," Westmon Randy Sticha said. "His stupidity helped us — s same car and speeding."

Police believe Faul Ross with a large bu sometime between 8 a. a.m. on Saturday in the u room of the two-story to mother owns.

Faulkner's mother c Ross' body when she about three hours later multiple stab wounds in t

The knife that police su

Rick Breeden, left, and his father, Dick, who run Waud New Zealand Gala apple trees at the orchard as they g season. The orchard opened for picking over the wee

Apples outshin

Yield is average for orchards,

By Natasha Korecki
Daily Herald Staff Writer

This summer's intense heat may have damaged corn and bean crops throughout Lake County, but apple orchards are opening with prime picking

actual number of children who have the disability has risen.

A 1994 change in federal law created an educational diagnosis of "autism" for the first time. Before that, children who had been diagnosed with autism by psychiatrists or neurologists were considered "communication disordered" or suffering from developmental disabilities.

That change alone brought more attention to autism, and more cases being diagnosed.

In District 15, the number of students with autism more than doubled from 16 to 33 in the past two years. That follows a statewide increase from 615 in 1994 to 1,398 in 1997, the last year the state board of education has statistics available.

At the same time, psychiatrists and neurologists have learned autistic children can be helped, especially by early, intensive therapy while their brains are still developing.

Lora Harrington researched the growing base of information about autism when Tommy was diagnosed nearly three years ago, she said.

She found information about applied behavior analysis, along with many other therapies. It was the therapy with the most scientific data backing it up, she said.

Harrington started a program for Tommy with the help of consultant Dr. Ann Maxwell. In applied behavior analysis, children learn new skills one small step at a time. Therapists keep detailed, objective records about the child's behavior to tailor the program to the student. Most students do it at home.

Harrington hired mostly psychology students to do the therapy under Maxwell's supervision.

In the beginning, Maxwell told Tommy to sit in his chair. When he did not, she would place him in the chair, and Tommy would shriek.

Three weeks later, Tommy sat in his chair at his table and named circles, squares and triangles as Maxwell showed him the shapes.

Lora Harrington invited Tommy's playgroup, teachers and several District 15 administrators to a workshop Maxwell presented at the Harrington's home. None of the school officials attended, she said.

Later that spring, when it was time to make Tommy's preschool plan, Harrington asked the district to continue the 30 to 40 hours a week of therapy he was getting at home.

In return, District 15 proposed putting Tommy into a class with up to nine other preschool students with a variety of disabilities. Such a class typically would have a teacher and two assistants. Tommy would have attended school for 2½ hours a day, four days a week.

The district's team of educators made that decision after evaluating Tommy, said Darrell Mittelheuser, district director of student services.

"We had some experience working with children with autism, and we felt we had a program designed for him," Mittelheuser said. "We

cost the district an average of [illegible] than $13,000 each.

Since the state does not reimburse all the costs for special education, especially for unusually intensive programs, local taxpayers pick up a big chunk of the bill. Districts cannot raise taxes beyond the tax cap limitations, so that money must be taken from somewhere else.

District 15 is trying to stop that from happening. It has appealed one part of Moran's ruling, arguing the state should be responsible for the cost of Tommy's education.

Mary E. Moran, one of the Harringtons' attorneys, said she understands why school districts would want to try to hold down what they spend on special education, although she disagrees with the practice.

"It's a can of worms," she said. "Special education can be a bottomless pit."

But Tommy's education didn't have to be any more expensive than what the district was prepared to do, the attorney said. Early on, the Harringtons offered to settle for the amount the district would have spent on their son in preschool, about $18,000 a year, applied to in-home therapy, according to Harrington and Mary Moran.

Harrington said she didn't ask for any more than Tommy was entitled.

"We didn't want anything special," Harrington said. "But really, if you look at the idea of 'if you have to do it for one, you have to do it for everybody' ... I think every kid should have this."

Mittelheuser said the district has not changed how it educates children with autism, although the district last year hired an autism specialist and created a self-contained classroom for students with autism.

"This is only one case involving one student. We are always learning," he said. "We change every year as we learn more."

Tommy began school this fall, half a day in a special education program for 5-year-olds with an aide and half the day doing therapy at home.

Mittelheuser said he hopes the boy will do well.

"We have been working with the family closely for the past six months," he said. "We have spent countless hours meeting with them."

Harrington said some of those hours were strained and antagonistic, but her family and the district finally came to an agreement.

Tommy now has a lot in common with most little boys. He likes dinosaurs and swimming. But he still has problems with behavior and communicating his thoughts.

While Tommy has not recovered, he communicates much better than he did three years ago.

"I longed to hear him call for me for three years," his mother said. "Every word he's learned, he's been taught to say very slowly, very methodically.

"He still struggles, but he says, 'Goodnight, Mommy.'"

with prime pickings.

While crop sizes are only average this season, they surpass last year's, when area orchards faced light harvests and subsequently raised prices.

"They look much better than last year," said Helga Ziegler of Ziegler's Apple Orchard in Grayslake. "The looks of the apple, the beauty of the apple is much nicer."

Rainfall a few weeks ago was enough to yield large, juicy fruit, orchard owners say.

Aside from nicer apples, customers can expect some slight price increases, more entertainment and long lines due to the permanent closure of the once-brimming Bell's Apple Orchard in Lake Zurich.

"From what we've seen out on the field, it seems like overall an average to good year. I would expect a great crop throughout Lake County this year," said Gregory Koeppen, public information director for the Lake County Farm Bureau. "A lot of trees are loaded with apples."

Besides the recent rainfall, apple crops avoided significant damage from the summer's heat and dryness for several reasons. Warm nights in the spring and summer encouraged pollination, and apple crops experienced only a mild, rather than hard, long frost last winter — a key period in crop development, Koeppen said.

Most orchards rent beehives and allow bees to work the blos-

Courtland apples, show among the first ready to

soms, but if it's too cold, the won't come out.

That was the problem las Too many cold nights hinde pollination, leading to fewe soms and, ultimately, fruit. shortage prompted orchard bump up prices for the first in years.

However, only two upped charges this season, which opened this past weekend a orchards.

Wauconda Orchards will half-bushels for $20, up fro last year.

Quig's Apple Orchard in Mundelein will charge $14 half-bushel, up from $13.80 year.

Ziegler's Orchard in and Heinz Orchard in tyville will charge the same year, about $12 for a half-bu

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To: Gary Mayerson
From: Ivor
Invig & PAC

Building a Blueprint for Defensible Autism Programs

6 Locations for Fall 1999

Hey all, it now

Baltimore, MD, October 28	San Francisco, CA, November 5
No. New Jersey/NYC, October 29	Columbus, OH, November 19
St. Louis, MO, November 4	Raleigh, NC, December 3

Hotel Information

Over the past ten years the number of autism-related cases has sky-rocketed as has public awareness of, and interest in, autism. School districts have been inundated with parental requests for funding for in-home educational programs and other therapies claiming to "cure" or "recover" autistic children. Such programming or therapy commonly costs more than $60,000 per year and is usually requested during the child's preschool years. Educators are being faced with these requests, often supported by the recommendations of physicians, psychologists, and other professionals. As a result, schools are searching for information to explain what autism is, and is not, and what educational strategies are effective to teach children with autism social, communicative, self-help, behavioral, and academic skills.

What You Don't Know Could Cost You!

- What are "LOVAAS" therapy and the "TEACCH" program? Are these programs effective for educating children with autism?
- What are the essential components in an educational program for children with autism?
- How does a school district develop a successful and defensible educational program for students with autism? What resources are available and how can they be accessed?
- What factors influence courts and hearing officers in autism-related cases?
- Is it cheaper to "fight" an autism case than to "give in?"
- What is the "trump card" for school districtsin LOVAAS litigation?
- How do you analyze your autism-related case to determine the chances of winning in court?

Workshop Details

The purpose of these workshops is two-fold. First, participants will benefit from an overview of the most commonly implemented educational programs for children with autism and autism-related disorders, including LOVAAS, TEACCH, PECS, etc. Ms. Genaux will present the components needed to design and implement a defensible educational program for students with autism. She will

(App. 10)

also provide a demonstration of the use of Applied Behavior Analysis, as well as other typical educational strategies. Next, Ms. Baird will analyze the federal and administrative case law on autism, reviewing each case for the factors that were persuasive to the judge or hearing officer. She will also provide a "blueprint" for winning based on the patterns that have emerged in autism litigation and her own experience in representing school agencies.

Agenda:

Click here to meet the presenters.

7:30AM
Registration (Coffee & Muffins)

8:30AM
Educational Issues Part 1
10:00AM
Refreshment Break

10:15AM
Educational Issues Part 2
12:00PM
Box Lunch (provided)

12:30PM
Legal Issues Part 1
2:00PM
Refreshment Break

2:15PM
Legal Issues Part 2
3:30-PM
Conference Concludes

Registration Information

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Wednesday Edition • October 11, 2000

Committee Bound by Vote on Teaching Plan

By John Caher
New York Law Journal
Friday, October 6, 2000

ALBANY — In a first impression ruling with potentially broad ramifications, an upstate judge has held that while school district committees are not obligated to vote democratically on special education issues for children, if they do so they are bound by the results.

