

## DEPARTMENT OF HEALTH AND HUMAN SERVICES

45 CFR Parts 1385, 1386, 1387, and 1388

RIN 0970-AB11

### Developmental Disabilities Program

**AGENCY:** Administration on Developmental Disabilities, Administration for Children and Families, HHS.

**ACTION:** Notice of proposed rulemaking (NPRM).

**SUMMARY:** This rule proposes clarifications and new requirements to implement the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act of 2000). Of particular note, the proposed rule covers responsibilities of the Secretary in the area of program accountability and the indicators of progress. Under the proposal, one or more measures of progress must be used to measure the goal(s) developed for each area of emphasis. The areas of emphasis include: (1) Quality assurance activities; (2) education activities and early intervention activities; (3) child care-related activities; (4) health-related activities; (5) employment-related activities; (6) housing-related activities; (7) transportation-related activities; (8) recreation-related activities; and (9) other services available or offered to individuals in a community, including formal and informal community supports that affect their quality of life.

**DATES:** Comments will be accepted through June 9, 2008.

**ADDRESSES:** Interested persons are invited to submit comments regarding this proposed rule to: Commissioner, Administration on Developmental Disabilities, Administration for Children and Families, 370 L'Enfant Promenade SW., Mail Stop: HHH 405D, Washington, DC 20447. Persons may also transmit comments electronically via the Internet at: <http://www.regulations.acf.hhs.gov>. Electronic comments must include the full name, address, and organizational affiliation (if any) of the commenter. All comments and letters will be available for public inspection, Monday through Friday 7 a.m. to 4 p.m., at the address above, by calling (202) 690-5841 to set up an appointment and gain entry to the building. Electronically-submitted comments will be available for viewing immediately. To download an electronic version of the rule, you should access ACF's regulation page at: <http://www.regulations.acf.hhs.gov> or [www.regulations.gov](http://www.regulations.gov).

**FOR FURTHER INFORMATION CONTACT:** Elsbeth Porter Wyatt, Administration on Developmental Disabilities, telephone (202) 690-5841 (Voice). The TDD telephone number for the Administration on Developmental Disabilities is (202) 690-6415. These are not toll-free numbers. This document will be made available in alternative formats upon request.

#### SUPPLEMENTARY INFORMATION:

#### I. Developmental Disabilities Assistance and Bill of Rights Act of 2000

In 1963 the President signed into law the Mental Retardation Facilities and Construction Act (Pub. L. 88-164). It gave the authority to plan activities and construct facilities to provide services to persons with mental retardation. This legislation was significantly amended a number of times since 1963 and most recently by the Developmental Disabilities Assistance and Bill of Rights Act of 2000, Public Law 106-402 (the DD Act of 2000). The DD Act of 2000 directs the Secretary of Health and Human Services to implement an accountability process to monitor the grantees that receive funds under the Act (Section 104(a)(3), 42 U.S.C. 15004(a)(3)). The process is to identify and report on progress achieved through advocacy, capacity building, and systemic change activities. Indicators of progress are to be developed for each area of emphasis and each entity receiving funds is required to meet these indicators of progress. A report to the President, Congress, and the National Council on Disability must be prepared using information on grantee progress with regard to these indicators every two years. Activities that focus on coordination and collaboration within and across the programs must be included in the report.

The accountability system and the new reporting requirements form the substantive basis of this proposed rule. In addition, the proposed rule addresses the following changes made by the DD Act:

- The DD Act of 2000 also requires State Councils to set-aside 70 percent of the Federal funds for activities tied to Council goals (Section 124(c)(5)(B)(i)). The previous amount was 65 percent. Also, the DD Act of 2000 increases the percentage from 50 percent to 60 percent of representation by individuals with developmental disabilities on Councils (Section 125(b)(1)(C)(3)).

- The DD Act of 2000 also requires that a Protection and Advocacy (P&A) governing board be selected by the P&A and be subject to the policies and procedures the P&A chooses to establish. The membership of the board

is now subject to term limits set by the P&A to ensure rotating membership. The DD Act of 2000 strengthens provisions regarding access to service providers and records of individuals with developmental disabilities in order to investigate potential abuse and neglect. Also, the State must now provide information to a P&A about the adequacy of health care and other services, supports, and other assistance that individuals with developmental disabilities receive through home and community-based waivers.

- Additionally, under the Act, the University Affiliated Programs are renamed University Centers for Excellence in Developmental Disabilities Education, Research, and Service (referred to as UCEDDs). Each UCEDD receives a core award. When appropriations are sufficient to provide at least \$500,000, as adjusted for inflation, in funding to each existing UCEDD, ADD is required to award grants for national training initiatives and is authorized to create additional UCEDDs or to make additional grants to existing UCEDDs. New UCEDDs created under this authority or additional grants to existing UCEDDs would be in States or for populations that are unserved or underserved due to such factors as population, a high concentration of rural or urban areas or a high concentration of unserved or underserved populations (Section 152(d)).

- Finally, the DD Act of 2000 authorizes Federal interagency initiatives to carry out projects relating to the development of policies that reinforce and promote the self-determination, independence, productivity, and inclusion in community life of individuals with developmental disabilities through the Projects of National Significance program.

While not the subject of this proposed rule, the DD Act of 2000 also established two additional program authorities, title II—Families of Children with Disabilities Support Act of 2000, and title III—Program for Direct Support Workers Who Assist Individuals with Developmental Disabilities.

#### II. Grantees of the Administration on Developmental Disabilities (ADD) Network Under the Act

##### A. Protection and Advocacy of Individual Rights

Formula grants are made to each State and other eligible jurisdictions for the establishment of a system to protect and advocate for the rights of individuals with developmental disabilities (P&As).

The system must have the authority to pursue legal, administrative, and other appropriate remedies or approaches to ensure the protection, advocacy and rights of individuals with developmental disabilities who are or who may be eligible for treatment, services, or habilitation, or who are being considered for a change in living arrangement, with particular attention to members of ethnic and racial minority groups. The system must provide information and referral for programs and services addressing the needs of individuals with developmental disabilities, and have the authority to investigate incidents of abuse and neglect of individuals with developmental disabilities if the incidents are reported to the system, or if there is probable cause to believe that the incidents occurred.

#### *B. Federal Assistance to State Councils on Developmental Disabilities*

Formula grants are made to each State and other eligible jurisdictions to support a State Council on Developmental Disabilities to engage in advocacy, capacity building, and systemic change activities that assure that individuals with developmental disabilities and their families participate in service and program design, and have access to needed community services. Formula grants provide individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life through culturally competent programs. Activities contribute to a coordinated, consumer and family-centered, consumer and family-directed, comprehensive system that includes needed community services, individualized supports, and other forms of assistance that promote self-determination for individuals with developmental disabilities and their families.

#### *C. Projects of National Significance*

Under subtitle E of title I of the Act, ADD may award grants, contracts or cooperative agreements for Projects of National Significance (PNS) to enhance the independence, productivity, and inclusion of individuals with developmental disabilities. Generally, projects are to promote promising practices, demonstrate innovative approaches, provide technical assistance, collect data, educate policymakers, disseminate information, and expand opportunities for individuals with disabilities to participate in decision making and community life.

#### *D. National Network of University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDDs). [Formerly University Affiliated Programs/UAP]*

In order to provide leadership, advise Federal, State, and community policymakers, and promote self-determination, independence, productivity, and full integration of individuals with developmental disabilities, grants are awarded to entities designated as Centers in the States and other eligible jurisdictions. The Centers are interdisciplinary education, research, and public service units of universities or public or not-for-profit entities associated with the universities that engage in the core functions of interdisciplinary pre-service preparation and continuing education of students and fellows, provision of community services, conduct of research, and dissemination of information related to activities undertaken to address the purpose of title I of the Act.

### **III. Discussion of NPRM**

This proposed regulation addresses the requirements of the DD Act of 2000 and reflects input from the grantees of the ADD network (State Councils on Developmental Disabilities, P&As, UCEDDs, and the national organizations that represent them: The National Association of Developmental Disability Councils (NADDC), the National Association of Protection and Advocacy Systems (NAPAS), and the Association of University Centers on Disabilities (AUCD)).

*Key proposed provisions are as follows:*

(a) The Definitions section (§ 1385.3) of the regulations has been updated to reflect terms defined in the statute that apply to all of the programs authorized by the DD Act of 2000;

(b) Section 1385.5 of the regulations has been added to address program accountability and indicators of progress requirements for the State Councils on Developmental Disabilities, P&As and UCEDDs as added by Section 104(a) of the DD Act of 2000;

(c) Current section 1386.22 of the regulations addresses access to records, facilities and individuals with developmental disabilities. We propose to move and revise this section to establish these regulations as a separate subpart C for the Protection and Advocacy Program;

(d) Section 1388.5 of the regulations addresses the five-year plan and reporting requirements for UCEDDs. This section proposes a new Annual

Report for UCEDDs to meet the requirements of the Act (42 U.S.C. 15064).

