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New Functional Assessments for Children Raise Eligibility Questions

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Health, Education, and
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The Honorable Herb Kohl
The Honorable David Pryor
United States Senate

The Honorable George W. Gekas
The Honorable Gerald D. Kleczka
The Honorable Blanche Lambert Lincoln
The Honorable Nick Smith
House of Representatives

The number of children receiving Supplemental Security Income (SSI) benefits has nearly tripled over the last 5 years from 300,000 to almost 900,000, and benefit payments now exceed $4 billion annually. The Social Security Administration (SSA) awards SSI benefits to disabled children who live in families with low incomes and limited resources. A number of factors have contributed to the growth in children's awards, including outreach efforts by SSA and child advocates, rising numbers of children in poverty, and major changes in the criteria for determining whether children are disabled. Growth has been especially rapid in awards to children with mental impairments.

Particularly troublesome have been allegations that parents coach their children to fake mental impairments by misbehaving or doing poorly in school so that they can qualify for cash benefits. These benefits can amount to almost $5,500 per year for each disabled child.[1] The coaching allegations, which have been widely reported by the media, have created the perception among the public that the program is vulnerable to fraud and abuse. In addition, concerns have been raised that the program could foster lifelong dependence on government assistance if children come to view the label "disabled" as a lifetime entitlement to income and medical benefits. Finally, concerns have been raised about whether the program's eligibility criteria for children are too lenient. As a result of these concerns, reform of the SSI childhood disability program is now the subject of congressional scrutiny.

In our October 21, 1994, briefing, you asked us to report on SSA's new way of assessing children's impairments using the individualized functional assessment (IFA) process mandated by the Supreme Court in Sullivan v.

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[1] Benefits generally are provided without regard to the number of SSI recipients in the household. SSA estimated in March 1994 that 125,000 children receiving SSI lived in households with at least one other SSI recipient.

Zebley. The new IFA process permits the award of benefits to children with impairments that are less severe than the impairments that previously could justify an award. We assessed (1) the IFA's impact on the SSI rolls, (2) its implementation by SSA, and (3) its vulnerability to coaching.

To develop the information in this report, we (1) reviewed SSA's childhood disability program policies, procedures, and records, and discussed the IFA process with SSA program officials on the national, regional, and local level; (2) interviewed officials in state disability determination services (DDSS); (3) reviewed SSA's study of decisions made on childhood cases involving behavioral and learning disorders; and (4) attended a June 1994 SSA training course designed to address the problems raised in the study. We also discussed eligibility issues with officials of the Department of Health and Human Services' (HHS) Office of Inspector General (IG), which recently issued two reports on the SSI childhood disability program. (See app. I for more details on our scope and methodology.)

Results in Brief

Changes in the regulations governing childhood eligibility for SSI have had a significant impact on the growth and composition of the childhood disability rolls. In particular, awards have been made to more than 200,000 children who did not meet SSA's listing of impairments but instead qualified for benefits based on the less restrictive IFA criteria. These awards account for about $1 billion a year in benefit payments. About 84 percent of the children qualifying based on IFAs have mental impairments, and about one-half of the awards for behavioral disorders, including attention deficit hyperactivity disorder, are based on the IFA criteria.

In our analysis, we found fundamental flaws in the IFA process. Specifically, each step of the process relies heavily on adjudicators' judgments, rather than objective criteria from SSA, to assess the age-appropriateness of children's behavior. As a result, the subjectivity of the process calls into question SSA's ability to ensure reasonable consistency in administering the SSI program, particularly for children with behavioral and learning disorders.

In addition, rapid program growth, particularly in the award of benefits to less severely impaired children, may also have contributed to the public concern that parents could be coaching their children to fake mental impairments in order to qualify for benefits. Studies that we reviewed, however, have found little evidence that coaching is widespread, but they relied solely on documentation in case files and, therefore, cannot rule out coaching. Although coaching allegations are troublesome, substantiating them and measuring the extent of coaching is virtually impossible.

Background

Since 1974, the SSI program, under title XVI of the Social Security Act, has provided benefits to low-income blind and disabled persons—adults and children—who meet financial eligibility requirements and SSA's definition of disability. SSA determines applicants' financial eligibility; state DDSs determine their medical eligibility. DDSs are state agencies that are funded and overseen by SSA. To meet the financial test, children must be in families with limited incomes and assets.

In 1994, children's federally administered SSI payments totaled $4.52 billion. Depending on the family's income, an eligible child can receive up to $458 per month in federal benefits; 27 states also offer a supplemental benefit payment. Because SSI is an individual entitlement, no family cap exists on the amount of benefits received in a household. With SSI eligibility usually come other in-kind benefits, most notably Medicaid and Food Stamps.

The Social Security Act defines a disabled child as a person under age 18 who "suffers from any medically determinable physical or mental impairment of comparable severity" to one that disables an adult. The statute defines adult disability in terms of an inability to work either in a former job or in any other job in the national economy. Specifically, adult disability is defined as the inability

> "to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to last a continuous period of not less than twelve months."

Because children are not expected to work, however, this definition is not applicable to measure disability in children.

At a DDS, childhood disability determinations are made by an adjudication team consisting of an examiner and a medical consultant. For mental impairments, the consultant must be a psychiatrist or child psychologist. The examiner collects all medical evidence—physical and mental—either from medical sources who have treated the applicant or from an independent consultant if more medical information is needed. The examiner supplements the medical information with accounts of the child's behavior and activities from the child's teachers, parents, and others knowledgeable about the child's day-to-day functioning.

Working together, the DDS adjudication team determines whether the applicant's medical condition matches or is equivalent to an impairment found in SSA's listing of medical impairments.[2] If so, benefits are awarded. If, however, the applicant's condition is not severe enough to meet or equal the severity criteria in SSA's medical listings, the team uses the evidence to perform an IFA. If the IFA shows the child's impairment substantially reduces his or her ability to function age-appropriately, benefits are awarded. If not, a denial notice is issued, and applicants are informed of their appeal rights.

SSI Childhood Eligibility Criteria Have Undergone Major Changes

During a 2-month period, SSA issued two sets of new regulations that significantly changed the criteria for determining children's eligibility for SSI disability benefits.[3] One set of regulations, issued in accordance with the Disability Benefits Reform Act of 1984 (DBRA), revised and expanded SSA's medical listings for evaluating mental impairments in children to incorporate recent advances in medicine and science. The second set of regulations was issued in response to the Sullivan v. Zebley Supreme Court decision, which required SSA to make its process for determining disability in children analogous to the adult process. Both sets of regulations placed more emphasis on assessing how children's impairments limit their ability to act and behave like unimpaired children of similar age. Both also emphasize the importance of obtaining evidence from nonmedical sources as part of this assessment.