The decision by Justice Anthony Kane in *Matter of Sackets Harbor Central School District*, 2527/00 (Albany County), could give parents and their chosen advocates a far more definitive voice in determining the taxpayer-funded services that will be provided for disabled children.

But at the same time, it gives school districts a powerful incentive to avoid doing something they have no absolute obligation to do — namely, to hold a vote.

Justice Kane suggested it may well take an act of the Legislature to resolve the question of who is entitled to vote at meetings where education plans are formulated. Absent that, however, he said if a committee decides to take a vote, it must be prepared to live by the consequences.

His decision arises out of a matter involving an autistic child and the parents' attempt to amend the boy's Individualized Education Program (IEP) to include 36 hours of home-based Applied Behavioral Analysis (ABA). ABA is an effective regimen, particularly with autistic children. However, it is costly and not appropriate in every case.

With the parents and Sackets Harbor Central School District at an impasse over whether ABA was an appropriate service for the child in this case, the Committee for Preschool Education (CPSE) called a meeting to resolve the issue. The chairwoman declared that since consensus was impossible, the matter would be resolved by a vote. That raised a question of who would be allowed to vote: just the members of the CPSE or also individuals with specialized knowledge or expertise, who are legally entitled to attend and who were brought to the meeting by the parents.

The committee decided to poll everyone in attendance. Although the

App. 11

members of the CPSE voted 4-2 against ABA, they were outvoted by a majority of the individuals at the meeting. The district then concluded that it was not bound by the vote, and the parents appealed.

Federal Impact

A hearing officer held that while the district's IEP was appropriate and that it was not obligated to provide ABA, it violated the federal Individuals with Disabilities Education Act (IDEA) by refusing to count all the votes. He instructed the CPSE to submit a new recommendation to the Board of Education and ordered the district to reimburse the parents for the cost of funding their son's ABA program since Sept. 18, 1998.

On appeal to the Office of State Review, the district argued that the law limited voting rights to specifically designated CPSE members. The State Review Officer rejected that argument, but then found that the child in this case did not need an ABA program.

An Article 78 proceeding ensued, with the district pursuing its argument that the votes of six people who attended the meeting but were not members of the CPSE should not have been included in the tally.

At issue in a proceeding under Article 78 of the Civil Practice Law and Rule (CPLR) is whether a government agency or official acted arbitrarily and capriciously, or failed to perform a required duty.

Ruling in the Article 78 matter, Justice Kane found that the district was "not only a willing participant in the voting process" that it now complains of, but actually initiated the vote. Under his order, all of the votes count, the child is entitled to ABA services and the parents are entitled to reimbursement.

Justice Kane did not dispute that opening up voting to a vaguely described group of attendees at a committee meeting creates a "circus-like" atmosphere in which both sides will attempt to stack the deck. However, he said it is up to the Legislature to resolve that problem.

"It is not the function of this Court to determine who would be designated a person with knowledge or special expertise regarding the disabled child," Justice Kane wrote in a 27-page opinion.

Counsels' Views

Attorney Gary S. Mayerson of Manhattan, who represented the parents, said the district had adopted a "heads-I-win, tails-you-lose" position, maintaining in essence that it would abide only by votes it won.

"What New York is recognizing here is a basic fundamental principle of fairness, but a very narrow principle," Mr. Mayerson said. "This judge has not held that you must have a vote. He simply said that if you do, you have to live with it. I think the judge was struck by the inequity of initiating a vote, thinking they were going to win, and then reneging when it didn't go their way."

Mr. Mayerson said the ruling is likely to have a significant impact on disability cases, and could well lead to more unilateral determinations by school districts that ultimately spark lawsuits by parents.

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Mr. Mayerson said the ruling is likely to have a significant impact on disability cases, and could well lead to more unilateral determinations by school districts that ultimately spark lawsuits by parents.

"If I am a school district reading this, I might take the position that the district is never going to hold a vote," Mr. Mayerson said.

That, however, is probably impractical, as the judge noted.

"If a consensus cannot be reached, as a practical matter, it appears that voting is the only method by which to resolve such an impasse," Justice Kane wrote.

Edward J. Sarzynski of **Hogan & Sarzynski LLP** in Binghamton, who appeared for the district, agreed the decision has broad implications statewide, largely because there is nothing in either federal or state law that provides clear guidance on how education committees are to formulate their recommendations. He said the federal Education Department has opined that it is inappropriate to make IEP decisions by majority vote. However, Justice Kane found the opinion advisory and not binding.

Mr. Sarzynski said he is asking the State Education Department to consider drafting legislation to clarify voting at committee meetings. In addition, he said his client, a school district near Watertown, is reviewing the decision and considering an appeal to the Appellate Division, Third Department.

"There are a lot of ramifications of the judge's decision because there are occasions when people in good faith cannot reach consensus," Mr. Sarzynski said. "If you give everyone a vote, there is no accountability. People would be casting a vote who are not accountable to the district."

The State was represented by Assistant Attorney General Robert A. Siegfried.

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regard to a recommendation after reviewing the merits of the respective positions of the participants at a meeting. We are not aware of any federal or State law or regulation, court or SRO case, or any official position paper of the State Education Department to support that proposition. Indeed, a Chairperson making such a determination, which would largely be subjective if no vote is taken, would in this writer's opinion be creating potential legal liability until specific authorization has been provided either under statute or regulation. An effective argument could be made by a parent that such a one-person determination is contrary to the Committee concept contained in the Education Law and regulations as well as in numerous court, Commissioner, and State Review Officer decisions, as well as contrary to the provisions of the federal regulations which provide that an *IEP team* must make certain decisions regarding the provision of a free appropriate public education to a disabled student.

If a Chairperson of a CPSE or CSE intends to follow the advice given that the Chairperson can make a determination after reviewing the merits of the participants' respective positions at a meeting, I strongly recommend that the advice relied upon be put in writing. Caution should be exercised regarding such advice even if given by a representative of the State Education Department, since the Sackets Harbor Central School District CPSE had relied on the opinion of SED contained in Rita Levay's letter. The State Review Officer chose not to refer to that letter in rendering his decision.

In the interim, if consensus cannot be reached at a Committee meeting, it is this writer's opinion that a vote should be taken of those entitled to vote until such time as a court has been able to decide the appeal of the State Review Officer's decision. Although this approach may indeed create substantial difficulties in scheduling and conducting Committee meetings, this process should at least not subject the Chairperson or the District to potential legal liability in making recommendations regarding a disabled student.

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What kind of legal liability?

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Mr. BURTON. Mr. East.

Mr. EAST. Thank you, Mr. Chairman.

My name is Bill East, and I'm pleased to represent the State directors of special education here today. I am executive director of the National Association of State Directors of Special Education, an organization based in Alexandria, VA, with members in the 50 States and Federal jurisdiction.

My organization supports State education agencies in providing leadership for the implementation of the Federal special education law, the Individuals With Disabilities Education Act. In celebrating the advances made possible by this law, we recognize that special education is a complex system with many challenges. The 1997 reauthorization significantly raised the bar for students, parents and schools. State directors of special education realize that the revised Special Education Service System can only be implemented with effective collaboration with general education, a strong focus on student and system results, and less emphasis on special education process and paperwork, sufficient numbers of properly trained personnel and full funding.

Generally, most children with disabilities receive the services they need. However, the 6 million children served by this law could benefit from a system with higher expectations and increased accountability. While the needs of students with disabilities have always presented challenges for schools and families, the increasing numbers of children diagnosed with autism and learning disabilities have created more challenges. Further, the increasing number of students served outside the traditional school environments, such as charter schools, juvenile justice centers and other alternative environments, make it more difficult to ensure educational quality and procedural compliance. Schools are working to include students with disabilities in the general curriculum assessment and accountability systems in the context of increasingly higher standards.

State directors of special education welcome these challenges, but know that the work force is not adequate to meet current demands. Schools are working to provide free appropriate public education to all students with disabilities. However, the system on any given day will probably never be in compliance if compliance means 100 percent student success rate or 100 percent adherence to many regulations put in place to implement the law. It is quite possible to have all the procedural paperwork in order without good teaching and learning going on.

The system has adequate procedures to deal with the disputes between parents and schools with complaint, mediation, due process and litigation options. We must not necessarily equate disagreements between parents and schools with noncompliance. Even within a compliant system, disagreements about services will occur.

State directors believe that monitoring efforts must be strengthened, but the focus needs to change from an emphasis on the special education process to an emphasis on student results and system accountability.