Technical and conforming changes to other sections of the rules for the DD Act programs have been made to address new terminology and revised statutory cites and to provide clarity. For ease of public understanding and comment, we have republished the regulatory text of all provisions of 45 CFR Chapter XIII, Subchapter I, The Administration on Developmental Disabilities, Developmental Disabilities Program in full.

In developing this proposed regulation ADD examined many issues tied to the legislation and the administration of the programs funded under the DD Act.

One issue for which we specifically seek public comment is whether the current process involving class action lawsuits provides adequate protection for individuals with developmental disabilities. For example, in order to include an individual as a member of a class what criteria should be applied or clearance process should be followed? Informed consent is a cornerstone of class action lawsuits to protect the rights of individuals who may choose to be or not to be members of a potential class. When an individual has a developmental disability a guardian may have a role in that decision. State laws vary greatly with regard to the roles and authority of guardians. What happens when there is a difference of opinion between the individual and guardian on whether to be a member of a class action lawsuit? It would be very helpful to receive comments on the procedures used to reach decisions on whether to pursue class action lawsuits and the method of informing/obtaining consent. We will carefully consider all comments provided to determine whether any changes are warranted in the final regulations to ensure adequate protection of individual choice.

Another issue is the question of which activities grantees may engage in to influence legislation and still be in compliance with statutes, regulations and OMB Circulars which generally restrict such activities and other activities ordinarily referred to as "lobbying." The questions arise because State Councils, Protection and Advocacy agencies (P&As), University Centers for Excellence and Projects of National Significance are authorized under the provisions of the DD Act, to "educate," "advise" or "inform" Federal, State and local policymakers. Sections 125(a)(5)(j), 143(a)(2)(L), 153(a)(1), and 161(2)(D)(iii). The "policymakers" referred to in the statute

include members of Congress, officials of the Federal executive branch, Governors, members of State legislatures and staff of State agencies.

Congress customarily has included in the annual appropriations acts for HHS language restricting the use of appropriated funds to influence legislation. *See, e.g.,* Section 503 of Public Law 209–149. Additionally, all projects funded by ADD, including those projects funded for the purpose of informing, educating or advising policymakers, are subject to restrictions on the use of Federal funds for lobbying purposes. Non-profit organizations receiving ADD awards are subject to the requirements of OMB Circular A–122, Attachment B, Paragraph 25, pertaining to lobbying.

A section-by-section discussion of the significant changes made by this proposed regulation follows:

#### **PART 1385—REQUIREMENTS APPLICABLE TO THE DEVELOPMENTAL DISABILITIES PROGRAMS**

##### *Section 1385.1 General*

Section 1385.1 General, covers administrative requirements for the ADD Network grantees. We are proposing to amend § 1385.1 of this part by revising the introductory text to include a reference to section 1385.5 Program Accountability and Indicators of Progress. Paragraph (a) is proposed to be amended to update the name of the State Developmental Disabilities Councils to State Councils on Developmental Disabilities. Similarly, paragraph (b) is proposed to be amended to update the reference from Protection and Advocacy of the Rights of Individuals with Developmental Disabilities to Protection and Advocacy of Individual Rights. Paragraph (d) is proposed to be amended to update the reference from University Affiliated Programs to National Network of University Centers for Excellence in Developmental Disabilities Education, Research, and Service. These changes are proposed to conform the regulations with the language of the DD Act of 2000.

##### *Section 1385.2 Purpose of the Regulation*

This section of the NPRM proposes to update the statutory reference to reflect enactment of the Developmental Disabilities Assistance and Bill of Rights Act of 2000.

##### *Section 1385.3 Definitions*

This section of the NPRM updates terminology and definitions resulting from enactment of the Developmental

Disabilities Assistance and Bill of Rights Act of 2000 and other necessary updates.

##### *Section 1385.4 Rights of Individuals With Developmental Disabilities*

We are proposing to amend paragraph (a) to update the statutory citations. Section 109 of the Act is only applicable to State Councils on Developmental Disabilities. Additionally, the DD Act of 2000 repealed the requirement that Councils, UAPs and Projects of National Significance provide assurances of compliance with Section 110 of the Act.

Similarly, we are proposing to amend paragraph (b) to update statutory and U.S. Code citations for this requirement of the Councils and the submission of the State plan.

We are proposing to amend paragraph (c). The PNS reference is being deleted as the Act no longer contains this provision or a comparable requirement. The UAP reference is proposed to be updated to refer to UCEDD and the application's assurance of compliance cite is being changed to Section 101(c) of the Act as provided in Section 154(a)(3)(D) of the Act of 2000.

##### *Section 1385.5 Program Accountability and Indicators of Progress*

We propose to add under section 1385.5, previously reserved, the Program Accountability and Indicators of Progress requirements for ADD grantees.

*The DD Act of 2000 requires that:* (1) There be indicators of progress for each area of emphasis; (2) the indicators of progress be used by the Secretary and grantees to describe and measure at a minimum progress in advocacy, capacity building, and systemic change activities by satisfaction, collaboration, and improvement; (3) the indicators of progress be complied by grantees; (4) the indicators of progress result in information which can be included in the Secretary's report to Congress; and (5) the Secretary have a monitoring process for establishing program accountability that incorporates the indicators of progress.

As proposed in section 1385.3, the areas of emphasis under the DD Act include: quality assurance activities; education activities and early intervention activities; child care-related activities; health-related activities; employment-related activities; housing-related activities; transportation-related activities; recreation-related activities; and other services available or offered to individuals in a community, including

formal and informal community support that affect their quality of life.

The NPRM establishes the requirements for State Councils, P&As, and UCEDDs to identify, characterize, and track progress on grant goals. Each goal must be related to an area of emphasis. First, a grantee must select a goal or goals for the year in question. Second, a grantee must select a type of activity—advocacy, capacity building, or systemic change—through which each goal shall be undertaken. Third, a grantee must track progress on each goal by establishing measures of progress.

*The measures of progress must describe and measure:* (1) Consumer satisfaction with the services provided through the activities of the grantee under its ADD funded program; (2) collaboration with other ADD grantees subject to the regulation; and (3) improvements in the ability of individuals with developmental disabilities to make choices about and exert control over the services which they receive, to participate in the full range of community life with persons of the individual's choice, and to access services, supports, and assistance to ensure the individual is free from exploitation, violations of legal and human rights, and inappropriate restraint or seclusion.

The approach taken by the Administration on Developmental Disabilities in developing the proposed regulations was to comply with the requirements of the Act while preserving the capacity of grantees to design their programs to meet the needs of their individual communities as provided under the Federal Assistance to State Councils on Developmental Disabilities, the system of Protection and Advocacy of Individual Rights, and the national network of University Centers for Excellence in Developmental Disabilities Education, Research, and Service.

The proposed regulations were developed in response to these requirements as follows: paragraph (a) Program Accountability Process; paragraph (b) Measures of Progress; paragraph (c) Indicators of Progress; paragraph (d) Measures of Consumer Satisfaction; paragraph (e) Measures of Collaboration; and paragraph (f) Measures of Improvement.

For each area of emphasis under which a goal has been identified, each State Council on Developmental Disabilities, P&A, and UCEDD must state in its required planning document (State plan for Councils, Statement of Goals and Priorities for P&As, and the Five-Year plan for UCEDDs) the measures of progress (measures of

consumer satisfaction, improvement, and collaboration) to be applied to its goals in the areas of emphasis selected for each year covered by the planning document. Each UCEDD plan also must categorize its goals under both an area of emphasis and one of its four core functions. *Those functions are:* (1) Interdisciplinary pre-service preparation and continuing education of students and fellows; (2) community services that

provide training or technical assistance; (3) conduct of research; and (4) dissemination of information.

Accordingly, under paragraph (a)(1) as proposed, the required planning document must classify under one or more areas of emphasis each of the goals related to advocacy, capacity building, and systemic change activities to be pursued during the year. The areas of emphasis selected may vary from

grantee to grantee. UCEDDS also must classify any goal activity in terms of mandated core functions. Following is an example of the Education and Early Intervention area of emphasis using the goal of children with developmental disabilities being included in preschool programs:

*Example:* Area of Emphasis: Education and Early Intervention.