DBRA Regulations Changed SSA's Medical Listings for Assessing Mental Impairments in Children

SSA issued new regulations in accordance with DBRA on December 12, 1990. These new regulations revised and expanded SSA's medical listings for childhood mental impairments to reflect up-to-date terminology used by mental health professionals and recent advances in the knowledge, treatment, and methods of evaluating mental disorders in children. The new medical listings for mental impairments provided much more detailed and specific guidance on how to evaluate mental disorders in children than the former regulations, which were published in 1977. In particular, the new medical listings placed much more emphasis on assessing how a

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[2] SSA's listing of medical impairments describes impairments—in terms of signs, symptoms, and laboratory findings—that are presumed to be severe enough to disable an individual.

[3] For a complete description of these changes, see Social Security: Rapid Rise in Children on SSI Disability Rolls Follows New Regulations (GAO/HEHS-94-225, Sept. 9, 1994).

child's mental impairment limits his or her ability to function in age-appropriate ways. SSA made this change because mental health professionals consider functional factors particularly important in evaluating the mental disorders of children.

The former medical listings for mental impairments emphasized the medical characteristics that must be met to substantiate the existence of the impairment. Specific areas of functioning sometimes were and sometimes were not mentioned as a factor in this determination. In contrast, the new medical listings provide much more detailed guidance on assessing the functional aspects of each impairment. The standard for most impairments is divided into two parts: medical and functional criteria, both of which must be satisfied for the applicant to qualify for a benefit.

The functional criteria are described in terms of the age of the child and the specific areas of functioning—such as social, communication/cognition, or personal/behavioral skills—that must be assessed. The new medical listings emphasize the importance of parents and others as sources of nonmedical information about a child's day-to-day functioning. In general, the childhood mental listings require children over 2 years old to have marked limitations in two of the four areas of functioning to qualify for benefits. Further, when standardized tests are available, the listing defines the term "marked" as a level of functioning that is two standard deviations below the mean for children of similar age.

The new medical listings also classified childhood mental disorders into more distinct categories of mental impairments. Previously, there were 4 impairments listed—mental retardation, chronic brain syndrome, psychosis of infancy and childhood, and functional nonpsychotic disorders—now there are 11. Several of the newly listed impairments, such as autism and other pervasive developmental disorders, mood disorders, and personality disorders, describe impairments that were previously evaluated under one or more of the four broader categories of childhood mental impairments. Several other impairments are mentioned for the first time, such as attention deficit hyperactivity disorder and psychoactive substance dependence disorders.

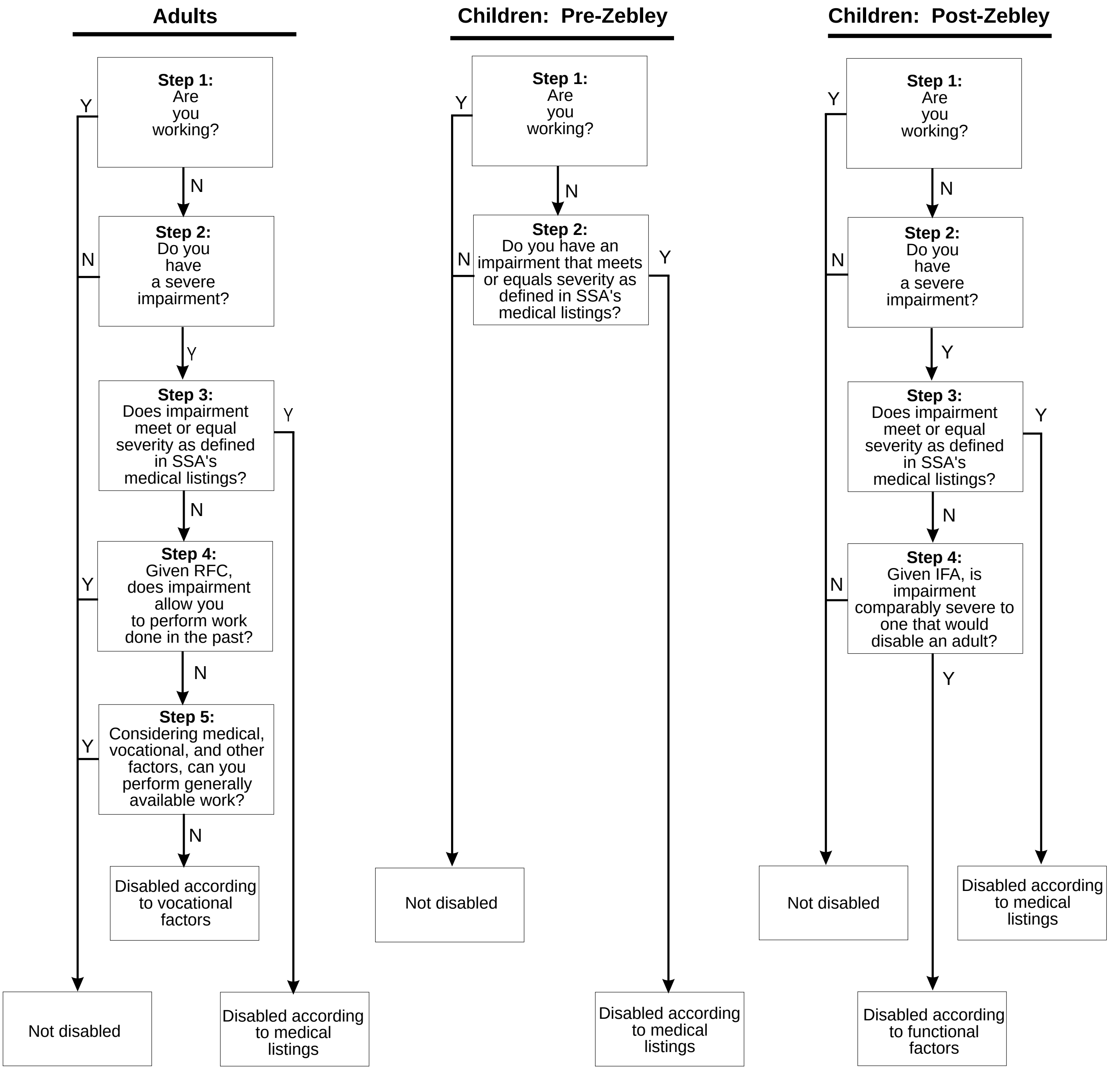
Zebley Regulations Added Separate Functional Assessment Process

On February 20, 1990, the Supreme Court ruled that SSA's process for determining disability in children under 18 years old violated the Social Security Act because the process held children to a more restrictive disability standard than it did adults. In its opinion, the Court found that the process for children

> "does not account for all impairments 'of comparable severity' [to adults], and denies child claimants the individualized functional assessment that the statutory standard requires . . . ."