With each IDEA reauthorization, new amendments and implementing regulations bump more legal costs into the system. Sometimes due process hearings and litigations are necessary, but other

times the problems can be resolved in less adversarial and costly ways. State directors of special education believe that dispute resolution and mediation systems should be promoted as more desirable avenues for resolving complaints.

Federal funding for special education programs has always been inadequate, and full funding is needed to ensure equal opportunity. Funds appropriated for special education are making it into the classroom, but more is needed. Federal funds utilized by State education agencies also benefit local schools. As increased funds are made available, State education agencies must receive more because they are accountable for implementing the IDEA.

Families and schools face many challenges in providing services. While these differ from place to place, personnel issues are on everyone's list. The quality and availability of personnel is a critical matter demanding immediate attention. Higher education personnel preparation programs must be restructured to meet current needs. Schools must better recognize and utilize the expertise parents have related to their children's skills and abilities. And finally, the needs of children from other cultures and languages must be met as they often move into communities ill-prepared to receive them.

In my written testimony I have some 10 suggestions that are ripe for support by the Federal Government, and I'll let you read those, and we may get to them in the questions, and I just want to emphasize three or four as I close: Continue efforts to fully fund the IDEA; help States provide sufficient numbers of properly trained personnel; hold States accountable for student outcomes, while providing increased flexibility as an incentive for results; and last, acknowledge the important leadership and oversight roles State education agencies play in implementing the IDEA, and support them with the resources to be successful.

Thank you.

Mr. BURTON. Thank you, Mr. East.

[The prepared statement of Mr. East follows:]

TESTIMONY BEFORE THE

U.S. HOUSE OF REPRESENTATIVES

COMMITTEE ON GOVERNMENT REFORM

HONORABLE DAN BURTON, CHAIRMAN

FEBRUARY 28, 2001

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My name is Bill East and I am pleased to represent the State Directors of Special Education in providing testimony for the Committee. I am the Executive Director of the National Association of State Directors of Special Education (NASDSE), an organization based in Alexandria, Virginia, with members from the 50 states and federal jurisdictions.

I have worked as a teacher and administrator in the fields of education and mental health for over 30 years. Prior to my present position, I served as the State Director of Special Education in Alabama. In my professional career, I have worked with local, state and federal stakeholders involved in the education of people with disabilities including parents, service providers, higher education professionals and policymakers. My organization supports the work being done by state education agencies in providing leadership for the implementation of the federal special education law, the Individuals with Disabilities Education Act (IDEA).

Three months ago, families, service providers, policymakers and many others celebrated the 25th anniversary of the IDEA. In celebrating the advances made possible by this law, we

recognize that special education is a complex system with many challenges. The major changes included in the 1997 IDEA reauthorization, while seen as necessary for people with disabilities to participate fully in the educational experience and post-school success, have significantly raised the bar of expectations for students, parents and schools. State Directors of Special Education are providing leadership to assist local school districts with the higher expectations, but realize that to be successful, the enhanced special education service system can only be implemented with (1) effective collaboration with general education, (2) a strong focus on student and system results and less emphasis on special education process and paperwork, (3) sufficient numbers of properly trained teachers and other service providers, and (4) full funding that will ensure success for every child.

Generally, children with disabilities are receiving the services to help them be successful, and most parents are satisfied with the results. However, the six million children served by this law, like their non-disabled peers, could benefit from an enhanced education system with higher expectations and increased accountability for results. While the wide range of needs of students with disabilities has always presented challenges for schools and families, the increasing numbers of students diagnosed with autism and learning disabilities have created more challenges. Further, the increasing numbers of students served outside of the traditional school environment, as evidenced by expanding enrollments in charter schools, juvenile justice centers and other alternative environments, make it more difficult to ensure educational quality and procedural compliance for special education students. School districts and states are working hard to include all students with disabilities in the general curriculum, assessment and accountability systems in the context of increasingly higher standards and high-stakes promotion and graduation requirements. State Directors of Special Education welcome these challenges,

but know that the current workforce, in terms of numbers and training, is not adequate to meet current demands.

Schools are working to provide a free appropriate public education to all students with disabilities as expected by Congress. However, the system on any given day will probably never be in compliance, if compliance means a 100 percent student success rate, or 100 percent adherence to the many detailed regulations put in place by the Department of Education, and sometimes states, to implement the law. At the local level, educators attempt to implement this very prescriptive process, and with a desire to avoid legal proceedings, document it with such detail that I hear many educators say that they are so busy implementing the law that they do not have time to educate the children. It is quite possible to have all the procedural paperwork in order without good teaching and learning. The system has adequate procedures in place to deal with disputes between parents and schools with the availability of complaint, mediation, due process hearing and litigation options. We must not necessarily equate disagreements between parents and school personnel with non-compliance with the law. Even within a compliant system, disagreements about services will occur. Further, monitoring systems at the federal, state and local levels help ensure compliance with the law. State Directors believe that monitoring efforts need to be strengthened, but the focus needs to change from an emphasis on the special education process to a focus on student results and system accountability.

Legal costs incurred in school districts and states take away from other programs and services that benefit all children. Education agencies are responsible for paying for their own legal bills, and those of the parents when parents prevail at due process hearings or in the courts. The cost of a single due process hearing is in the thousands of dollars, and hearings costing $10,000 to $20,000 are common, with many costing much more. As stated earlier, states also

must maintain complaint, mediation and due process hearing systems and these are costly as well. With each IDEA reauthorization over the years, new amendments and implementing regulations have brought more legal costs into the system. Sometimes due process hearings and litigation are necessary, but at other times the presence of attorneys prevents parents and educators from resolving problems in a less adversarial and costly way. State Directors of Special Education believe that dispute resolution and mediation systems should be promoted as more desirable avenues for resolving disputes than due process hearings and litigation.

Federal funding for special education programs has always been inadequate and full funding is needed to ensure equal opportunity for children and youth with disabilities. Funds already appropriated for special education are making it into the classrooms of America and are used appropriately. Typically, personnel costs alone account for more than 85 percent of the expenditures in schools. We have seen the escalation of high cost services for children with more extensive intervention needs such as autism. However, states and local school districts are using increased federal dollars and coordinated service models to meet the needs of these students. Federal funds utilized by State Education Agencies also benefit local schools through the provision of technical assistance, monitoring, training for personnel and parents, and other expenditures for systems and services described elsewhere in this paper. With the desire to see every dollar possible go to classrooms, Congress has limited the amount of funds State Education Agencies have for these purposes. As increased funds are made available for this program, State Education Agencies must receive more funds. They are designated by law as the single entity with accountability for implementing the IDEA in states. It is only right that they have sufficient funds to accomplish their mandate.

Families, teachers and administrators face many challenges in providing services and support to help students with disabilities benefit from their educational programs. While these challenges differ from one place to another, personnel issues seem to be on every list. The quality and availability of special education personnel is a critical matter demanding immediate attention. General education teachers already in the field need training in appropriate instructional and behavioral strategies for students with disabilities. Special education teachers need training in course content areas. Higher education teacher and administrative preparation programs must be restructured to meet current needs in schools. All school personnel need training for including special education students in the general education curriculum and assessment systems. Schools need to better recognize and utilize the expertise parents have related to their childrens' skills and abilities. And finally, the needs of children from other cultures and languages must be met as they often move into communities ill-prepared to receive them.

Throughout my testimony, I have discussed areas that are ripe for support by the federal government. In closing, I want to list several areas for your consideration:

(1) Continue efforts to fully fund the IDEA, including Parts B, C, and D of the Act.

(2) Help states provide sufficient numbers of properly trained teachers, other service providers and administrators.

(3) Help promote a strong focus on student results and system accountability, with less emphasis on the process and paperwork that reduces instructional time.

(4) Help promote a unitary education system where all personnel collaborate effectively.

(5) Help decrease the adversarial nature of the law by promoting conflict resolution and mediation systems in lieu of unnecessary due process hearings and litigation.

(6) Promote effective parent-school partnerships.

(7) Hold states accountable for student outcomes while providing increased flexibility as an incentive for results.

(8) Provide strong support and resources for general education teachers to meet the needs of a more diverse student population, thus reducing the need to identify many children for special education services.

(9) Promote and adequately fund Part D of IDEA, which provides for technical assistance, research and demonstration projects and other areas that make up the special education support network.

(10) Acknowledge the important leadership and oversight role State Education Agencies play in implementing IDEA, and support them with the resources to be successful in providing meaningful assistance to local school districts.

I want to thank the Committee for allowing me to provide testimony on this important matter.

Mr. BURTON. Mr. Amundson, did I pronounce that correctly?

Mr. AMUNDSON. That's close enough. Thank you. Thank you, Chairman Burton. You have my written testimony. I would like to apply adult learning theory and not read to you what you have in your hands, and just give you some other comments that may be relevant.