Long-term goal	Short-term objective	Role of State Council	Role of P&A	Role of UCEDD
Children with developmental disabilities are included in preschool programs.	Number of children with developmental disabilities in Head Start programs will increase by 10%.	Present information to Head Start directors on number of children with developmental disabilities waiting for inclusive preschool programs. Attend meetings of Head Start directors to outline issues and barriers. Convene meeting of Head Start directors and DD Act network to develop plan of action.	Train parents on legal rights of children with developmental disabilities to participate in preschool programs. Include information on accessibility, ADA, assistive technology, etc.	Train Head Start providers on inclusion of children with developmental disabilities in the classroom. Follow up to determine actual increase in number of children included.

Paragraph (a)(2) requires that for each area of emphasis the required planning document must include measures of progress for goals identified measuring: Consumer satisfaction; collaboration; and improvements in outcomes for persons with developmental disabilities. Measures of progress developed must be able to, over time, demonstrate whether the grantee has achieved progress in meeting the goals of the Act through its advocacy, capacity building, and systemic change activities.

Paragraph (a)(3) provides that the measures of progress must meet all applicable program regulations. In the event the planning document fails to meet these regulatory requirements, the Commissioner shall decline to accept the planning document.

Paragraph (a)(4) requires that the results of the application of the measures of progress for each area of emphasis under which a goal has been established be reported.

Paragraph (c) of the proposed rule requires that for each of the areas of emphasis under which the State Councils on Developmental Disabilities, the P&A, or UCEDD has classified activities, the indicators of progress shall be the grantee's achievement of the measures of progress it has established pursuant to this section for the years on which the grantee is reporting. Each State Council on Developmental Disabilities, the P&A, and UCEDD is required to meet the indicators of

progress for each of the areas of emphasis in which it has classified activities for the year on which it is reporting.

Measures of consumer satisfaction are addressed under proposed paragraph (d). Under this paragraph, each State Council on DD, P&A, and UCEDD must establish criteria on the level of consumer satisfaction to be attained for each area of emphasis for each goal identified and track its progress.

Any grantee that is a member of the ADD Network must establish a goal or goals in one or more areas of emphasis. For each area of emphasis selected, a grantee must measure progress related to its goal(s) through activity(ies) in terms of consumer satisfaction in each of its selected area(s) of emphasis. Consumer satisfaction may be measured by the results of surveys of individuals with developmental disabilities affected by its activities, surveys of stakeholders, focus groups, and phone interviews. A grantee may include reports on whether the planned activity associated with a goal resulted in improved access to services for individuals with developmental disabilities.

The following is an example of consumer satisfaction measures with respect to a Council. A State does not currently have a program to financially assist families who care for their children with developmental disabilities who live at home. A Council plans to fund a voucher program to

support these families and children. Using examples from other States, several different approaches will be used with vouchers going toward different services including housing and child care. The Council plans to locate families and provide vouchers. Consumer satisfaction is measured through a post-activity questionnaire. A consumer survey of the program is planned to provide this information. The survey will address how the activity: (1) Improved the ability of individuals with developmental disabilities to exert choice and control over the services, support, and assistance; (2) Improved the ability to participate in community life; (3) Improved the ability to access services in a way that the individual is free from abuse, neglect, exploitation, and harmful treatment; and (4) Improved the individual's situation and circumstances. A final evaluation will lead to the development of a legislative proposal to introduce a permanent program for the State. This would be a Council systemic change, capacity building activity. The results of these measures must be reported in the annual Program Performance Report.

The following is an example for P&As. A P&A plans to represent children who are not being allowed into an inclusive program at schools within the State. Looking at enrollment data the P&A targets three counties. The P&A identifies the cases of greatest need. The

P&A then works with the school districts on Individualized Education Programs, facilitating the placement of children with developmental disabilities into regular classrooms. The P&A documents the numbers of children placed in inclusive programs as a result of the intervention, surveys those involved with this initiative and obtains their input to assist the P&A with future advocacy activities. This is a P&A advocacy activity. The goals in this example focus on: Identifying clients to be served; targeted education and early intervention as the area of emphasis; tracking progress through improvement measures; and, surveys that measure client satisfaction.

The following is a UCEDD example. A UCEDD wants to train a group of pediatricians to serve individuals with developmental disabilities. The UCEDD identifies the group and provides the training. It checks back with the pediatricians to see if the training helped them. Consumer satisfaction is measured through a survey of a sample of patients or family members/advocates to assess the level of their satisfaction with their pediatricians trained by the UCEDD and to receive recommendations on expansion or changes in the training activities. This is a UCEDD capacity building activity. The goals in this example focus on the health area of emphasis. The type of activity includes training via curricula, role playing, case example, and/or consumer or family member/advocate interview or presentation. The UCEDD measure of progress would be an increase in pediatricians' caseloads of clients with developmental disabilities and patients being satisfied with the care they received from trained pediatricians.

Proposed paragraph (e) specifies the requirement related to measures of collaboration. Under this paragraph, we propose to require each Council, P&A, and UCEDD to identify collaborative activities it will implement for each area of emphasis related to a goal. Under the proposal, UCEDDs also must identify interstate collaborative activities. In-state collaborations must include a meeting or Memorandum of Understanding on the proposed collaborative activities.

Collaboration among a State's ADD grantees is very important. By collaboration ADD means efforts in which all three categories of a State's grantees work together (State Council, P&A, and UCEDD). In some States there are multiple UCEDDs. In these States the multiple UCEDDs would be expected to collaborate with each other and the State's Council and P&A.

Proposed paragraph (f) specifies requirements related to measures of improvement. Under this proposed paragraph, State DD Councils, P&As, and UCEDDs must establish measures of improvement they will attain for each area of emphasis where a goal has been established by assessing the extent to which grantee activities have improved outcomes for individuals with developmental disabilities.

Specifically, under the proposed rule, improvement measures assess the contribution of a grantee's activity to the ability of individuals with developmental disabilities to: (1) Make choices and exert control over the type, intensity, and timing of services, supports, and assistance that the individuals have used; (2) participate in the full range of community life with persons of the individual's choice; and (3) access services, supports and assistance in a manner that ensures that such an individual is free from abuse, neglect, sexual and financial exploitation, violation of legal and human rights, and the inappropriate use of restraints and seclusion.

Improvement measures a grantee selects will be influenced by the nature of the goal(s) set by a grantee for its selected area(s) of emphasis. Describing and measuring improvements requires collection of baseline data and then tracking change. It would be appropriate to use either qualitative or quantitative measures, or both. ADD recognizes that a goal, rather than an area of emphasis, may be a determinant factor when a grantee decides on which improvement measures to use.

The following is an example of improvement measures with respect to a Council. A Council selects the area of emphasis on employment. A goal is established that individuals with developmental disabilities will be employed through a variety of flexible employment options, including self-employment and working for temporary service agencies. The activities are to foster collaboration, provide technical assistance and training. The Council will work with the Division of Vocational Services (DVS) who will then contact interested individuals to develop work plans. Such plans will include marketing strategies and budgeting for fiscal responsibility. The Council will coordinate small, low-interest loans through the local Business Leadership network and the Chamber of Commerce. Measures of progress will include: Adults have jobs of their choice through Council efforts; increased dollars leveraged for employment programs; employment programs or policies are created/improved; and

individuals with developmental disabilities have additional employment opportunities.

An example of an improvement measure with respect to an agency designated to administer the State P&A system follows. A P&A agency selects the area of emphasis on employment. A goal is established to reduce discrimination in the hiring, promotion, termination and failure to provide reasonable accommodations for people with developmental disabilities. The activities will be tied to requests for assistance. A case comes up involving a thirty year old person with mental retardation who lives in the community and has worked in the mailroom of a local bank for seven years. Following a change in management, the individual has a new supervisor. This supervisor has been increasingly hostile to the individual, including making it difficult for the individual's job coach to provide on-site assistance. In this case, the P&A will document that they provided training to management of the bank on the Americans with Disabilities Act, information on what constitutes a reasonable accommodation and information on the importance of natural supports to assist individuals with developmental disabilities to live and succeed in the community. This information included literature and contact information. The measure of progress will include increased consumer satisfaction with changes in workplace conditions after P&A intervention, and individuals with developmental disabilities will retain jobs in competitive workplace environments. The P&A would use this measure as baseline and work towards increasing the number of individuals being served.

An example of improvement measures with respect to a University Center follows. A UCEDD wants to develop, implement, and evaluate a comprehensive statewide training program for direct support professionals (e.g., personal care assistants, occupational and physical therapy aides, home health aides, medical assistants, and human services case managers). The UCEDD establishes a timeframe of five years. The UCEDD develops a curriculum, obtaining input from other UCEDDs and other network partners and from individuals with developmental disabilities or family members/advocates. The UCEDD trains direct support professionals with the curriculum. The UCEDD evaluates its program annually and at the end of the five-year period, using input from all parties involved with respect to their satisfaction and recommendations for

future activities and revision of materials. The goals of this example focus on the health area of emphasis. The type of activity includes training via modules, role-playing, case examples, and/or consumer or family member/advocate interview or presentation. The proposed UCEDD measure of progress would be an increase in the number of direct support personnel successfully trained.