To determine adults' eligibility for disability benefits, SSA uses a five-step sequential evaluation process. Before Zebley, it used only a two-step process to determine children's eligibility for benefits. (See fig. 1.) Children were awarded benefits only if their impairments met or equaled the severity criteria in SSA's medical listings. All other children were denied benefits. In contrast, adults whose conditions were not severe enough to qualify under the medical listings could still be found eligible for benefits if an assessment of their residual functional capacity (RFC) showed that they could not engage in substantial work. No analogous assessment of functioning was done for children who did not qualify under the medical listings.

Figure 1: Disability Evaluation Process for Adults Versus Children



To eliminate this disparity, the Court mandated that for those children who do not qualify for benefits under the more restrictive medical listings, SSA must add a less restrictive individualized assessment of how the child's impairment affects his or her ability to function in age-appropriate ways—that is, to act or behave in ways that children of similar ages normally do—before it could decide whether the child was eligible for benefits. The Court said that although a vocational analysis does not apply to children because they are not expected to work, SSA could make

> "an inquiry into the impact of an impairment on the normal daily activities of a child of the claimant's age—speaking, walking, dressing and feeding oneself, going to school, playing, etc."

Although the Court required the functional assessment, it did not define the degree of limitation necessary to qualify for benefits, except by analogy to the adult definition of disability.

To implement the Zebley decision, SSA convened a group of experts in April 1990 to help formulate new regulations using age-appropriate functional criteria. Included were experts in general and developmental pediatrics, child psychology, learning disorders, and early and adolescent childhood education as well as advocates from groups such as Community Legal Services in Philadelphia (plaintiff's counsel in the Zebley case), the Association for Retarded Citizens, and the Mental Health Law Project. SSA also consulted with its regional offices and the state DDSS.

Building on the functional criteria added to the listings after DBRA, SSA issued regulations implementing the Supreme Court's decision on February 11, 1991.[4] According to these regulations, for the child to be eligible for disability benefits, the IFA must show that the child's impairment or combination of impairments limits his or her ability "to function independently, appropriately, and effectively in an age-appropriate manner." Specifically, the impairment must substantially reduce the child's ability to grow, develop, or mature physically, mentally, or emotionally to the extent that it limits his or her ability to (1) attain age-appropriate developmental milestones; (2) attain age-appropriate daily activities at home, school, play, or work; or (3) acquire the skills needed to assume adult roles. Although SSA officials describe these as state-of-the-art

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[4] Final regulations incorporating voluminous public comments were issued on September 9, 1993. These regulations, which were not substantially different from the February 1991 interim final regulations, have a September 9, 1997, sunset date, after which time they will no longer be effective, unless the Secretary of HHS extends, revises, or reissues them.

criteria for assessing children's functioning, they concede that many of these concepts are not clear cut.

As a result of these regulations, DDSs now perform IFAs to assess the child's social, communication, cognitive, personal and behavioral, and motor skills, as well as his or her responsiveness to stimuli and ability to concentrate, persist at tasks at hand, and keep pace.[5] Like the DBRA regulations, the IFA process requires DDSs to supplement medical information with information about the child's behavior and activities from the child's teachers, parents, and others knowledgeable about the child's day-to-day functioning in order to make these assessments. Generally, if the IFA shows that a child has a moderate limitation in three areas of functioning or a marked limitation in one area and a moderate limitation in another, benefits are awarded. In contrast, the more restrictive functional criteria under SSA's mental listings require two marked limitations.

In addition to measuring functioning as part of the IFA process, the Zebley regulations added the concept of functional equivalence to SSA's medical listings. Before Zebley, a child qualified for benefits only if his or her impairment met or was medically equivalent to the severity criteria in the listings. After Zebley, a child could qualify if his or her impairment was functionally equivalent to an impairment in the medical listings, as long as there was a direct, medically determinable cause of the functional limitations. The regulations provide 15 examples of conditions—such as the need for a major organ transplant—presumed to be functionally equivalent to the listed impairments.

IFA Process Has Had a Major Impact on the Rolls

Of the 646,000 children added to the SSI rolls from February 1991 through September 1994, about 219,000 (one-third) were awarded benefits based on the less restrictive IFA process. If all 219,000 children receive the maximum benefit, their SSI benefits would cost about $1 billion a year. About 84 percent of these children had a mental impairment as their primary limitation, and about 16 percent had physical impairments. (Fig. 2 shows a breakdown of the impairments.)

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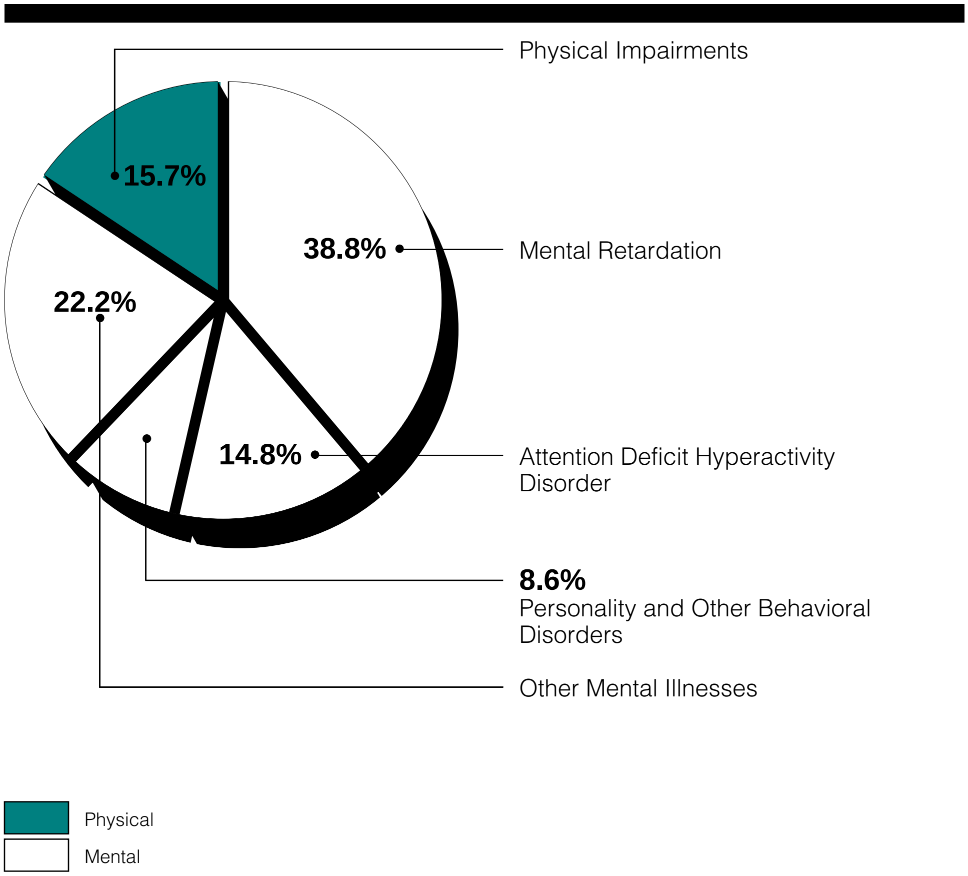
[5] Social, communication, cognitive, and motor skills are assessed for children of all ages; personal and behavioral skills are assessed for children 1 year old and older. The ability to concentrate, persist at tasks at hand, and keep pace are assessed for children 3 years old and older; responsiveness to stimuli is assessed in children under 1 year old.