My name is Ed Amundson, and I serve as the chair of the National Education Association's Caucus for Educators of Exceptional Children. In that role for the past 5 years, I have been involved in the reauthorization of IDEA as well as the implementation with the Federal partners that were created under the reauthorization of IDEA with ASPIRE, ILIAD and some of the other groups.

I speak to you today not in that capacity. I speak to you today as a classroom teacher who is teaching for more than 20 years. In fact, I can remember my career started when I was in fourth grade doing a carnival for muscular dystrophy. By the time I was in junior high school, I was working with aphasia children and working in summer camp programs. So this was a life decision that I do today.

I'd like to tell you that NEA has long supported the Individuals with Disabilities Education Act. It's a good law that holds lots of promise. In fact, NEA played an integral role in the reauthorization. At one point when the law looked like it was going to fail, all the stakeholders, including parents, State directors of special ed, administrators, were brought into the building, and they came up with a compromise. With all compromises not everybody got what they wanted, but they got what they needed, and we all agreed it was a good law.

I look around this room today, and I see many of those people, and I like to refer to it as the reunion of the class of 1997 that worked so hard on the reauthorization, but IDEA does hold a lot of promise. Unfortunately, lack of information, inadequate funding, misplaced emphasis on paperwork rather than teaching has created onerous burdens for educational personnel and have jeopardized the education for all students.

I can remember before IDEA 97 was Public Law 94–142. When that law was passed, we would come together in an IEP meeting, and there was a sense of trust. There was a sense of accomplishment as we sat with parents, teachers, administrators and developed a program that would meet the needs of that child. We all felt good about what we did. We'd hold hands and sing Kumbaya and feel good that we had done something positive. Unfortunately today that trust has been broken.

Many times parents come to an IEP meeting feeling that they're going to ask for things that the schools will not give them, and many times the schools are afraid the parents are going to ask for things they cannot give, and the trust is broken. We no longer have an atmosphere of cordiality. We have an atmosphere of hostility and lack of trust.

I've talked with NEA members across the country who routinely express their frustration with the unwanted paperwork. It was not the intent of IDEA to create more paperwork. In effect, educators have made a real commitment and received additional training to teach special needs students; however, they find themselves filling

in the boxes and less time filling in the kids. What we have now is we have more focus on the IEP product and no longer focused on the IEP process.

Much of the paperwork burden stems from the people, the misunderstanding of what IDEA intended. Many times many State and local administrators apply paperwork requirements that are basically to assure they're in compliance, and that's the problem. Under 94–142, we used to look to see if people were in compliance. Today the focus is looking to see if people are out of compliance. That does not lead to good practice. That does not lead to good education.

We need the Federal Government to provide leadership under IDEA 97, to let people know what they truly need and what they do not need in their monitoring process. Too often the district will have things in there that they do not need, and they're not told that you don't need this extra paperwork, and when they're told something is wrong, they don't change it. They add more to it.

NEA also supports the appropriation of sufficient Federal resources to hire professionally certified medical personnel to provide safe quality medical services to our students. In the school district I teach in, we have over 5,000 special ed students. We have four full-time nurses assigned to those 5,000 students. One of those nurses is full time in the school for children with severe disabilities. The other three cover the other 5,000. That's not an appropriate service for our children.

Parents have the right to expect the highest quality services for their children and should not be forced to rely on ill-prepared educators to perform procedures for which they are not trained.

NEA also believes that students who engage in violent or disruptive behavior should be subject to similar disciplinary actions, including suspension and expulsion, as their nondisabled peers, where the misconduct is unrelated to either their disability or improper placement. Too often, however, fear of litigation prevents schools from taking action even when students pose a danger to themselves, other students or school employees. The law allows people to do the job they can if the law is applied and due process is followed. Unfortunately many school districts are afraid of litigation and do not follow the process.

NEA also supports the ramping up to the full 40 percent over the next 6 years for IDEA funding. Let's be honest, IDEA funding is a grant program. There was a promise by the Federal Government that we've never come close to reaching. The current law provides an excellent framework for ensuring the highest quality education for all students with disability. With the proper supports our special education system will meet the needs of all students with disabilities.

I'd like to close to tell you that we have a parallel system operating today. The law now that we have before us allows for the different uses of the funds. We have permissive use of funds that can allow for early intervention programs that hopefully will avoid some of the problems we see today. I remember the day when students could not touch my special ed eraser if they were not special ed students. The law allows us that flexibility. However, we have students in the system that do not have that, were not available

to them at that time, and they present special needs to us. We need to find a way to not only meet the needs of the students who are coming into the system today, but to also meet the needs of the students that are with us.

And finally, when I talk to teachers around the country, I tell them that they're heroes. What they do every day, they're heroes. And a teacher said to me, I'm not a hero, I'm just an ordinary person; a hero is a fireman who runs into a burning building. Well, I would submit to the members of this committee that the teachers are heroes. They do run into burning buildings every day. Unfortunately, like firefighters, they're not adequately trained or prepared to deal with the problems that they will have to face when they run into that burning building.

And last, when I talked to a group of teachers one time about a student with special needs that was about to be included in their school, we went around the room and posted on all four corners of the walls all the concerns these teachers had about educating this child, and at the end I asked them, now that we know what your concerns are, what are your fears, and the teacher looked at me and said, I am a good teacher, and if I do not know how to meet the needs of this child, I will fail, and as an educator I cannot do that.

I ask that we look for providing the adequate training and resources to support the people who do the job every day, and I'd be happy to answer any questions.

Mr. BURTON. Thank you, Mr. Amundson.

[The prepared statement of Mr. Amundson follows:]

STATEMENT OF

ED AMUNDSON

ON BEHALF OF

THE NATIONAL EDUCATION ASSOCIATION

BEFORE THE

COMMITTEE ON GOVERNMENT REFORM

U.S. HOUSE OF REPRESENTATIVES

ON

THE INDIVIDUALS WITH DISABILITIES EDUCATION ACT

February 28, 2001

Chairman Burton and Members of the Committee:

Thank you for the opportunity to speak with you about the critical issue of special education.

My name is Ed Amundson and I have served as the Chair of the National Education Association's (NEA) Caucus for Educators of Exceptional Children for seven years. I speak to you today not only in this capacity, but as a teacher with years of hands-on classroom experience with special needs students. I have taught for over 20 years in California's Sacramento City Unified School system, working with learning disabled students in reading, English, and government studies. I previously worked with severely disabled students in San Mateo County. I have a Master's degree in special education, and am credentialed in both general and special education.

The members of the National Education Association – like all of my colleagues throughout my nearly 30 years of teaching – are committed to providing the best possible education to all students, including those with disabilities. NEA has long supported the Individuals with Disabilities Education Act (IDEA) – a good law that holds a lot of promise. Unfortunately, lack of information, inadequate funding, and a misplaced emphasis on paperwork rather than on teaching have created onerous burdens for educators and have jeopardized the education provided all students.

These burdens have also undermined the fundamental trust among parents, educators, and administrators. Over time, I have witnessed an erosion in this trust, with parents believing that schools do not meet their needs, and school staff believing that parents are asking for services

they simply cannot provide. Parents and educators should be allies – all seeking to ensure the best possible services for students with disabilities. Meeting this goal requires addressing basic implementation problems of the federal law: excessive paperwork, lack of trained personnel, inconsistent discipline rules, and inadequate funding.

Relieving Excessive Paperwork Burdens

NEA members across the country routinely express frustration that unwarranted paperwork is undermining the intent of IDEA to ensure a quality education to students with disabilities. In effect, educators who have made a real commitment and have received additional training to teach special needs students are finding themselves spending more time filling out forms and less time "filling in" students. Documentation is certainly essential to ensure that students get appropriate and necessary services. But, allowing the Individualized Education Plan (IEP) product to take precedence over the process of teaching serves neither students nor educators.

Much of the paperwork problem appears to stem from lack of information at the state and local level regarding federal law. Often, local administrators unfamiliar with the federal law or fearful of litigation require paperwork not mandated under federal law. For example:

- In Birmingham, Alabama, parents must come to the school to sign paperwork stating their agreement to attend a meeting at a later date. Also in Birmingham, all notes about a student's progress on the IEP must be handwritten in the presence of the parent.
- In Port Orchard, Washington, special education teachers need an additional hour each day to complete required paperwork. Paperwork burdens in this district have turned special

education into an entry-level position, with more experienced teachers transferring to general education to avoid the paperwork.

- A Laredo, Texas, NEA member reports that the paperwork problem is exacerbated by the changes in special education forms every two years.
- In Buffalo, New York, teachers are required to write progress reports for each special education student for each goal in the IEP, even though this effort duplicates report cards already sent to parents.
- Teachers in Oklahoma City are required to write behavior management plans for all special education students, even those without behavior problems.

Paperwork burdens are also exacerbated by the federal monitoring process, which has shifted from determining whether schools are "in compliance" and doing their jobs well to looking at whether they are "out of compliance" and failing to do their jobs. Thus, monitors note all failures to provide sufficient paperwork, but never identify excessive or unnecessary paperwork.