As indicated above, under this proposed rule the areas of emphasis may vary from grantee to grantee. Examples that highlight the flexibility grantees have in selecting areas of emphasis include: (1) State Councils—One Council may focus on activities that support individuals with developmental disabilities in obtaining employment, while another Council may award funding to a model demonstration project to provide vouchers for respite care to families of persons who have developmental disabilities; (2) Protection and Advocacy System (P&A)—One P&A may spend time assisting children with developmental disabilities to secure an education in their neighborhood schools, while another P&A may focus on abuse and neglect within a large State-run residential facility; (3) University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDDs)—One UCEDD may provide direct clinical services by performing diagnostic evaluations on children with developmental disabilities, while another UCEDD may be involved with aging issues and people with developmental disabilities. This NPRM maximizes flexibility and fosters collaboration among grantees of the ADD Network.

These proposed provisions are based in part on input from the field. The requirements also represent an evolution of a product called the ADD Roadmap to the Future, written prior to the DD Act of 2000. The Roadmap was developed to establish performance measures. Reporting mechanisms were developed in response to the requirements of the Government Performance and Results Act (GPRA) in 1993.

GPRA was passed in response to ongoing concerns that policy making, spending decisions, and program oversight were being hindered by insufficient information about program performance and results. GPRA holds agencies accountable for program performance by requiring the development of a five-year strategic plan, an annual performance plan, and an annual performance report. The strategic plan must include a

comprehensive mission statement and general goals and objectives covering the major functions and operations of the agency. The annual performance plan must: (1) Be consistent with the agency's strategic plan; (2) establish measurable performance goals; and (3) describe the operational processes, resources and technology required to meet the performance goals. The agency must submit an annual performance report to the President and the Congress on the results for the previous fiscal year. The performance report compares the annual performance goals established for the fiscal year with the actual performance achieved in that year. The report assesses the progress made in achieving the goals and explains factors causing deviations from the original goal targets.

It is important that the ADD programs continue to focus on the GPRA measures, where applicable, as well as the goals and activities tied to the measures of progress.

Prior to 2002, ADD's GPRA measures focused on consumer impact, systemic change, and the establishment of baseline data in the areas of employment, housing, education, health, self-determination, and community inclusion. Although grantees may focus on any area(s) of emphasis through their goals, we encourage that goals be tied to ADD's GPRA measures.

#### *Section 1385.6 Employment of Individuals With Disabilities*

This section of the regulation addresses grantee responsibilities regarding affirmative action and employment tied to disability without discrimination and is proposed to be published unchanged except to update statutory and U.S. Code citations.

#### *Section 1385.7 Reports of the Secretary*

We are proposing to add a new section covering Reports of the Secretary as required by Section 105 of the DD Act of 2000 (42 U.S.C. 15005) at § 1385.7 which is currently reserved. Under the proposed language, in order for ADD to have the required information to prepare the Report to Congress all grantees would be required to submit plans, applications and reports that label goals, activities and results clearly in terms of the following: Area of emphasis, type of activity, and categories of measures of progress.

#### *Section 1385.8 Formula for Determining Allotments*

This section addresses how the Commissioner will allocate funds

appropriated under the Act for the Councils and the P&As. This section of the regulation is proposed to be published unchanged except to update the reference from State Developmental Disabilities Councils to State Councils on Developmental Disabilities.

#### *Section 1385.9 Grants Administration*

The NPRM proposes technical changes to § 1385.9 to include reference to two additional parts of title 45 CFR that apply to grants under this section, 45 CFR part 76—Government-Wide Debarment and Suspension (Non-Procurement) and Government-Wide Requirements for Drug-Free Workplace and 45 CFR part 93—New Restrictions on Lobbying, and to delete reference to Part 75—Informal Appeal Procedures, as these requirements have been withdrawn by the Department of Health and Human Services. Other changes are proposed to address terminology changes made by the DD Act of 2000.

### **PART 1386—FORMULA GRANT PROGRAMS**

#### *Subpart A—Basic Requirements*

##### Section 1386.1 General

The NPRM proposes technical changes to § 1386.1 to update the terminology.

##### Section 1386.2 Obligation of Funds

Similarly, the NPRM revises § 1386.2 to update terminology.

We propose to revise the title of subpart B to read: Subpart B—Protection and Advocacy of Individual Rights.

##### Section 1386.19 Definitions

This section of the NPRM revises the terms and definitions that apply in §§ 1386.20, 1386.21, 1386.24 and 1386.25 of this subpart and to subpart C. Specifically:

- The definition of "abuse" has been revised to be consistent with the interpretation contained in the preamble accompanying the Protection and Advocacy for Individual with Mental Illness (PAIMI) regulation, at 62 FR 53551 (Oct. 15, 1997). The current regulation includes a list of acts that constitute abuse. The new language indicates that what constitutes abuse is not limited to these acts. The regulation does not define specifically the threshold at which a violation of an individual's rights constitutes abuse. Such a decision would be up to the P&A system to determine based on their intimate knowledge of the situation on behalf of an individual with developmental disabilities. The definition is not intended to limit the authority of the courts to review the

determinations of P&As of whether individuals with developmental disabilities have been subject to abuse.

- The definition of "American Indian Consortium" was added to clarify the eligibility requirements for the award of an American Indian Consortium under the P&A program. The American Indian Consortium is unique to the P&A program and carries out the responsibilities and exercises the authorities specified for a state.

- The definition of "complaint" has been revised from language indicating that the complaint be tied to alleged abuse or neglect of an individual with a developmental disability to broader language indicating that the complaint relates to the status or treatment of an individual with a developmental disability.

- The definition of the term "facility" was deleted. The Act no longer refers to "facilities," but instead refers to "a location in which services, supports, or other assistance are provided to an individual with a developmental disability." See 42 U.S.C. 15043(a)(2)(H) (access authority) and 42 U.S.C. 15043(c) (definition of "records"). The Act's use of this phrase confirms that P&As may serve persons residing in community settings so we also are deleting the definition of "Community living arrangements."

- The term "full investigation" has been revised to delete reference to "facilities" and "clients" to be replaced with the phrase "individuals with developmental disabilities" as all eligible persons are to have access to P&A services, not just those where a client relationship has been established.

- The definition of "neglect" has been revised to indicate that an individual perpetrating the act of neglect now must be responsible for providing "services, supports or other assistance" rather than an individual providing "treatment or habilitation services."

- The definition of "probable cause" has been revised. The proposed regulation indicates that the P&A system is the final arbiter of probable cause between itself and the organization or individuals from whom it is seeking records. The definition is not intended to affect the authority of the courts to review the determinations of P&As of whether probable cause exists.

- Additionally, a new definition of "Service Provider" has been proposed. The definition states, the term "service provider" refers to any individual (including a family member of an individual with a developmental disability), or a public or private organization or agency that provides,

directly or through contract, brief or long-term services, supports or other assistance to one or more individuals with developmental disabilities. Service providers include, but are not limited to, locations such as group homes, board and care homes, individual residence and apartments, day programs, public and private residential and non-residential schools (including charter schools), juvenile detention centers, hospitals, nursing homes, homeless shelters, and jails and prisons.

- A definition of "State Protection and Advocacy system" has been added to clarify that the term "State Protection and Advocacy System" is synonymous with the term "P&A" used elsewhere in this regulation, and the terms "system" and Protection and Advocacy system used in this part and in Part C.

#### Section 1386.20 Agency Designated To Administer the State Protection and Advocacy System

ADD is proposing to revise the title of section 1386.20 to Agency Designated To Administer the State Protection and Advocacy System from Designated State Protection and Advocacy Agency. The statute makes a distinction between the "system" which must be in existence and the agency implementing the system. See 42 U.S.C. 15043(a)(4). This phrase has been substituted throughout this section of the proposed rule as appropriate.

ADD also is proposing to revise paragraph (e)(6) regarding redesignation to clarify that the P&A and the designating official will have an opportunity to respond to comments from agencies administering the Federal protection and advocacy program. Additionally, statutory citations have been updated for paragraphs (d)(2)(i) and (f)(2), and paragraph (d)(4) has been slightly edited.

#### Section 1386.21 Requirements and Authority of the State Protection and Advocacy System

ADD is proposing to revise the title to include a reference to "State" in relation to the Protection and Advocacy System for clarity. In paragraphs (a) and (f) we are proposing to update terminology and statutory cites. We are proposing two substantive changes. First, we propose to revise paragraph (c) to include additional language regarding prohibited State actions which would diminish or interfere with the exercise of the P&As required authority. Second, in order to ensure that the notice and the opportunity for comment is given to all individuals who might potentially be interested in commenting, ADD is proposing to revise paragraph (h) to

indicate that prior to any Federal review of the State program, a 30-day notice and opportunity for public comment must be provided in the **Federal Register**.