Figure 2: Most IFA Awards Go to Children With Mental Impairments

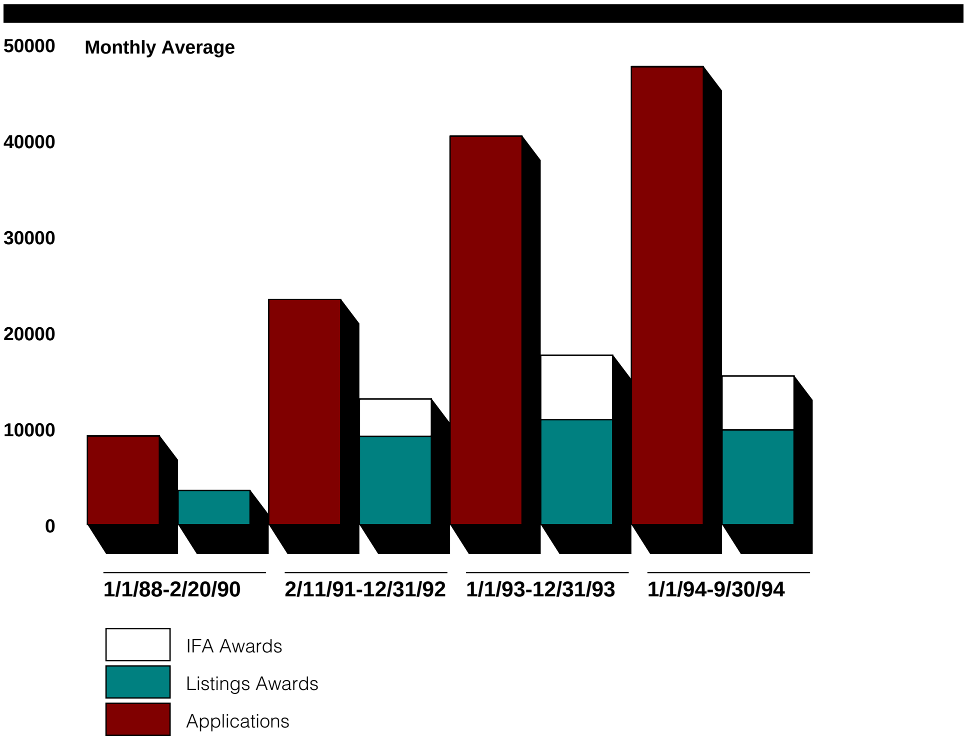


Source: Analysis of SSA's 831 file.

Figure 3 shows the substantial increase in the number of awards. Much of this increase was due to the implementation of new medical listings for mental impairments. The IFA process also added to the growth in the rolls and accounted for a substantial portion of new awards. Figure 3 also shows that the average monthly number of applications jumped dramatically after Zebley and has continued to grow. Many observers attribute this increase in applications to the publicity surrounding Zebley, as well as to increased outreach by SSA, some of which was congressionally mandated.

Also, some of the increase in awards may have been attributable to the close scrutiny of the IFA process by courts and disabled child advocates, which some believe may have resulted in some DDSs feeling pressured to increase their award rates during the 1991-1992 period. (App. II provides a chronology of their actions.) Before the IFA process was introduced in 1991, the national award rate for all types of childhood cases was 38 percent, but the award rate jumped to 56 percent in the first 2 years after the IFA and DBRA regulations were issued. More recently, during 1993 and 1994, the award rate has dropped dramatically. The national award rate for 1994 was 32 percent—lower than it was in the 2 years before Zebley.

Figure 3: IFA and Changes in Medical Listings Both Contribute to Growth in the Rolls



Source: Analysis of SSA's 831 file.

IFA Process Has Been Difficult to Implement Consistently

Our review indicates that the IFA process has been difficult to implement consistently and reliably, particularly for children with mental impairments, because the process requires adjudicators to make a series of judgment calls in a complex matrix of assessments about age-appropriateness of behavior. SSA and IG studies of children with mental impairments have borne out these difficulties. Although SSA has tried to add rigor to the IFA process through guidance and training, we believe that problems will likely continue because of the difficulties inherent in using age-appropriate behavior as an analog for the adult vocational assessment of residual functional capacity.

IFA—A Complex Process That Relies Heavily on Adjudicator Judgment

Determining disability for children with impairments that are not severe enough to match a listed impairment can be a highly subjective process. SSA designed the IFA process to provide DDS adjudicators with a structure to help them make uniform and rational disability determinations for children with less severe impairments. Even so, the necessity to assess a child's ability to function age-appropriately requires DDS adjudicators to make a series of judgments, which we believe raises questions about the consistency and reliability of DDS decisions. SSA and IG studies and our analysis document problems throughout the IFA process, especially for mental impairments. (See app. III for a more detailed discussion of the problems that SSA and the IG identified.)