Easing paperwork burdens thus requires both better training of federal monitors and improved communication of federal requirements to state and local administrators, educators, and parents.

Providing Adequately Trained Staff for Medical Procedures

Over the course of my career, I have witnessed a dramatic change in the types of services required by students with disabilities. Major medical advances have enabled more students with severe disabilities to attend public schools. Students on ventilators and using feeding tubes now often attend general education classes, taught by general education teachers, with their non-disabled peers. These remarkable achievements have made a critical difference to children with

disabilities and their families. Yet, our special education system has not kept pace with the changing environment, leaving many educators ill-prepared to deal with these new challenges. Most educators have not received adequate training to serve this new generation of students with severe disabilities. Many feel uncomfortable performing medical procedures for which they are not trained, but fear reprisals – including termination or transfer – for failure to provide requested services.

Medical procedures should be performed only by adequately trained and supervised personnel. NEA supports the appropriation of sufficient federal financial resources to hire professionally certified medical personnel to provide safe, quality, medical services for students with disabilities. Unfortunately, such resources are not available in most school districts. For example, my district has only four full-time nurses serving over 5,000 special education students.

Unfortunately, the issue of medical services in the classroom has divided parents and educators – a division that has led to costly and protracted litigation, but has not produced a real solution to the underlying problem. Parents have a right to expect the highest quality services for their children and should not be forced to rely on ill-prepared educators to perform procedures for which they are not trained. Similarly, educators want to ensure the best services for their students.

Allowing Appropriate Discipline

NEA believes that students with disabilities who engage in violent or disruptive behavior should be subject to similar disciplinary actions – including suspension and expulsion – as their non-disabled peers, where the misconduct is unrelated to either the disability or to improper

placement. Too often, however, fear of litigation prevents schools from taking action, even where students pose a danger to themselves, other students, or school employees. For example, school administrators recently prevented a Tennessee teacher who was assaulted by a student from filing a police report, even though the state has a zero-tolerance law requiring such reporting. Thus, fear of a lawsuit and of publicity prevented the school from taking action permitted under federal law and required under state law, and left the teacher and other students in danger.

Students with disabilities subject to disciplinary action should certainly receive due process prior to any disciplinary action. In addition, students with disabilities who are removed from the classroom should continue to receive educational and social services in an alternative setting. These protections should ensure appropriate discipline implemented in a fair and equal manner, and should protect education employees and students from potentially dangerous behavior.

Ensuring Sufficient Funding

Providing a quality education for all students, including those with disabilities, requires federal assistance to help states and school districts fund special education services. In fact, a number of the problems discussed here today are attributable at least in part to lack of funds.

IDEA '97 authorized the federal government to provide up to 40 percent of the nationwide average per pupil expenditure (APPE) to help meet the cost of educating students with disabilities. In fact, since the enactment of the original Education for All Handicapped Children Act of 1975, the federal government has pledged to pay 40 percent of the APPE. Currently,

however, the federal share totals only around 15 percent. Consequently, many states and local school districts are unable to meet the educational needs of students with disabilities.

Lack of funding often leads administrators to make decisions based not on the best interests of the student, but on budgetary considerations. Schools may seek to reduce the number of students classified as special needs or to restrict the services available to students. And, as I noted earlier, administrators may require additional paperwork as cover to avoid costly litigation. Perhaps most troubling, inadequate funding means that many schools lack the necessary trained staff to provide needed services.

The lack of sufficient funding to meet the needs of students with disabilities also places considerable strain on the entire school budget, as administrators are forced to increase tax revenue or cut other critical programs to provide mandated IDEA services. In addition, efforts to improve student achievement through implementation of higher standards, and other discretionary educational reforms, often must take a back seat to the provision of mandatory IDEA services.

NEA supports "ramping up" to the full 40 percent of APPE over the next six years. Students with disabilities and their families deserve more than an empty promise. NEA also supports making IDEA funding mandatory, thereby ensuring full funding of all necessary services, protecting special education from the unpredictable annual appropriations process, and freeing significant discretionary funds for other critical priorities.

Conclusion and Recommendations

Current law provides an excellent framework for ensuring the highest quality education for all students with disabilities. For example, today's early childhood intervention programs may help address many behavioral and learning issues before they become real problems for students. With the proper supports, our special education system will be able to meet the needs of all students with disabilities in the future.

However, our task now must be to ensure the best services for those students currently in school. Doing so requires recognizing the changing nature of special education and the students we serve, including:

- Reducing paperwork burdens so education employees can focus on teaching;
- Addressing the needs for additional training and resources for both general and special education employees;
- Recognizing the impact of the addition of special needs students to general education classrooms, and providing the supports to overcome these challenges;
- Ensuring that parents, education employees, and administrators understand the requirements of federal law and have reasonable expectations of what services can be provided;
- Providing appropriate training for federal monitors to allow them to focus on helping schools do their jobs well;
- Allowing schools the flexibility to discipline students with disabilities who may pose a danger or who disrupt classroom activities; and
- Ensuring full funding of the federal government's commitment to pay 40 percent of the APPE.

Overall, we must make a real commitment, at the federal, state, and local levels to support special education – with sufficient financial resources to ensure the highest quality services. If we do not do this, we risk losing the talented professionals who have dedicated themselves to teaching students with disabilities, and we risk failing the students and families who rely on us.

Thank you.

Mr. BURTON. First of all, I'd like to ask all of you if you could—I'd like to ask all of you the same things that I have asked the other panel, and that is, suggestions that you might have that could improve the IDEA program. I think it's important that we realize that there are some shortcomings, and we're not pointing fingers at any individuals or any group of individuals, and if we can figure out a way to make it better, make it more effective without creating more bureaucracy and more paperwork, then I think that would be a giant step in the right direction.

So while you're thinking about them, let me just ask a couple of questions.

Ms. Baird, as Mr. Mayerson was saying, I'm looking at this program agenda, I guess, for one of your presentations. It says, special education for early childhood autistic students, how to avoid parent demands for LOVAAS/TEACCH methodologies. You know, I mean, maybe that's a legitimate topic, but it seems to me that maybe could have been worded a little bit differently, because parents are concerned about the well-being and the education of their children, and having been involved personally in one of these meetings and experienced it, I think that you know parents don't want to demand any more than they think is necessary for their kids. They want them to be educated. They want them to be able to be educated. They don't want them to be a burden on society.

I mean, my grandson, I'm going to give you an example, he's going to be 6 foot 10. You know, I'd like for him to be in the NBA so he can support me, you know, and I'm kidding, of course, but the point is the doctor said he's going to be very big. Now, he's autistic. He ran around the house flapping his arms and—but he's doing much better now. His doctor, who is an expert in this field, said that he needs at least 2 hours a week of speech therapy, and so he can progress properly. The school, as you heard previously, had a meeting before we even got there and had decided that 1 hour was sufficient without even talking to my daughter or myself.

And those sorts of things really bother parents because they have an expert in the field, a doctor who studied, who got his degree in that area, and who has worked with thousands of children, and a young lady who is 23 or 24 years old in the school system there, probably a very good speech therapist and good teacher, made a determination that half of that was sufficient. And so when I see something like this and a parent hears about that or hears you making a statement at a meeting that, you know, parents want a Cadillac, but you guys only have to give them a Chevrolet, explain that to me.

Ms. BAIRD. I'd be happy to explain that, and I appreciate you giving me the opportunity to explain that. I suppose that the statements you're referring to, although I don't recall it directly, is from the program that I recently did. The title of the program was Building a Blueprint for a Defensible Autism Program. The intent of that——

Mr. BURTON. A defensible autism program?

Ms. BAIRD. Yes. And never in my career have I had such a response from a title of a program. Let me explain and clarify.

Mr. BURTON. Sure.

Ms. BAIRD. A defensible autism program is one that is appropriate for the individual child based on that child's unique needs. The whole intent of that program—and, frankly, I was a little personally affronted by it, because myself and Melissa Genaux, who was my colleague, who did the programs, developed those programs and went on the road to do that for one reason and one reason only, and that was to take information to school districts about what they were going to have to do to develop appropriate programming for children with autism. In no way was it in an effort to get around appropriate programming or to somehow avoid it.

And I would love to explain the Chevy versus Cadillac analogy. That is not mine.

Mr. BURTON. Before we get to that, if you could explain how to avoid parent demands? I mean, gee whiz, you have a parent who's not a Congressman, who doesn't have all the ability to raise hell about these things, they don't know the legal process, and they see that you're talking to people in a school corporation and you're saying how to avoid parent demands, and they've got a child that's autistic, how are they supposed to interpret that?

Ms. BAIRD. Well, again, Congressman, all I can tell you is that the intent of the program was to educate schools about providing appropriate programs. I'm not an expert on autism. Neither do I claim to be. I'm an attorney who's had some experience in this field. I have had a lot of experience with parents making demands for particular methodologies, including LOVAAS/TEACCH, the Orton Gillingham method for children with learning disabilities, different methodologies.