To improve organization of the regulation, ADD is proposing to redesignate current § 1386.22 as section 1386.25 that would be included under a new subpart C. This section is discussed in more detail later in the preamble.

Current section 1386.23 is proposed to be revised and redesignated as § 1386.22, Periodic Reports: State Protection and Advocacy System.

Under proposed section 1386.22 ADD is proposing to revise the title to include a reference to "State" in relation to the Protection and Advocacy System for clarity. ADD is proposing to revise paragraph (a) to address the requirements of Section 144(e) of the Act (42 U.S.C. 15044), the applicable regulations and include information on the system's program necessary for the Secretary to comply with Section 105(1), (2), and (3) of the Act (42 U.S.C. 15005). Each system must report on its achievement of the measures of progress for the proceeding year pursuant to section 1385.5.

ADD is proposing to revise paragraph (b) to clarify what financial report is required and that the report shall be submitted semiannually.

ADD also is proposing to revise paragraphs (c) and (d) to update terminology, including converting references to "Statement of Objectives and Priorities (SOP)" to Annual Statement of Goals and Priorities (SGP). Under paragraph (c), we also are proposing to include language regarding each area of emphasis and the measure of progress (measures of consumer satisfaction, improvement, and collaboration) as provided under section 1385.5 of this part to measures goals. If changes are made to the goals or the measures of progress established for a year, the SGP must be amended to reflect those changes. The SGP must include a description of how the Protection and Advocacy system operates, and where applicable, how it coordinates the State Protection and Advocacy program for individuals with developmental disabilities with other Protection and Advocacy programs administered by the State Protection and Advocacy system. This description must include the System's processes for intake, internal and external referrals, and streamlining of advocacy services. The description also must address collaboration, the reduction of duplication and overlap of services, the sharing of information on service needs,

and the development of statements of goals and priorities for the various advocacy programs. In addition, we are proposing that each Protection and Advocacy system be required to disclose in its SGP whether it will be requesting or requiring fees or donations from clients as part of the intake process. This new requirement is being proposed in order that the public will have notice of such a policy and an opportunity to comment on it as part of the process required under paragraph (d).

Section 1386.24 Non-allowable costs for the State Protection and Advocacy System of the current regulations is proposed to be redesignated as section 1386.23. ADD is proposing to revise the title to include a reference to "State" in relation to the Protection and Advocacy System for clarity. We are republishing the full text of newly designated § 1386.23, Non-allowable costs for the State Protection and Advocacy System for the ease of public comment. No changes are proposed to be made in this section.

Finally, section 1386.25 Allowable litigation costs for the State Protection and Advocacy System, is proposed to be redesignated as section 1386.24. ADD is proposing to revise the title to include a reference to the "State Protection and Advocacy System" for clarity. We are republishing the remaining text for the ease of public comment.

#### *Subpart C—Access To Records, Service Providers and Service Recipients*

ADD is proposing to create a new subpart C. This change is being proposed because of the increased level of importance and detail that accessing records of individuals with developmental disabilities plays in supporting the P&A system in investigating suspected cases of abuse and neglect. ADD also is proposing to make the regulation on access to records consistent, where applicable, with the PAIMI regulation referenced earlier (42 CFR part 51.41). The goal is to ensure that all facets of the P&A system administered by the Department are subject to the same legally supportable requirements. ADD is the lead agency that administers the P&A system and the DD Act establishes those requirements. Many of the changes reflect the new access authority language contained in 42 U.S.C. 15043(a)(2)(I) and (J). Where we exercise discretion, we do so in the belief that the proposed provisions are necessary to meet Congress' underlying intent to ensure necessary access to records to promote the System's authority to investigate abuse and neglect and ensure the protection of rights. This broad interpretation of

available records and reports also is consistent with the requirements of the PAIMI regulations.

This NPRM addresses key provisions in subtitle C (42 U.S.C. 15043(a)(1); (2)(A), (H), (I), (J)); and (c) Protection and Advocacy of Individual Rights, in the DD Act that pertain to P&As access to service providers, access to recipients of services (*i.e.*, individuals with developmental disabilities) and access to records when incidents of abuse or neglect are suspected or reported, the health and safety of individuals with developmental disabilities are in jeopardy or are suspected of being in jeopardy, or in the case of a death of an individual with a developmental disability. In addition, the NPRM addresses provisions in Subtitle C concerning when consent for access to records from an individual with a developmental disability or the individual's guardian, conservator or legal representative is required and when it is not required. Moreover, the NPRM addresses provisions in Subtitle C that describe examples of the types of records to which a P&A shall have access. Given the obligation of P&As to conduct investigations of the incidences described here and in certain circumstances to contact an individual's guardian, conservator or legal representative, the Administration on Developmental Disabilities takes the position in this NPRM that a P&A shall have prompt access to contact information of such individuals. The law and this NPRM make distinctions about when a P&A will have access to records between "routine incidents" and other incidents involving abuse, neglect, health, safety, or a death.

The NPRM approach to addressing these key provisions are not only consistent with the DD Act but also consistent with the 2nd Circuit decision in "State of Connecticut Office of Protection and Advocacy for Persons with Disabilities and James McGaughey, Executive Director, State of Connecticut, Office of Protection & Advocacy for Persons with Disabilities v. Hartford Board of Education, Hartford Public Schools and Robert Henry, Supt. Of School."

Consistent with the DD Act, the 2nd Circuit's decision, and the proposed definition of "service provider" elsewhere in this NPRM, when schools provide services to individuals with developmental disabilities, they must provide P&As with access to locations, individuals, and records under the conditions spelled out in the DD Act (42 U.S.C. 15043(a)(1); (2)(A), (H), (I), (J); and (c)).

Second, the 2nd Circuit decision and this NPRM track the DD Act, requiring that a P&A have access at reasonable times to any individual with a developmental disability in a location in which services, supports, and other assistance are provided to such an individual, in order to carry out the purpose of Subtitle C ((42 U.S.C. 15043(a)(2)(H)). It is important to note that the DD Act, and therefore this NPRM makes no distinctions on the basis of age with regard to access an individual by the P&A.

Third, the 2nd Circuit in its decision and this NPRM recognize that the charge to P&As is to engage in a *range* of activities—protect the legal and human rights of individuals with developmental disabilities and monitoring for incidents of abuse or neglect and the health and safety of individuals with developmental disabilities. Thus, a P&As work does not end when it investigates and brings to closure a specific incident of abuse or neglect or risk to health and safety. We interpret the DD Act as providing P&As with the authority to pro-actively monitor situations where abuse and neglect or risks to health and safety may occur. We believe this NPRM outlines reasonable parameters for which P&As may have access to individuals with developmental disabilities, their records, their service providers, and the locations where services are provided to them, even under non-emergency situations (*i.e.*, those not involving allegations of abuse or neglect, probable cause to believe that the health or safety of the individual is in serious and immediate jeopardy, or in the case of a death).

Fourth, this NPRM and the DD Act are very specific in terms of when consent for records is required. In situations in which an individual's health and safety are in immediate jeopardy or a death has occurred, no consent is required and access to records should be provided no later than within 24 hours (42 U.S.C. 15043(a)(2)(J)(ii)). The 2nd Circuit in its decision recognizes and cites the DD Act as having special conditions (noted here) when an emergency situation is the issue (*i.e.*, those involving allegations of abuse or neglect, probable cause to believe that the health or safety of the individual is in serious and immediate jeopardy, or in the case of a death).

Fifth, the 2nd Circuit, the DD Act (at 42 U.S.C. 15043(a)(2)(I)(iii)(III)–(V)), and this NPRM recognize the importance of having contact information when P&As are conducting investigations. As such, and consistent with the 2nd Circuit, this NPRM proposes to require that P&As

have access to contact information when conducting an investigation. In incidences of suspected or reported abuse or neglect (when such incidents have been reported or good cause has been shown), risks to health and safety, or in the case of a death of an individual with a developmental disability, timing is a vital factor. Service providers should maintain up-to-date contact information for individuals with developmental disabilities, and parents, guardians, legal representatives, or conservators for individuals with developmental disabilities. In the situations noted here, when asked by a P&A for this contact information, a service provider should provide the information immediately.