Extensive evidence needed: To make disability determinations, DDSs use information from both medical and nonmedical sources, including teachers, day care providers, parents, and others knowledgeable about the child's day-to-day behavior and activities. For the functional assessment, observations are needed about the child's behavior over a long period of time, so evidence-gathering can be a considerable task. SSA found in its 1994 study that the lack of sufficient supporting documentation was the most common problem in its sample of childhood disability decisions.

School officials in particular are an important source of nonmedical data on children's behavior over time. Each DDS develops its own questionnaires for eliciting the data, and inquiries are made on virtually every applicant because this information is also used to assess functioning under the medical listings. We estimate that the process now results in about 500,000 inquiries to schools each year, a substantial reporting burden. Some parties believe that the open-ended questionnaire design in many states and the burden on school officials faced with many inquiries may be contributing to poor quality data from this key source.

Difficulty classifying limitations: If an IFA is needed, a disability adjudicator must classify the child's limitations in the appropriate areas of functioning, as shown in figure 4. This is a complex judgment because some areas are closely interrelated and impairments may or may not affect functioning in more than one area. If, for example, evidence indicates that a child gets in fights at school, the adjudicator must determine whether the specific behavior is evidence of a limitation in social skills, personal and behavioral skills, or some combination of these. SSA found that in cases of incorrect awards a common mistake that adjudicators made was to count the effect of an impairment in two areas when only one was appropriate. This resulted in the impairment seeming more severe than it actually was.

Problems defining degrees of limitation: Once the areas have been identified, the adjudicator must judge the degree of limitation. Because only certain conditions—such as low intelligence quotient (IQ)—can be objectively tested and determined, SSA has defined the severity of limitations by comparison with expected behavior for the child's chronological age. Figure 4 shows the degrees of limitation adjudicators use to assess children 3 through 15 years old. SSA's guidance defines a limitation in the moderate category as more than a mild or minimal limitation but less than a marked limitation. The terms "mild" and "minimal" are not defined, but SSA guidance describes an impairment in the marked category as one that "seriously" interferes with a child's ability to function age-appropriately, while a moderate limitation creates "considerable" interference. Within each category, adjudicators are expected to be able to differentiate the degree of limitation. For example, a moderate rating can range from a "weak moderate" (just above a less-than-moderate) up to a "strong moderate" (just below a marked limitation).

Figure 4: Structure of the IFA Process

	Degree of limitation				
Area of limitation	No evidence	Less than moderate	Moderate	Marked	Extreme
Cognitive ability	↔	↔	↔	↔	↔
Communication ability	↔	↔	↔	↔	↔
Social skills	↔	↔	↔	↔	↔
Personal/behavioral patterns	↔	↔	↔	↔	↔
Concentration, persistence, and pace in completing tasks	↔	↔	↔	↔	↔
Motor skills	↔	↔	↔	↔	↔
Response to stimuli	↔	↔	↔	↔	↔

Limited guidance for summing the result: Because the IFA process is inherently subjective, SSA cannot provide an objective procedure for summarizing the IFA results. Therefore, SSA instructs adjudicators to step back and assess whether the child meets the overall definition of disability. As an example to guide adjudicators, SSA has said that an award may generally be granted if a child has a moderate limitation in three areas. However, SSA officials stress that this statement assumes “three good, solid moderates,” and they characterize it as a general guideline, not a firm rule. Also, they stress that other possible combinations of ratings, such as two strong moderates, could justify finding a child disabled, depending on the individual child’s circumstances. In the end, officials stress that adjudicators are expected to award or deny benefits based on an overall judgment, not on any specific sum of severity ratings.

SSA and IG Studies Highlight IFA Difficulties

SSA’s 1994 study of 325 childhood awards highlighted the difficulties in using the IFA process to reliably identify disabled children, particularly children with behavioral and learning disorders.[6] In the study, SSA's Office of Disability selected cases of 325 children with behavioral and learning disorders who had been found eligible. The majority were found eligible based on IFAS. These cases had been decided by DDS adjudicators, based on their understanding of existing guidance from SSA. Then, SSA's regional quality assurance staff had reviewed the decisions and found them accurate. The study involved a third group of experts in the Office of Disability who reviewed the same cases and found inaccuracies in the decisions. Based on their findings, we concluded that about 13 percent of the awards reviewed by SSA had been made to children who were not impaired enough to qualify. Also, another 23 percent of the awards had been made without sufficient supporting documentation.[7]

A January 1995 IG report focused on IFA-based awards to children with mental impairments. IG staff, with assistance from the Office of Disability, reviewed 129 IFA-based awards for mental retardation, attention deficit hyperactivity disorder, and other behavioral or learning disorders. The IG found that 17 (13 percent) of the awards should have been denials and another 38 (29 percent) had been based on insufficient evidence. The IG attributed this to DDS adjudicators' difficulty interpreting and complying with SSA's IFA guidelines for assessing the severity of children's mental impairments. Many adjudicators reported that they found the SSA guidelines unclear and not sufficiently objective. The IG stated that this group of children had less severe impairments than those children determined disabled based on the medical listings, making the assessment of their impairments' effect on their ability to function age-appropriately more difficult.

We observed firsthand the difficulty that adjudicators face in making the judgments required by the IFA process for children who have behavioral and learning disorders. In June 1994, we attended 1-day training sessions for DDS adjudicators and SSA's regional quality assurance staff from across the nation. The Office of Disability presented the findings from its 1994 study and discussed the policies and procedures that DDS and quality assurance staff had misapplied. In this training, Office of Disability staff presented case studies of children included in the 1994 study. After those in attendance reviewed the evidence for each child's case, they were asked to assess the degree to which the child's impairment limited his or her functioning. The attendees' opinions were tallied and in all cases they were split. During discussions of each case, attendees often voiced

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[6] The study's sampling methodology does not permit the results to be projected to the universe of childhood cases or to any subset of the universe.

[7] See appendix III for details on the study and how we calculated these percentages.

differing views on why they believed, for example, that the child's limitation was less than moderate or moderate, or whether a moderate limitation was a good, solid moderate, or a weak moderate. In some cases, the opinion of the majority of attendees turned out to be different from the conclusion of the Office of Disability.

In addition to the national training in June 1994, SSA took other steps to correct implementation problems, including (1) issuing numerous instructional clarifications and reminders, (2) requiring DDSs to specially code certain types of mental impairments and all decisions based on three moderate limitations (to facilitate selecting samples of cases for further study), and (3) establishing more rigorous requirements for documenting awards that are based on three moderate limitations. The Office of Disability plans to do a follow-up study to assess the effectiveness of its remedial efforts.