So the intent of the program was not to say to a parent, you can't have what you want. The intent of the program was to educate school districts. And I might add that in every single session if you want to get down to the bottom line of the session, my message to school districts was, and here I will agree with Mr. Mayerson, that the LOVAAS methodology, which is conditioned upon the principles of applied behavior analysis and discrete trial training, has been scientifically proven to be a positive methodology for children with autism and other children with severe disabilities, and as a matter of fact, I have heavily advocated to my clients and to those people who have come to the seminars that they must include applied behavior analysis and discrete trial training in any effective and appropriate program they develop for children with autism, and I have been very consistent about that.

Mr. BURTON. I will have some more questions, but I will now yield to Mr. Allen for questions.

Mr. ALLEN. Thank you, Mr. Chairman.

Mr. BURTON. I believe you have been here longer. Would you like to go first?

Mrs. MALONEY. Absolutely. And I was listening, I had some constituents who came to visit me, and I was out in the hall.

Mr. BURTON. And I know that you're very resigned to always being last and everything, but I don't want you to get upset today. So go ahead.

Mrs. MALONEY. Thank you, Mr. Chairman, but I really would like to followup on your level of questioning and the theme that you have presented.

I'd like to ask Mr. Mayerson, are there sufficient remedies at present to ensure that school districts will comply with IDEA, and if not, do you have any recommendations for the committee?

Mr. MAYERSON. Well, I think as we've said today that really is the million-dollar question. I don't think I'll have to call my lifeline to answer that one. First of all, I think—the parents have to have faith in the integrity of the system. We start with that. That means in order to have an impartial hearing, it really has to not only be impartial in fact, it has to look impartial.

For example, in the State of Utah, where there's a Federal lawsuit pending right now to challenge the way that they select their hearing officers, the fact of the matter is not a child has ever won in the State, has ever been the substantially prevailing party ever in the State of Utah, ever. No child has ever won. Now, that may actually have an impact on the kind of statistical data that Ms. Baird is collecting recently and have something to do with the fact that virtually all of the hearing officers that are on the list—to get on the list, virtually all of them are connected. They're either the special administration director of the neighboring school district, or they're the attorney for the neighboring school district, and a parent doesn't have a chance. So that's one thing, create an integrity in the system.

Two, there's a section that you have in this Code of Federal Regulations, 34 CFR, section 300.403, and what this section does, it says that if the hearing officer finds that the parents engaged in some kind of inequitable conduct or unreasonable conduct, that a child that otherwise would have prevailed at the hearing, the hearing officer has the discretion to knock down the award or even to eliminate the award.

You know what? That's fair, but what's fair is fair, too, and I say if you're going to have a section like that that basically puts the onus on parents, that if they're not unreasonable, that they could lose their child's award, that you must also have the same kind of accountability for school districts; and that if, in fact, you have the kind of examples of patent bad faith that I've appended to my submission, that if the parent can prove that and has to go through, as I've recently gone in Ms. Baird's home State of Tennessee, a 30-day hearing for a family that is teetering on the verge of bankruptcy, that if a family like that can prove bad faith, like almost a punitive damage kind of remedy, that I don't want to encourage litigation, but if it reaches a certain level of patent bad faith, and the hearing officer so finds, that's the kind of accountability that I believe that school districts will be very careful about, because right now if you're the school district, it's not like the parent that has to go and open a checkbook. Everybody can point the finger at everyone else. It's no one's checkbook because it's the district's checkbook. And if the district has to just give, at the end of the line of the litigation, after 30 days of hearing, precisely what they should have given without litigation, maybe some attorneys' fees, you know what, it's no big deal because many districts are afraid of precedent. They're saying, you know—and it's in my submission—they say, we are afraid not of this child, but of the maybe six or seven other children we may have to pay for. So we would

rather delay this child in a 30-day hearing and maybe we'll buy 2 years than to give all six of those children an intervention.

And I just want to point out one other thing about the cost aspect in answering because this is a huge point. This is the point, the cost. There is a cost-benefit analysis that's appended to my papers, was published in a peer review journal, that shows that you might for these children with autism spend several hundreds of thousands dollars on an up-front basis to get them the right intervention, but if you don't do the lifetime costs of it are totaling several million dollars per child. That's something I think Congress can easily understand.

Even if you look at this from the perspective of the administrator, who may be looking at just this year's budget, let's just fix this year's budget, you have to have a long view, and if you take a long view, it is more cost-efficient to provide the intervention up front even if it does take several hundred dollars. It's not cheap. We give children that need lifesaving operations $300,000 surgeries, and we should, but we shouldn't shirk from giving those children the same type of interventions if it is required to get them into—to have some kind of functioning so they can join society and have jobs and be in regular education.

Thank you.

Mrs. MALONEY. Well, my time is up, but did you mention that Ms. Baird had visuals and brochures of how the school districts did not have to live up to their responsibility?

Mr. MAYERSON. Well, yes, there are——

Mrs. MALONEY. Could you give them for the record?

Mr. MAYERSON. They are in the record, and I put them in the record. One of them in particular is how to build a legally defensible autism program. Another one of the brochures is also in there. Apparently there's hundreds of them, and they are not for parents. I take issue—although some parents have been managed——

Mrs. MALONEY. They're not for parents? They're for the school district? Who are they for?

Mr. MAYERSON. No. The first brochure that I put in is called a private briefing for administrators, school districts and so forth. Maybe a parent might accidentally be able to get in and see what goes on, and that's, in fact, how I got the first brochure.

Mrs. MALONEY. Do you mean to tell me that they're handing out brochures on how school districts will not respond to parents or live up to the law; is that what you're saying? Is that what you're saying?

Mr. MAYERSON. Congresswoman Maloney, not only am I saying it, I have one of the brochures, which is tab 6 of my presentation. It's entitled "A Private Briefing Designed for School Board Members, Central Office Administrators, Special Education Directors, Building Administrators and Regular Educators Focusing on Special Education Issues." It was presented by a law firm in Missouri called Peper, Martin, Jensen, Maichel and Hetlage, as well as the Missouri Association of School Administrators and the Missouri U.S. Insurance Council, which insures the districts when they get hit with due process complaints. And page 2 is entitled——

Mrs. MALONEY. Is that legal to hand out that kind of information on how to shirk the law basically?

Mr. MAYERSON. In fact, I wrote to everybody involved and expressed my outrage that taxpayer money, which obviously the school districts that attend this have to pay with taxpayer money to attend these seminars, and expressed my outrage that this—such money was going for such purposes, and all that has succeeded in doing is sanitizing these kind of presentations so now we have this thing called "How to Build Legally Defensible Autism Programs." I think it's the same presentation, just under a different name.

Mrs. MALONEY. That's unconscionable.

My time is up. Thank you, Mr. Chairman, for focusing sunshine on this issue. I think it's a very important one.

Mr. BURTON. I hope that you and possibly Mr. Allen and others on both sides of the aisle will work with us to create maybe some corrections to the IDEA law so that we can make sure that some of these problems are eliminated.

Mr. Allen.

Mr. ALLEN. Thank you, Mr. Chairman, and thank you for holding these hearings. I certainly appreciate the chance to focus on this particular area, I guess I should say.

Let me just say a few words. I come from the State of Maine. I represent the district around Portland, ME, and over the last month I've had about four different meetings, actually about six, with parents and educators and teachers. In four of those meetings in specific school districts, we were running through a list of different problems that they were having, and in Maine you should know we have about 230 school districts. We are sparsely populated, we're spread out, and our school districts tend to combine several different municipalities at once.

The No. 1 problem mentioned over and over again was the level of special ed funding from the Federal Government. The other two were how are we ever going to recruit new teachers, and how are we going to build new schools, but those were the three. Special ed was the top.

In Maine I think we've got a special ed program that in broad measures works and works fairly well; 16 percent of all Maine children are in some form of special ed. We're doing a good job, I think, of identifying the kids who need it and making sure they get the services they need, but we do have resistance from school boards because despite the success of the program overall, there is a huge problem.

Special ed spending at the local level is eating up a large part of the available increases in funding overall. So there are three groups that are impacted, special ed kids, kids with disabilities, and the property taxpayers who are now picking up an undue share of the expense. It seems to me that because the Federal Government issued a mandate for special ed and then didn't fund it at the goal of 40 percent, we're putting a tremendous financial burden on our municipalities and school boards, and it seems to me—oh, one other thing just by way of background, Maine does an educational assessment for 4th-graders, for 8th-graders and 11th-graders, and it takes about a week. It covers a whole variety of subjects. One superintendent told me the other day that the fourth grade—

in his fourth grade reading test, 14 percent of the kids failed. Of those, despite the special help, 60 percent were special ed.