As indicated previously, section 1386.22 is proposed to be redesignated and renamed section 1386.25 Access to Records. We are proposing to revise section 1386.25(a)(3), as redesignated, to incorporate monitoring activities and changing reference to "health and safety" to "abuse or neglect." In paragraph (3)(i), we propose to add a requirement for disclosure of the name and address of a representative be given to the P&A promptly. ADD believes that it is critical to the investigative function that P&As be given access to the names of representatives promptly. This requirement prevents undue delay in the P&As' intervention in the prevention of further abuse and neglect. Paragraphs (a)(2)(iii) and (3)(ii), as redesignated, are republished with slight edits. Paragraph (3)(iii) has been changed to read, "the representative has failed or refused to act on behalf of the individual."

We also are proposing to make changes to section 1386.25(b) as redesignated. In paragraph (b)(1) we propose to delete reference to "supportive" and refer instead to "supports or assistance" and "service provider" to be consistent with the Act. The language regarding reports available to the P&A is based on Congress' intent to ensure access to records to promote the System's authority to investigate abuse or neglect and ensure the protection of rights. The remainder of paragraph (b) has been revised to reflect editorial changes.

ADD also is proposing to revise paragraph (c) of this section to reflect new authority contained in the DD Act of 2000. Specifically, the second sentence of (c)(1) proposes language related to access to the records of a deceased person without any showing of probable cause, and is based on our interpretation of 42 U.S.C. 15043 (a)(2)(j)(ii)(II). The provision also requires that a P&A have access to records of an individual with a

developmental disability within 24 hours of the P&A's written request when the P&A has probable cause to believe that the individual is in serious and immediate jeopardy. In the case of a deceased individual or where the P&A has probable cause to believe the individual is in serious and immediate jeopardy, the consent of another party is not necessary for access to the records. ADD is also proposing to set a standard in the regulation for determining whether a decedent had a developmental disability. The proposed regulation provides: "Any individual who dies in a situation in which services, supports, or other assistance are, have been, or may customarily be provided to individuals with developmental disabilities shall, for purposes of the P&A's obtaining access to the individual's records, be deemed an individual with a developmental disability." The purpose of this proposal is to simplify the task of P&As in establishing that the decedent was an individual with a developmental disability. Proving that the functional definition of the developmental disability which appears in Section 102(8) of the Act applies to a living person can be difficult; it will be all the more difficult to prove its application to an individual who is no longer living. In making this proposal ADD is seeking to avoid making access to the records of a deceased individual so difficult that the intent of Congress in enacting Section 143(a)(2)(j)(ii)(II) of the Act would be frustrated.

ADD is proposing to remove all of section 1386.25(e) as redesignated and consolidate the provisions into section 1386.28(e), discussed later in this preamble.

Proposed section 1386.25(d) addresses the remaining provisions regarding sharing and copying of records. This paragraph proposes, "If the organization or agency having possession of the records copies them for the P&A system, it may not charge the P&A system an amount that would exceed the amount it customarily charged other non-profit or State government agencies for reproducing documents." These revisions also will make this new section consistent with the PAIMI regulation. The PAIMI regulation states (42 CFR 51.41) that the P&A system may not be charged for copies more than is "reasonable" according to prevailing local rates, and certainly not a rate higher than that charged by any other service provider, and that nothing shall prevent a system from negotiating a lower fee or no fee. Many service providers have tried to impose excessive costs on P&As for

copies as a means of obstructing access. The above clarifications are necessary to prevent this from occurring. Also the clarification on the time frame during which copies of records must be provided to P&As is necessary to avoid the frequently long delays in this regard. Often it is the service provider and not the P&A which makes the copies of the requested records. Prompt access for the P&A to inspect records is of little assistance in its investigation if copies of the records themselves are not provided quickly.

In § 1386.25(d) it is not the intent of ADD that the requirement for P&As to have a right to use their own equipment for copying be used to require that organizations being investigated allow P&As to remove records from the organization's premises to make the copies. The remaining provisions of 1386.25 as redesignated, ((current regulations section 1386.22 (f), (g), (h) and (i)), are proposed to be incorporated into new §§ 1386.26 and 1386.27 as discussed below.

ADD is proposing a new section 1386.26 named "Denial or Delay of Access." This section parallels the PAIMI regulation at 42 CFR 51.43. Under this paragraph, P&As must be able to obtain the identities of service recipients from service providers (who have control of this information). The confidentiality of such P&A records as proposed are protected under other provisions of this regulation. In emergency situations or in the case of a service recipient's death, section 143(a)(2)(j)(ii) of the DD Act provides P&As with access to records of service recipients within 24 hours after written request is made and without consent. In that vein, we propose a one-business day deadline for providing the written justification denying access. ADD believes that such standards are necessary in recognition of the consequences of not accessing individuals quickly when there are allegations of abuse or neglect, probable cause to believe that the health or safety of the individual is in serious and immediate jeopardy, or in the case of a death.

Section 1386.26 concludes with a description of the information that should be included in the justification denying access. This provision is contained in current regulations at 1386.22(i).

ADD is proposing a new section 1386.27 Access to Service Providers and Service Recipients to replace section 1386.22(f) of the current regulations. Under this section, the term "service provider" is substituted throughout for the term "facility." The language

otherwise remains the same except for editorial changes. We are proposing changes under (b)(1) through (3) to address the times and circumstances under which access shall be afforded. This language is consistent with the PAIMI regulation (62 FR 53561–62).

In this NPRM, we propose that P&A systems should not be required to provide notice to a service provider when they are coming to investigate an allegation of abuse or neglect, when they have probable cause to believe that the health or safety of the individual is in serious and immediate jeopardy, or in the case of a death. However, P&As should give notice when it will be visiting a service provider as part of an investigation in non-emergency situations (those not involving allegations of abuse or neglect, probable cause to believe that the health or safety of the individual is in serious and immediate jeopardy, or in the case of a death).

ADD is proposing that P&A systems should have the right to access service providers “all times necessary \* \* \*” to conduct a full investigation, and particularly when the system has determined “probable cause” that there is or may be imminent danger of serious abuse or neglect of an individual. ADD believes that immediate access is necessary with respect to service providers to permit P&As to uncover situations that may involve immediate threats to health or safety. It also is necessary to prevent interested parties from concealing situations involving abuse or neglect or taking actions which may compromise evidence related to such incidents (such as intimidating staff or service recipients).

To address this, ADD is proposing a new subsection 1386.27(c) which replaces section 1386.22(g) of the current regulation. We are proposing to add new language in paragraph (c) to read, “A P&A also shall be permitted to attend treatment planning meetings concerning individual service recipients with the consent of the individual or his or her guardian, conservator or other legal representative. Access to facilities shall be afforded immediately upon an oral or written request by the P&A system. Except where complying with the P&A’s request would interfere with treatment or therapy to be provided, service providers shall provide access to individuals for the purpose covered by this paragraph within 24 hours of the system’s making a request. If the P&A’s access to an individual must be delayed beyond 24 hours to allow for the provision of treatment or therapy, the P&A shall receive access as soon as possible thereafter. Service recipients

subject to the requirements in this paragraph include adults or minors who have legal guardians or conservators. P&A activities shall be conducted so as to minimize interference with service provider programs, respect service recipients’ privacy interests, and honor a recipient’s request to terminate an interview.” Under the proposed rule, such access is for the purpose of:

(1) Providing information, training, and referral for programs addressing the needs of individuals with developmental disabilities, and information and training about individual rights, and the protection and advocacy services available from the P&A system, including the name, address, and telephone number of the P&A;

(2) Monitoring compliance with respect to the rights and safety of service recipients; and

(3) Inspecting, viewing and photographing all areas of a service provider’s premises which are used by service recipients or are accessible to them.

ADD is proposing these changes to clarify that access be permitted to treatment planning meetings (with the consent of the individual or his or her guardian), as such access is needed to assure that service providers are protecting the health and safety of service recipients. The limitation related to individual/guardian consent would provide an appropriate safeguard concerning privacy. Consent of other individuals who may be receiving treatment or services at the same location (for example, group therapy situations) will be tied to the policies of the premises where the care is being provided.

The ADD proposed regulations support the PAIMI Act regulation. For example, such access is supported by the legislative history of the PAIMI Act, which provides that P&As must be afforded “access to meetings within the facility regarding investigations of abuse and neglect and to discharge planning sessions.” S. Rep. 454, 100th Cong., 2d Sess. (1988). Based on this statement (and in the interest of assuring consistency with the PAIMI Program), the P&A also should be authorized to attend treatment team meetings, which serve some of the same purposes as discharge planning sessions. The DD Act and its case law generally support extremely broad access to individuals to monitor conditions relating to safety and health. We interpret these authorities, then, to generally support treatment team access; as such access is an important strategy in monitoring the adequacy of health care.

We are further proposing to move section 1386.22(h) in the current regulation to section 1386.27(d) in the proposed regulation. Changes proposed are only editorial.