Some experts believe that further steps could be taken to improve the IFA process. For example, experts we contacted commented on the need for more complete longitudinal evaluations by professionals. They pointed out that more complete examinations—sometimes including multiple visits and observations of both parents and children—would help to address concerns about the adequacy of information from schools and medical sources and provide higher assurance of good decisions. They stated that because professionals are trained to identify malingering in mental examinations, the expanded examinations might also help relieve concerns about coaching. They agreed that such examinations would raise the program's administrative costs considerably, but because a child can receive almost $5,500 a year in benefits (which can continue for life) they believed that the costs would be justified.

SSA's efforts and experts' suggestions are geared toward improving the process rather than addressing the underlying conceptual problems with the IFA. The difficulties so far in implementing the IFA bring into question whether these types of incremental actions can ensure consistently accurate decisions for children with mental impairments, especially behavioral and learning disorders.

Extent of Coaching Unknown

The rapid growth in awards to children with mental impairments—particularly behavioral and learning disorders—has contributed to the public perception that the SSI program for children is vulnerable to fraud and abuse. The media have reported allegations that parents coach their children to fake mental impairments by misbehaving or performing poorly in school so that they can qualify for SSI benefits. Critics believe that cash payments and Medicaid act as incentives for some parents to coach and, therefore, they are concerned about the extent to which parents can manipulate the disability determination process. However, we believe that measuring the extent to which coaching may actually occur is extremely difficult.

Unless parents admit to it, coaching is almost impossible to substantiate. The nature of the parent-child relationship makes investigating coaching allegations difficult. Many communications between parent and child take place at home, out of the view of outside observers. In addition, the variability of children's behavior makes knowing whether a child's behavior is the result of coaching difficult. Behavior can vary naturally among children of the same age—or in the same child over time—as they go through stages in development or respond to changes in their home or school environment. If a child started misbehaving in school, investigators would need baseline evidence to establish that the child had not misbehaved extensively in the past. Finally, even if investigators could identify a sudden change in behavior, they would have to rule out other reasons for the change, such as changes in the child's household or neighborhood environment. In short, knowing whether the child is performing poorly or misbehaving because of coaching or for other reasons is difficult.

Because coaching is difficult to detect, the extent of coaching cannot be measured with much confidence. In recent studies, SSA and the HHS IG reviewed case files and identified scant evidence of coaching or malingering.[8] In the rare instances where they found evidence of possible coaching or malingering, most of the claimants had been denied benefits anyway. (App. III summarizes the results of the SSA and IG studies, including their scopes and methodologies.)

Actions to Reduce Program's Possible Vulnerability to Coaching

To protect program integrity, SSA has taken several steps to help provide assurance that the process can detect coaching or malingering and then make the appropriate eligibility determination. In June 1994, SSA began requiring DDSs to report to SSA's regional quality assurance units any case

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[8] SSA considered possible coaching to be involved in any case in which the child reported or an information source suspected that the parent or other caregiver had told the child to misbehave or perform poorly. SSA also looked for evidence that the child had malingered; that is, deliberately provided wrong information or did not put forth his or her best effort during testing, regardless of whether coaching was suspected.

with an allegation or suspicion of coaching. Such cases include those in which teachers, physicians, or psychologists indicate that (1) the child's behavior was atypical of the child's customary school behavior, (2) the child was uncooperative during testing, or (3) the child's behavior deteriorated without explanation during the 6-month period preceding the application. According to SSA, its regional quality assurance units review all alleged cases of coaching. As of mid-January 1995, DDSs nationwide had reported alleged coaching in 674 childhood cases—or less than one-half of 1 percent of all childhood applications filed during the period—and fewer than 50 of these children had been awarded benefits.

Along with this new requirement, in August 1994, SSA required DDSs to send applicants' schools a set of questions specifically designed to elicit the teacher's views on whether the child had been coached. Additionally, each SSA regional office has established toll-free telephone numbers for the exclusive use of teachers and school officials to notify the regional quality assurance unit of coaching allegations. In mid-November 1994, SSA instructed DDSs to begin distributing these toll-free numbers to schools. Also, SSA has instructed its field offices and telephone service centers to report to the regional quality assurance units any allegations of coaching received from the general public. As of mid-January 1995, from all of these sources, SSA had received a total of 42 telephone calls with allegations of coaching involving 54 individuals. According to SSA, each allegation from teachers, school officials, or the general public is reviewed if the child was awarded benefits.

Conclusion

Childhood disability decisions based on the IFA process are among the toughest that DDSs must make. Particularly in assessing behavioral and learning disabilities, the level of judgment required makes the IFA process difficult to administer consistently. Moreover, the high level of subjectivity leaves the process susceptible to manipulation and the consequent appearance that children can fake mental impairments to qualify for benefits. Indeed, the rise in allegations of coaching may reflect public suspicion of a process that has allowed many children with less severe impairments to qualify for benefits. Although scant evidence exists to substantiate that coaching is a problem, coaching cannot be ruled out and its extent is virtually unmeasurable.

We believe that a more fundamental problem than coaching is determining which children are eligible for benefits using the new IFA process. Our analysis documents the many subjective judgments built into each step of the IFA process to assess where a child's behavior falls along the continuum of age-appropriate functioning. Moreover, studies by SSA and the IG of children awarded benefits for behavioral and learning disorders illustrate the difficulties that SSA has experienced over the last 4 years in making definitive and consistent eligibility decisions for children with these disorders.

SSA's efforts have been aimed at process improvements rather than reexamining the conceptual basis for the IFA. Despite its efforts, too much adjudicator judgment remains. Although better evidence and more use of objective tests where possible would improve the process, the likelihood of significantly reducing judgment involved in deciding whether a child qualifies for benefits under the IFA is remote. We believe that more consistent decisions could be made if adjudicators based functional assessments of children on the functional criteria in SSA's medical listings. This change would reduce the growth in awards and target disability benefits toward children with more severe impairments.

Matter for Consideration by the Congress

Given widespread concern about growth in the SSI program for children and in light of our findings about the subjective nature of the IFA process, the Congress could take action to improve eligibility determinations for children with disabilities. One option the Congress could consider is to eliminate the IFA, which would require amending the statute. The Congress could then direct SSA to revise its medical listings, including the functional criteria, so that all children receive functional assessments based on these revised criteria.

We did not request official agency comments from SSA on a draft of this report. However, we discussed the draft with SSA program officials, who generally agreed that we had accurately characterized the IFA process and the results of studies. SSA officials had some technical comments, which we have incorporated where appropriate.