So one of my questions is to you, Mr. Amundson. I am concerned if we start to do relatively high-stakes testing, it seems to me we're going to come back to a problem of whether or not our special ed programs are working well enough so that kids who are getting these services being brought up to a par with regular students. That may not be possible, but it seems to me that the testing issue is very much connected to the funding issue.

Before I let you speak, I want to say one more thing. I believe we need to do full funding now, no phase-in, no nothing, just go straight to full funding now. It is $11 billion more than current levels for the next year, and this is probably the only time in the next 10 years that we can do it, and we can only do it if the tax cut, the proposed tax cut, is reduced by the $150 billion or $200 billion it would take to fully fund special ed over 10 years. That, I think, would transform the effect of this program on our local school districts, and I know you have been calling for it, and other people have called for it. This is the only chance I think we'll have to do it, and it seems to me it ought to be done, but I would like Mr. Amundson or anyone else to turn back for this question of how a testing—a tougher testing regime will affect the overall special ed program.

Mr. AMUNDSON. Well, Congressman, several months ago I posed this question to my special ed class, government class, seniors. In California they're instituting an exit exam for all high school seniors in order to receive their diploma, as well as we have the API, the Academic Performance Index, which is based on standardized testing at all grade levels, and schools' performances are judged on these standardized tests.

As an organization, as a teacher, I believe in assessing my students. I believe that's important to find out the progress they're making, but I also believe the testing needs to be curriculum-based and based on the instructional strategies that I'm utilizing in my classroom and measuring what the students are learning. Too often the standardized test measures what the students do not know and doesn't really measure what they do know. I've heard students say that sometimes they just color in patterns on the test because it has nothing to do with the curriculum they have in the classroom, and we are using that as a measure of whether students or schools are succeeding. I saw a cartoon in the "USA Today" about today's curriculum the teacher's written on the board. We have art, poetry, recess, and then standardized testing, and that was today.

I think the testing does have a role, but what I'm seeing now is many teachers are afraid to have special needs students in the classroom because if they're going to be assessed on the success of those students, and the appropriate accommodations and modifications necessary are not allowed for those children, then the scores in the classroom could well come down, though research does show in many cases scores actually go up when students with special needs are included, because not all students are learning-disabled or have academic difficulty. But what does happen is teachers are fearful that they will be measured on things that they cannot control when they were the ones who said, I want this child in my

classroom, I want to educate this child, but now that I can't control an environment of the accommodations and modifications, I may be judged on that, and I may lose out on moneys or funds that will be given to the school, and I'm the one who volunteered to take this child.

So it does have an impact, and I think the exit exam in itself, we're going to be creating two separate educational systems, one for children who are on a diploma track and one for children who are not, and I think that's the concern, because if you look at what the standards are based on, 100 percent of the curriculum in high schools is geared toward the Carnegie units and how students apply to universities; 30 percent of the graduate population goes on to complete a 4-year degree; 70 percent of our population is left out of the goal of the high school curriculum, and it's not just special needs students. There are general ed students that are going to be involved, too. So I think we have a bigger question, not just on the special ed issue, but it does severely impact in what people are trying to do.

Mr. ALLEN. Thank you.

Mr. BURTON. If you'd like to ask more questions, I will get right back to you. Let me just followup on that, and this really, I guess, doesn't follow the topic of the hearing, but it seems to me that there ought to be some way to come up with some kind of a testing program that will be able to test whether or not the children across the country—some kind of a standardized test program that would take into consideration the special needs children and the other kids that are in the classroom, and I hope that the NEA will maybe work with those of us in Congress who believe that we've got to have some kind of a measuring device to decide whether or not kids are coming out with the kind of quality of education we want.

I don't know that you need to make a big, long comment on that, but, you know, the President has said I think in his State of the Union Message and others that he wants testing to make sure kids at certain grade levels are achieving. And I understand the concern of teachers who have special needs kids, and there are others who may not be able to move up as rapidly, and the average would bring them down and make them look like they're not good teachers, but there ought to be some system devised with the help of the NEA and other teachers' unions to take that into consideration.

Mr. AMUNDSON. Well, briefly, Congressman, you should take a great deal of pride that the State of Indiana has a very unique testing system that does not just base itself on standardized testing, but also has a special three-prong program. Students can go through and take the standard tests to receive their diploma. There's a second pathway that students who are enrolled in a special instructional program, when it seems that they have difficulty, to be able to do better on the test, and they receive extra tutoring. And there's a third program that requires 95 percent attendance as well as a portfolio of assessment of the student given to them by the teachers of them to say they may not do well on tests, but they demonstrate knowledge. And I think Indiana is a model that we're looking at that other States should be incorporating.

Mr. BURTON. Well, that might be one of the things that you could recommend that we'll take a look at, and I will talk to my col-

leagues in the Indiana Education Association, ISTA, and talk to them about that.

I don't want to get into a big, long debate about these issues. I know Ms. Baird has one position, maybe Ms. Guard has another, Mr. Mayerson has another, and Mr. East another. What I really would like to have is suggestions from you that we can all take a look at to make it—to make the IDEA program better, to make it more workable, to make sure that special needs children do get the best education possible. And so if you could just real briefly give me a couple of suggestions, or maybe if you're not prepared to do that right now, get them back to us. I really would appreciate it so that we can take a hard look at the current law and see if we can't make it better.

Parents like my daughter, parents like the ladies and gentlemen who testified here today who have autistic children or special needs children, they're so frustrated, they don't know what to do. Some of them have almost gone bankrupt trying to take care of their families, make sure their children get a quality education. So something needs to be done to make sure they have confidence in the system, No. 1; and No. 2, that the kids do not become a burden on society when they become 6 foot 10 and they're adults. I mean, my grandson is going to be a big guy walking around like Shaquille O'Neal, and I want him to be able to at least get a job. I don't want him to be sitting out under a tree someplace not able to deal with society. And I know parents all across the country feel like that.

So give me some ideas that we can incorporate into our thinking, and I will start with you, Ms. Guard. Do you have any that you would like—or would you like to get back to us?

Ms. GUARD. Yes. I can certainly tell you some of the challenges that districts are facing as they implement the current law. I'm not in a position to talk about changes that we would recommend for them.

Mr. BURTON. All right. Well, would you do me a big favor, and if you could get back to Beth, that's my chief expert on these issues, if you could get back to her with some suggestions we'd appreciate it.

Ms. Baird.

Ms. BAIRD. Yes, thank you. I would like to reiterate a theme we've heard all day long, and that's increasing funding for special education programs and services.

Mr. BURTON. We're going to work on that.

Ms. BAIRD. The other comments that I would make come to you from the many, many comments I hear from schoolteachers and administrators as I go out and talk with them. I know that there is pending legislation to retool or refine the discipline requirements in the IDEA. I can tell you from the local school base there's a lot of interest in doing that. I would hope that part of the increased funding could go for behavior management techniques and training for schoolteachers who are dealing with students with emotional problems and behavior problems and for alternative school programs.

Reduction in paperwork is a major priority that the people that I talked to are interested in. The paperwork burden has increased, not decreased, after the reauthorization. And one of the final——

Mr. BURTON. Let me just interrupt on that point. We need some guidance on how you reduce the paperwork. Just to make a general statement, reduce the paperwork, I mean, there must be forms and documents that have to be prepared about a special needs child. What I'd like to have more specific is how do we reduce the paperwork, how do we consolidate the amount of questions that are asked so that we can get through that quicker.

Ms. BAIRD. Well, it goes back to the requirements of the law, and I was about to say that in 1997 there were sweeping changes made in this law in order for school districts to document and prove that they are in compliance. And I agree with the comments Mr. Amundson made. Pardon me for mispronouncing your name. We have gone far beyond the original intent of what an IEP is supposed to be, and in order for a school to have a defensible appropriate program, it's an incredible amount of paperwork in terms of IEPs, goals, objectives, short-term objectives, manifestation determinations, and I'd be happy to provide a list of some of those things later.

There's also another area, the last one I'll mention. I get a lot of input and interest from clients and school personnel on the category of emotional disturbance. There's a tremendous increase in the number of students with behavior problems in public schools and a tremendous amount of longing among school personnel for techniques in how to deal with those students. The law has always and still does exclude students with social maladjustment, but we have never had a definition of what that means, and those would be the comments I would make.

Mr. BURTON. Mr. Mayerson.

Mr. MAYERSON. I know you're looking into the causes of autism, and we really have no control over that.

Mr. BURTON. No. We have people who testified today that the children were autistic from birth. We have others who had autism, they believe, coming right after certain kinds of vaccinations.

Mr. MAYERSON. I think in that case I would defer to science, and I know that right now if you look at science, there is no testing for autism which is scientifically reliable before the age of about 15 months, so that I think—and I also agree with you, Mr. Chairman, when you say that you have to look to parents, because if they're doing it 24/7 with the child, they know things that other people just don't know.