Similar to the approach used in the PAIMI regulation at section 42 CFR 51.45, ADD is proposing to incorporate in a new section 1386.28, Confidentiality of Protection and Advocacy Systems Records. This section will replace the current ADD regulation in 45 CFR 1386.22(e), Access to Records, Facilities and Individuals that deals with P&A access authority. Because the confidentiality provisions relate to a broad range of client information, and not only materials obtained through the P&A’s access authority, it is more appropriate to address the issues in a separate, dedicated section of the regulation. ADD also proposes that the new provision on confidentiality be modeled after the existing provision on this subject in the PAIMI regulation at 42 CFR 51.45, with certain alterations. Paragraph (a) and (a)(1) of section 1386.28 as proposed mirror the existing provisions (1386.22(e) and (e)(3)) with editorial changes. Paragraphs (a)(1)(i), (ii), (iii) and (iv) contain new language to clarify that the P&A must keep confidential—records and information, in any automated electronic database pertaining to clients; individuals who have been provided general information or technical assistance on a particular matter; the identity of individuals who report incidents of abuse or neglect, or who furnish information that forms the basis for a determination that probable cause exists and names of individuals who have received services; and names of individuals who have received services, supports or other assistance, and who provided information to the P&A for the record. Paragraph (a)(2) remains the same as current regulations (1386.22(e)(2)). Paragraph (a)(2) requires the P&A systems to have written policies governing the access, storage, duplication and release of information from client records. Paragraph (a)(3) as proposed requires the P&A system to obtain written consent from the client and/or various other individuals, before releasing information on such individuals to individuals not authorized to receive such information.

Proposed paragraphs (b) and (c) reflect the critical need for P&As to disclose to other investigative and enforcement agencies information about ongoing or potential abuse and neglect and specific individuals affected. Frequently, a P&A will uncover, as part of its own investigation or monitoring efforts, information about abuse and

neglect which must be addressed promptly by other agencies with specialized State or Federal authority and/or greater resources, such as State licensing and certification agencies, the Department of Justice, and the police. In order for these agencies to act promptly and effectively, they must be provided specific information about individuals subject to abuse or neglect and the relevant circumstances. We recommend that such information be disclosed where possible with significant restrictions on redisclosure and only under those circumstances in which the P&As have obtained the information pursuant to the authority under the DD Act.

The NPRM redesignates subpart C as subpart D and revises the material to update statutory and U.S. Code citations to conform to the Developmental Disabilities Act of 2000 and update the wording of the State Councils on Developmental Disabilities.

In § 1386.30, State plan requirements, we are proposing in paragraph (c) that the State plan must be submitted through the Electronic Data Submission system rather than any other format. In paragraph (c)(2) new language on the plan goals is being proposed. The goals must be clearly expressed in terms of the area(s) of emphasis to be covered, the types of activity to be undertaken (i.e., advocacy, capacity building, systems change), the specific measures of progress to be used (consumer, collaboration, improvement), and if applicable, and not reflected otherwise, the extent to which unserved or underserved individuals or groups, particularly from ethnic or racial groups or geographic regions (e.g., rural) were the target of assistance or services (see Section 125(c)(7) and Section 105(1)(C) of the Act).

Paragraph (c)(3) proposes that the plan provide for the establishment and maintenance of a Council and describe the membership of the Council. This includes the requirement that the non-State agency members of the Council shall be subject to term limits to ensure rotating membership. Paragraph (d) proposes to require that the State plan be updated as appropriate during the five-year plan period and specifies that amendments to plans are required when substantive changes are made, including changes under proposed paragraph (c)(2) related to performance activities. In paragraph (e) we are proposing time limits (no longer than five years) for demonstration projects and activities performed by the Councils. A five-year time limit has been established to coincide with the duration of the State plan. Paragraph (a) is republished with

updated statutory citations, and paragraphs (b) and (f) are republished with updated statutory citations and editorial changes.

In § 1386.31 State plan submittal and approval, we are proposing to revise paragraph (b) to require that the plan be submitted to ADD rather than the appropriate regional office. Also, we are proposing to revise the provision which requires the Governor or the Governor's designee approval of the State plan or amendment. The regulation proposes that the State plan or amendment must be approved by the entity or individual authorized to do so under State law. This requires States to determine who would approve the State plan or amendment, which could be the Council, the Governor or the Governor's designee. This authorization could be based on such actions as: executive orders, proclamations, State statute, common law, or the State constitution. In paragraph (c) we are proposing to indicate that plans received during a quarter of the Federal fiscal year are approved back to the first day of the quarter so costs incurred from that point forward are approvable. Paragraphs (a) and (d) are proposed to be republished without change.

In § 1386.32, *Periodic reports*: Federal assistance to State Developmental Disabilities Councils, we are proposing to revise the title to read § 1386.32 *Periodic reports*: Federal assistance to State Councils on Developmental Disabilities. ADD is proposing to revise paragraph (a) to clarify what financial report is required and that the report shall be submitted semiannually. In § 1386.32(b) the reference to a statutory cite is proposed to be updated and language is revised to clarify that State Council's Program Performance Report (PPR) must be clearly expressed in terms of area(s) of emphasis to be covered, the types of activity to be undertaken (i.e., advocacy, capacity building, systems change), the measures of progress to be used, and if applicable, and not stated elsewhere in the document, the extent to which unserved or underserved individuals or groups, particularly from ethnic or racial groups or geographic regions (e.g., rural), were the target of assistance or services (see Section 125(c)(7) and Section 105(1)(C)). Under paragraphs (b)(1)–(12), each report must contain information about the progress made by the Council in achieving its goals. In new section 1386.32(c) each State Council on Developmental Disabilities must include in its Annual Program Performance Report information on its achievement of the measures of progress established pursuant to section 1385.5.

Section 1386.33, Protection of employee's interests, is revised to update statutory cites and to provide clarity.

Section 1386.34, Designated State Agency, is revised to update statutory cites and technical changes are made to provide clarity.

Section 1386.35, Allowable and non-allowable costs for Federal Assistance to State Councils on Developmental Disabilities, is proposed to be revised to update statutory cites with technical changes to provide clarity.

Section 1386.36, Final disapproval of the State plan or plan amendments, is revised to update statutory cites, remove references to the HHS Regional Offices, and contains slight editorial changes.

Subpart E—Practice and Procedure for Hearings Pertaining to State's Conformity and Compliance with Developmental Disabilities State Plans, Reports and Federal Requirements, formerly subpart D, is being revised to make technical changes and is republished in full.

Specifically under the General section, in section 1386.80 Definitions, we are proposing to add the terms Act and Department. In section 1386.81, Scope of rules, we have updated the legal cites. No changes are proposed to section 1386.82–1386.85 but these sections are republished for the ease of public comment. Under the section on Preliminary Matters—Notice and Parties, section 1386.90 is proposed to be revised to update references to the State Councils on Developmental Disabilities. Section 1386.91–1386.94 are proposed to be republished unchanged. Under Hearing Procedures, sections 1386.100–1386.109 are republished with technical edits made to sections 101 and 106. Finally under the section on Post-hearing Procedures and Decisions, no change is proposed to section 1386.110 but it is being republished for the ease of public comments and sections 1386.111–1386.112 have been revised to update legal cites.

#### **PART 1387—PROJECTS OF NATIONAL SIGNIFICANCE**

In § 1387.1 General Requirements ADD is proposing to revise paragraph (a) to indicate that all projects funded under this part must be of national significance and serve or relate to individuals with developmental disabilities to comply with section 161 of the Act as well as section 162 of the Act. We are proposing to remove the current regulatory language of paragraph (b) as the requirement for the Secretary to publish the proposed priorities for PNS funding in the **Federal Register** for

public comments is no longer required under the Act. Current regulatory language of paragraph (c) will now become paragraph (b), indicating that the requirements concerning format and content of the application, submittal procedures, eligible applicants, and final priority areas will be published in program announcements in the **Federal Register**. Current regulatory language of paragraph (d), with minor edits, will now become paragraph (c), indicating that in general, Projects of National Significance provide technical assistance, collect data, demonstrate exemplary and innovative models, disseminate knowledge at the local and national levels, and otherwise meet the goals of Part E of the Act, 42 U.S.C. 15081.

As the DD Act provided several new types of activities allowable under Projects of National Significance we are proposing in paragraph (d) to indicate that Projects of National Significance may engage in one or more of the types of activities provided in Section 161(2) of the statute.

As provided under new paragraph (e), funding for projects are to be awarded to public and private non-profit entities for wide applicability and impact. A request for proposal process shall solicit applications from non-profits, institutions of higher learning, State and local governments, and Tribal governments for PNS funding.

As provided under new paragraph (f), faith-based organizations are eligible to apply for PNS funding, providing that the faith-based organization meets the specific eligibility criteria contained in the Program Announcement for a given Fiscal Year.