Please contact me on (202) 512-7215 if you have any questions about this report. Other major contributors are Cynthia Bascetta, Ira Spears, Ken Daniell, David Fiske, and Ellen Habenicht.

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Abbreviations

DBRA	Disability Benefits Reform Act of 1984
DDS	disability determination service
HHS	Health and Human Services
IFA	individualized functional assessment
IG	Inspector General
IQ	intelligence quotient
RFC	residual functional capacity
SSA	Social Security Administration
SSI	Supplemental Security Income

Scope and Methodology

To develop the information in this report, we (1) reviewed SSA's childhood disability program policies, procedures, and records, and discussed the IFA process with SSA program officials on the national, regional, and local level; (2) interviewed officials in state DDSS; (3) reviewed SSA's report on its 1994 study of children with behavioral and learning disorders; and (4) attended a June 1994 SSA training course that was based on findings from its study. We also discussed eligibility issues with officials of HHS' IG, which recently issued two reports on the SSI childhood disability program.[9]

To develop SSI childhood program award rate data, we obtained SSA's computerized records on the results of initial determinations and reconsideration disability decisions made by DDSS for children under 18 years old from 1988 through September 1994.[10] These records exclude the results of disability decisions made by administrative law judges. From these records, we determined (1) the overall award rate for children, (2) the percentage of IFA awards that were based on mental impairments versus physical impairments, (3) the average monthly number of childhood applications, and (4) the average monthly number of awards that were based on IFAS versus medical listings. These data, as applicable, were determined for the following periods: (1) 2 years before the Supreme Court's Sullivan v. Zebley decision (Jan. 1, 1988, through Feb. 20, 1990); (2) 2 years after the IFA process was implemented (Feb. 11, 1991, through Dec. 31, 1992); (3) January-December 1993; and (4) January-September 1994. Because no IFA process existed before the Zebley decision, no pre-Zebley awards were decided based on IFAS.

We excluded children who had applied during 1988 through February 10, 1991, from the universe of children on whom decisions were made from February 11, 1991, through September 30, 1994. We did this to minimize the extent to which data in these comparison periods reflect the result of cases readjudicated as part of the settlement in the Zebley class action lawsuit. We were not able to identify or exclude Zebley classmembers for whom benefits had been denied or terminated from 1980 through 1987 from any of the comparison periods. According to SSA, Zebley

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[9] See Concerns About the Participation of Children with Disabilities in the Supplemental Security Income Program (A-03-94-02602), Department of Health and Human Services, Office of Inspector General (Oct. 13, 1994); and Supplemental Security Income: Disability Determinations for Children with Mental Impairments (A-03-94-02603), Department of Health and Human Services, Office of Inspector General (Jan. 26, 1995).

[10] The childhood program statistics presented in this report were developed using the same basic methodology used in Social Security: Rapid Rise in Children on SSI Disability Rolls Follows New Regulations (GAO/HEHS-94-225, Sept. 9, 1994). This report focused on the growth in awards after SSA changed the disability criteria for children.

classmembers are more likely to have physical impairments than the general population of new SSI child applicants.

We performed our work from May 1994 through February 1995 in accordance with generally accepted government auditing standards.

Efforts to Affect Implementation of the Zebley Decision

January 1991

One month before SSA issued regulations implementing the new IFA process, the Zebley plaintiff's counsel submitted interrogatories to SSA asking, among other things, why nine DDSs with the lowest award rates for children had such low award rates.[11]

SSA regional officials were tasked with answering some of the counsel's interrogatories and, in some instances, the officials informed the states that they were the subject of the counsel's inquiry. Also, from time to time thereafter, SSA officials shared state-by-state award rate data with state DDSs. Some SSA regional officials stated that they believed some DDSs could have felt pressured to increase their award rates.

February 1991

In the month that SSA issued regulations implementing the new IFA process, a federal district court ordered SSA to perform special quality assurance reviews of disability applications denied under the new regulations. The court order required SSA to do quality assurance reviews of denials made by 10 state DDSs that, according to SSA, Zebley plaintiff's counsel had identified as denial prone due to their low award rates.[12] Based on its own studies, SSA had argued before the court that low award rates were not reliable indicators of whether special corrective action was needed to avoid incorrect denials, but the court required SSA to implement the special quality assurance reviews for these 10 states.

Under the court order, during the first month after the new regulations were in effect, SSA had to review the lesser of 100 or all denials for each denial-prone state. SSA reviewed only 25 denials for other states. A subsequent March 1991 court order required SSA, after the first month, to review at least 1,000 denials per month nationwide. SSA's sample of 1,000 denials included 15 percent of the denials from each of the 10 denial-prone states.

By memorandum in February 1991, SSA informed all DDSs of the special quality assurance requirements and identified the 10 states that had been classified as denial prone. The court order required that SSA send the results of the quality assurance reviews monthly to the Zebley plaintiff's counsel.

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[11] The nine states were Alabama, Arkansas, Colorado, Louisiana, Mississippi, Nebraska, South Carolina, West Virginia, and Wisconsin.

[12] The 10 states were Alabama, Arkansas, Colorado, Louisiana, Mississippi, Nebraska, New Mexico, South Carolina, West Virginia, and Wisconsin.

June 1991

The Zebley plaintiff's counsel wrote to the SSA Commissioner citing a "disturbing pattern" of low allowance rates in eight states and asked the Commissioner to take remedial steps.[13]

December 1992

In a newsletter to legal aid societies, the Zebley counsel listed 13 DDSs whose cumulative allowance rates were at 50 percent or below.[14] The counsel encouraged legal aid society representatives in those states to contact the DDS directors and "confront them with their sub-par performance."

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[13] The eight states were Connecticut, Kentucky, Louisiana, Nebraska, New Mexico, Texas, West Virginia, and Wisconsin.

[14] The 13 states were Arkansas, Connecticut, Louisiana, Maine, Mississippi, Missouri, Montana, Nebraska, New Mexico, South Carolina, Tennessee, Texas, and West Virginia.

Studies Done by SSA and the Inspector General

1994 Study by SSA's Office of Disability

SSA considers behavioral and learning disorders to be the most susceptible to coaching and malingering. In 1994, SSA's Office of Disability in Baltimore reviewed a national sample of 617 school-age children who had applied due to behavioral and learning disorders. Because the sample was small, the findings of the study cannot be projected to the universe of childhood disability claims or to the subset of specific impairments studied.