So anyhow, I would be saying that I would like to, with permission of the committee, I would propose to draft some proposed sections to modify the current statute in such a way that would, I believe, simplify; to provide a disincentive to school districts as well as to parents to engage in inequitable or bad faith conduct which nobody wants from either side; as well as the whole issue of oversight on the funding, where the money goes and how to make sure that it really gets to the children as opposed to just building up layers of administration and bureaucracy that nobody wants.

Mr. BURTON. We'll welcome your suggestions, and if you want to put those in writing, that would be very well received.

Mr. MAYERSON. I will do so.

Mr. BURTON. Mr. East.

Mr. EAST. Mr. Chairman, we will put our thoughts in writing as well.

I will just mention a couple of things. Once you get beyond the full funding issue, there are two things that really come to my mind that I hear from our members, and that is, there's just a critical shortage of properly trained personnel across this country that work with people with disabilities. That is not only special education teachers, but the general education teachers who are now dealing with special education students in their classrooms. They don't know what to do.

Mr. BURTON. Let me interrupt. We—I said in my opening statement, I don't know if you heard it or not, that we might come up with a program which would—in exchange for teachers being—getting their educational benefits provided for them, that would spend 4 or 5 years in special ed training and teaching of children in urban or rural areas, that they would get their expenses for education paid in exchange for the commitment to teach in that environment for at least 5 years. We do that for medical students. What do you think about that idea?

Mr. EAST. I think that's an excellent idea. What I'm concerned about, though—and that would help us in the future. What I'm concerned about is all the thousands of teachers that are already out there, and they have children in their classrooms right now, and they need training and support of general and special education teachers, because IDEA 97 did change the way that we do business because we're exposing children with disabilities, more and more of them, to the general curriculum. That's good, but the teachers that are teaching that general curriculum don't know how to work with these children.

Another thing is I think we need to continue to work toward a strong focus on student results and system accountability. State directors of special education promote this and support it. We have accountability now, higher standards, greater expectations for promotion and graduation. We want those for special education students as well, but we've got to focus on it. Special education for so long has been focused on do you have the paperwork in place, is everything in the folder in the right order. Now we need to focus on is the child learning, what are their scores on assessment, and what do they do in adult life after they leave us. And so the focus on results accountability is what we need to look at.

Mr. BURTON. If you could, we've written that down, but if you could send us any additional information you have, we'd like to have that.

Mr. EAST. We'd be glad to.

Mr. BURTON. Mr. Amundson.

Mr. AMUNDSON. There'd be three things. No. 1, we do need strong leadership from the Federal level. Too often the Feds take too much blame and too much credit for things about education, but we do need strong leadership as to what States are expected to do.

I also think that we need a maintenance of effort to assure that the increased funds that come in do not limit the obligation of State and local districts to what they're currently spending and to shift funds from one side to the other.

I think the issue of training is very significant, both pre-service and in-service training for our teachers, because if they don't adequately prepare, they won't be able to do the job.

I think your grant program is an excellent idea in some ways and the other way, one of the problems of special ed is, for many people it was the entryway into the education profession, and then after 5 years they leave when it becomes overly burdensome.

The problem is, because of the constraints and some of the difficulties in special ed, they leave. We can have lawyers and laws all we want, but once that bell rings and Betty Bob walks in the door, the door closes, and Mrs. Miller does her job. She teaches. If the system we have today doesn't change, Mrs. Miller won't be there, no matter how much money we have or how many laws we have. We need to make a program that allows teachers to do the job they need to do, which is to teach and work with parents.

I think those would be some of the key elements we need to look at.

Mr. BURTON. Do you think that the lack of discipline in schools is one of the major reasons why we're seeing an exodus of teachers?

Mr. AMUNDSON. I think the lack of understanding of how to implement the law in our schools is why we're seeing—in discipline.

I heard in Tennessee an administrator told a teacher they could not file a police report on a special ed student even though the law is very clear they're allowed to do that, and Tennessee law requires that to be done. So we have misapplication of the law, and that's one of the problems with discipline. The law allows us to deal with the discipline of children if the procedural safeguards are followed. Too often fear of litigation and publicity does not allow administrators to properly implement what was put in IDEA 97 which does hold students accountable for their behavior.

Mr. BURTON. Maybe we need to clarify that a little bit more if we're going to——

Ms. GUARD. Excuse me, Mr. Chairman. We did recently issue guidance for administrators to follow, to let them know what their requirements are and how to implement those requirements.

Mr. BURTON. That was widely disseminated?

Ms. GUARD. On our Web site.

Mr. BURTON. I want to thank you all very much for your suggestions and your patience and your hard work. And hopefully you will have some suggestions that can help us make some changes.

Thank you very much. We stand adjourned.

[Whereupon, at 4:22 p.m., the committee was adjourned.]

[The prepared statements of Hon. Thomas H. Allen and Hon. Dennis J. Kucinich follow:]

STATEMENT OF
REPRESENTATIVE TOM ALLEN
BEFORE THE GOVERNMENT REFORM COMMITTEE
ON THE INDIVIDUALS WITH DISABILITIES IN EDUCATION ACT

February 28, 2001

Mr. Chairman, thank you for calling this hearing to examine special education and the effectiveness of the Individuals with Disabilities in Education Act (IDEA). I commend your efforts to determine whether IDEA is working as Congress intended.

In conversations with teachers, legislators, families, and others back in my home state of Maine, it is evident that the number one challenge facing local school districts today is the cost of educating special education students. When IDEA was enacted in 1975, Congress authorized the federal government to cover 40 percent of the costs of special education in order to provide all students with disabilities with a free and appropriate public education. To date, however, the government has never provided more than 14.9 percent.

The failure to meet our long-standing commitment to help cover special education costs is unsettling and devastating. Everyone suffers. Students with disabilities suffer from inadequate services. Students without disabilities suffer because funding for their programs is diverted to special education. Homeowners suffer from high property taxes to make up for the federal government's reneging on its commitment.

Over the last few years Congress has heralded the need for full funding. But, we never get there. In the 106th Congress, the House passed a resolution urging Congress and the President to fund fully its obligations under IDEA. But we never got there. We repeatedly talk about gradual increases to 20 percent, and then 25 percent, and so on and so forth. But we never get there. It is time to forget the talk. We must act and provide 40 percent. We can get there, and we can do it now.

The budget debate in Washington right now is not about billions, but it is about trillions: $5.6 trillion in surpluses and $1.6 trillion (or more) in tax cuts. Last year, we spent $6.3 billion on grants to states for special education assistance. To reach the full 40 percent funding formula for FY 2002 it would cost approximately $17.6 billion. Therefore, full funding of IDEA would require an increase of a mere $11 billion. With these kinds of surpluses and tax cuts on the table, do not tell me it cannot be done. If we forgo only a fraction of the President's tax cut proposal and enact a responsible, fair cut, we can help states, towns, and cities meet the needs of all their students in a way they choose. Full funding of special education should be an old promise with a new future.

On the national agenda, there is much talk of education reform and how to leave no child behind. Proposals have been aired to cut funding for failing schools after three years. Well, Congress and the President should first look at its own track record regarding special education before we sanction others. We have been failing since 1975. But that does not mean we have to

keep failing. We can succeed by meeting our 40 percent obligation.

Again, thank you, Mr. Chairman, for arranging this hearing. I am eager to hear from all the panelists, and I look forward to working to ensure that the federal government finally meets its mandate of funding 40 percent of special education costs. The time is now.

Statement of Rep. Dennis J. Kucinich
Government Reform Hearing
"Special Education - Is IDEA Working as Congress Intended?"
February 28, 2001

Mr. Chairman, twenty-six years ago Congress passed the Individuals with Disabilities Education Act. This landmark legislation guarantees the right to a free appropriate public education for all students with disabilities. Before 1975 over one million students were excluded from public schools and denied the opportunity to live up to their potential and graduate from high school and obtain gainful employment.

Congress authorized the federal government to pay up to 40 percent of each state's excess cost of educating children with disabilities. However, not once has Congress fulfilled its obligation. Under the FY2001 appropriation for Part B of IDEA, $6.3 billion, states receive only about 14.9% of the additional cost required to educate students with disabilities.

As a member of the Education and the Workforce Committee I work to provide all students in this country with a quality education. As a Representative from Cleveland, Ohio I also closely monitor the education system in my district. In the Cleveland Municipal School District, of the 73,000 students enrolled, over 10,000 students have physical or mental disabilities. Nine thousand of these students suffer from major disabilities. In Ohio, students scoring below 80 on an IQ test attend special education classes. By not fully funding IDEA, school districts like Cleveland Municipal School District are not able to pay for priorities such as classroom size reduction, school renovations and computer equipment.

IDEA works. More students with disabilities are now graduating from high school, going to college and entering the workforce. It is imperative that every school is able to obtain the funds needed to provide disabled children with the quality education they deserves. Therefore, I strongly support fully funding 40% of the additional cost of educating children with disabilities.

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