Scope and Methodology

The 617 children were selected from those who had applied due to such impairments as attention deficit disorder, attention deficit hyperactivity disorder, personality disorder, conduct disorder, learning disorder, oppositional defiant disorder, anxiety disorder, developmental delay, behavior disorder, speech and language disorders, borderline intellectual functioning, and adjustment disorder. According to SSA, these types of disorders constitute about 20 percent of all childhood disability applications. SSA excluded cases involving extremely severe mental disorders, such as psychotic disorders and mental retardation.

SSA selected the 617 cases from final DDS decisions that SSA's regional quality assurance staff had already reviewed for accuracy. The 617 cases in the sample consisted of 325 awards and 292 denials that DDSS adjudicated during October 1992 through July 1993. SSA reviewed case file documentation for the 617 cases.

Coaching

In its review of case file documentation, SSA considered coaching to be involved in any claim in which the child reported or an information source suspected that the parent or other caregiver had told the child to act or respond in a manner that would make the child appear more functionally limited than he or she actually was. In addition, SSA looked for evidence indicating that the child had malingered; that is, deliberately provided wrong information or did not put forth his or her best effort during testing.

SSA found only 13 cases that showed any evidence of possible coaching or malingering, and only 3 of these cases were awards. In all cases, the evidence indicating possible coaching was provided by medical professionals or psychologists who performed consultative examinations for SSA. None of the evidence indicating possible coaching or malingering was provided by schools. The three questioned awards involved children who may have malingered during IQ testing. In these cases, however, the awards were based on factors other than the results of the testing. For example, one child with an oppositional defiant disorder appeared to malinger during IQ testing administered by a consultative examiner, but the award was based on other problems stemming from the disorder, not the results of the testing.

Incorrect Awards

Of the 325 awards reviewed by SSA, SSA found that 8.6 percent (28) should have been denials and another 27.7 percent (90) should not have been made without obtaining more supporting documentation. We asked SSA, based on experience in its quality assurance program, to estimate how many of the 90 cases with insufficient documentation would have been denials if all documentation had been obtained, and SSA estimated that 13 (or 4 percent of the 325 awards) would have been denials. Thus, we concluded that a total of 41 awards (12.6 percent of the 325 awards) should have been denials. By contrast, of 292 denials reviewed in the study, SSA found that only 1.4 percent (4) should have been awards, and another 1.4 percent (4) should not have been made without obtaining more supporting documentation.

Combining all decisional and documentational errors for the 617 denials and awards in SSA's study, the overall error rate for this group of cases was 20.4 percent.[15] This is about twice the maximum acceptable error rate of 9.4 percent that SSA allows for decisional and documentational errors combined for all initial disability decisions made by an individual DDS.

According to SSA's Office of Disability, a primary reason that DDSs made awards that should have been denials was that DDSs had frequently overrated—but rarely underrated—the severity of children's functional limitations. Such overrating occurred primarily because DDSs had (1) compared the child with the perfect child rather than the average child, (2) based the limitation on a single incident rather than behavior over time, (3) not considered the child's ability to function while on an effective medication regimen, and (4) based the limitation on the child's life circumstances rather than the effects of a medically determinable impairment.

DDSs also had mechanically applied SSA's guidelines on how to make awards using the results of the IFA process. SSA's guidelines instruct DDSs that they generally should award benefits to children who have moderate limitations in any three of the areas of ability assessed in the IFA process. SSA found, however, that DDSs had used this instruction as a rule rather

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[15] The overall error rate for the 617 cases was computed as follows: (28 award decisional errors + 90 award documentational errors + 4 denial decisional errors + 4 denial documentational errors)/ 617 = 0.204.

than a guideline. DDSs had automatically made awards to any child with three moderate limitations, regardless of how strong or weak the moderate limitations were. SSA stated that its guideline assumed "three good, solid moderates." SSA found that, when DDSs had identified two moderate limitations, they sometimes made special attempts to find a third moderate limitation even though the evidence did not support it.

DDSs had also "double-weighed" the effects of impairments in more than one of the areas of ability assessed in the IFA process, making the impairment seem more severe and pervasive than it actually was. For example, in some cases children displayed a lack of self-control by exhibiting more than one inappropriate behavior, such as fighting, aggressive behavior, disrespectful behavior, lying, oppositional behavior, and stealing. Although all these behaviors should have been rated only in the personal/behavioral area, DDSs had rated some behaviors in the personal/behavioral area and others in the social abilities area, giving the child moderate limitations in two areas rather than only one. This meant that the child needed only one more moderate limitation to have the three moderate limitations needed for approval.

SSA also found that DDSs had sometimes based decisions on old evidence when current evidence indicated children had improved and that DDSs had sometimes assessed limitations that could not be attributed to medical impairments.

Inspector General Study

As the IG reported in January 1995, IG staff reviewed the case files for a sample of 553 children whose applications were adjudicated by DDSs in 1992. Of the 553 children, 298 had been awarded benefits by 10 DDSs—Connecticut, Illinois, Kentucky, New York, North Carolina, North Dakota, Pennsylvania, South Dakota, Vermont, and Wisconsin. The remainder of the 553 cases consisted of a nationwide sample of 255 denials. Of the 298 awards, 129 (43 percent) had been decided based on an IFA, and 195 of the 255 denials (76 percent) had been decided based on an IFA. The IG targeted its study at cases involving mental retardation, attention deficit hyperactivity disorder, and other learning and behavioral disorders. Based on its review of these cases, IG officials told us that they had found no evidence of coaching.

As the IG reported, when the IG staff had questions about the accuracy of a DDS disability determination or about the sufficiency of the evidence supporting a determination, the IG provided the case file to SSA's Office of

Disability in Baltimore—the same staff responsible for conducting SSA's study of 617 childhood disability claims. The Office of Disability reviewed the accuracy of each of the questioned cases. The IG staff also visited the 10 DDSs to obtain their opinions on the adequacy of the SSA guidelines used to make disability determinations.

Of the 129 awards reviewed that were based on IFAs, the IG reported that 17 (13 percent) should have been denials and another 38 (29 percent) were based on insufficient evidence. The IG attributed this problem to DDSs having difficulty in interpreting and complying with SSA guidelines for obtaining and evaluating evidence concerning the severity of the mental impairments of children on whom IFAs are conducted. The IG stated that these children have less severe impairments than those children determined to be disabled based on the impairment listing, making the assessment of the effects of their impairments on their ability to function age-appropriately more difficult. In discussions with employees of the 10 DDSs, the IG reported that many expressed concern that the SSA guidelines for determining disability for children with mental impairments were not sufficiently clear or objective.

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