Program Announcements, requesting proposals, are published in the **Federal Register** and posted on ADD's Web site at <http://www.acf.dhhs.gov/programs/add>. A panel of experts shall review and score each eligible application, received by the submission deadline, based on the evaluation criteria in the Program Announcement. Final funding decisions are made by the ADD Commissioner.

**PART 1388—NATIONAL NETWORK OF UNIVERSITY CENTERS FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES EDUCATION, RESEARCH, AND SERVICE (UCEDDS)**

The Notice of Proposed Rulemaking for the UCEDDs includes a number of changes to part 1388. The DD Act of 2000 included a significant restructuring of subtitle D—National Network of University Centers for Excellence in Developmental Disabilities Education, Research, and Service. These changes have led to a

proposed reorganization of the regulation.

First, section 1388.1, Definitions, has been changed to Purpose. Several of the terms under the proposed rule appear in proposed § 1385.3 of the regulation and other terms were removed from the DD Act of 2000 and therefore are no longer needed in the regulation. In the case of the term “Mandated Core Functions”, these are now more clearly defined under section 1388.2. In addition, “Research and Evaluation” is included as a Core Function separate from dissemination of information. Both are included and described in § 1388.2 of the proposed regulation. Section 1388.1 Purpose, as proposed provides information about the Centers, including their intended functions.

Sections 1388.2–1388.7 of the current regulation provides information about ‘Program Criteria’ for the UCEDDs in the following areas: Purpose, Mission, Governance and Administration, Preparation of Personnel, Services and Supports, Dissemination, and Peer Review. The DD Act of 2000 deleted the provisions specifically associated with the ‘Program Criteria’ and the proposed changes to the regulation are necessary to make it consistent with the DD Act of 2000.

The title of section 1388.2 has been changed to Core Functions. The DD Act of 2000 now refers to Core Functions of Centers. This section proposes to provide information about Core Functions, including the provision of interdisciplinary pre-service preparation and continuing education of students and fellows, provision of community services, the carrying out of research, and dissemination of information.

The title of section 1388.3 has been changed to National Training Initiatives on Critical and Emerging Needs. Centers have discretion in selecting the activities they will pursue within the broad definition of their purpose in the statute and therefore the current regulation which defines the mission of the Centers as a group is not needed. ADD proposes that revised section

1388.3 contain information about the National Training Initiatives on Critical and Emerging Needs, which replaces the Training Initiative Projects (TIPs) that appear in the current regulation. Under this section, supplemental grant funds for National Training Initiatives on Critical and Emerging Needs will be reserved when each Center funded has received a grant award of at least \$500,000, adjusted for inflation. The critical and emerging needs grants are to pay the Federal share of the cost of training initiatives and will be awarded

on a competitive basis for periods of not longer than 5 years.

The title of section 1388.4 Program Criteria—Governance and Administration, has been changed to Applications and provides information about a Center's eligibility for grant awards through applications as well as required application contents such as the five-year plan describing the projected goal(s) related to one or more areas of emphasis for each of the core functions; a number of assurances, including how the Center will address the projected goals, carry out goal-related activities, collaborate with the consumer advisory committee comprised of a cross-section of stakeholders (e.g., individuals with developmental disabilities and related disabilities, family members of individuals with developmental disabilities, a representative of the State Protection and Advocacy System, a representative of a self-advocacy organization, and representatives of other relevant organizations), strategies for leveraging additional public and private funds, director qualifications, and plans for information dissemination. The applications section also includes reference to the measures of progress, which now represent the regulatory standards for the Centers. The program criteria of the current regulation had been the basis for such standards. In addition, the Applications section proposes to include information about the peer review process, including the composition of the peer review groups. Finally, information about the Federal Share under the proposed rule is provided in the Applications section of the regulation. For the purpose of determining the Federal share with respect to the project, expenditures on that project by a political subdivision of a State or by a public or private entity shall be subject to the provisions of 45 CFR part 93—New Restrictions on Lobbying (see section 1385.9 Grants administration) and must be considered as an expenditure of the Center under subtitle D.

Section 1388.5 of the proposed rule has been revised to address the five-year plan and annual report. Provisions on ‘Program Criteria—Preparation of Personnel’ are no longer needed in this section because of changes in the DD Act of 2000 and changes made in other sections of this proposed rule. Under the proposal, section 1388.5 addresses the five-year plan and annual report and includes requirements for Centers to report on their progress. The Annual Report must be submitted by July 31st of each year and include information on the progress made in achieving the

projected goals, proposed revisions to the goals, and a description of successful efforts to leverage funds. The timeframe for the Annual Report is tied to the UCEDDs fiscal and reporting cycle. The five-year plan must be amended to reflect changes made to the measures of progress established for any year.

We propose to delete the remaining paragraphs in section 1388 to reflect the DD Act of 2000 and changes made elsewhere in the proposed rule.

**Amended Proposed Regulations, 45 CFR Parts 1385, 1386, 1387, and 1388**

The Administration on Developmental Disabilities presents 45 CFR parts 1385, 1386, 1387, and 1388 as an amended whole in response to numerous requests by direct consumers, family members of individuals with developmental disabilities, members of advocacy organizations, and the Developmental Disabilities Network. Reprinting the regulation in its entirety to include the proposed new regulations and the current regulation will assist these individuals in responding to the proposed rule, especially the proposed measures of progress.

**Impact Analysis**

*Executive Order 12866*

Executive Order 12866 requires that regulations be drafted to ensure that they are consistent with the priorities and principles set forth in Executive Order 12866. The Department has determined that this proposed rule is consistent with these priorities and principles.

Executive Order 12866 encourages agencies, as appropriate, to provide the public with meaningful participation in the regulatory process. The proposed rule seeks to implement the Developmental Disabilities Act of 2000 and especially provisions of the Act addressing program accountability and indicators of progress. In developing

this regulation, we considered input we received from the developmental disabilities community, especially in relation to our extensive discussion on the issue of performance outcomes with the grantees of the ADD network (State Councils on Developmental Disabilities, P&As, UCEDDs, and the national organizations that represent them: The National Association of Developmental Disability Councils (NADDC), the National Association of Protection and Advocacy Systems (NAPAS), and the Association of University Centers on Disabilities (AUCD). In addition, we are providing a 60 day public comment period.

*Regulatory Flexibility Analysis*

The Secretary certifies under 5 U.S.C. 605(b), the Regulatory Flexibility Act (Pub. L. 96-354), that this regulation will not have a significant economic impact on a substantial number of small entities. The primary impact of this regulation is on State Councils on Developmental Disabilities, State Protection and Advocacy Systems, and UCEDDs. P&As are administered by small nonprofits. This regulation will support the work of the P&As by providing guidance regarding access to service providers and records of individuals in order to investigate potential abuse and neglect. Service providers will be impacted if a complaint is made against them. Similarly, this regulation will support the work of UCEDDs by providing guidance on the administration of the program, especially the measures of progress, which now represent the regulatory standards for the UCEDDs. The regulation does not have a significant economic impact on these entities. We estimate an average impact of \$300 per grantee, resulting in a total cost across the DD network of less than \$100,000.

This rule is considered a “significant regulatory action” as it relates to service

providers and the P&As. If a complaint is made against a service provider and the P&A investigates potential abuse and neglect, it may result in adversely affecting those service providers in a material way, (section 3(f)(1) of Executive Order 12866). Therefore, this proposed regulation has been reviewed by the Office of Management and Budget.

*Paperwork Reduction Act of 1995*

Sections 1386.22, 1386.32, and 1388.5 contain information collection requirements. In Section 1386 of the NPRM, the State Council on Developmental Disabilities Program Performance Report and the Protection and Advocacy Statement of Goals and Priorities required reinstatement from OMB. Further changes to these reports will be required once the indicators of progress are established through final regulations. For the Protection and Advocacy Program Performance Report in Section 1386 of the NPRM, the OMB Standard Form—PPR will be used.

Recordkeeping and reporting requirements for the UCEDDs (Part 1388) include the submission of an approved grant application (section 154(a)(2) of the Act (42 U.S.C. 15064)) and a new annual report (section 154(e)). The application for core funding uses OMB Standard Form 424—Application for Federal Assistance and Budget Information. The annual report will require a new reporting format that will address the satisfaction of individuals with developmental disabilities with advocacy, capacity building, and systemic change activities; the extent to which the advocacy, capacity building, and systemic change activities provided results through improvements; and the extent to which collaboration was achieved in the areas of advocacy, capacity building and systemic change activities.

**REPORTING AND RECORDKEEPING REQUIREMENTS IN PART 1386 AND 1388 OF THE NPRM**

		Expires	Annual number of respondents	Average burden response (hours)	Annual burden hours
1386.22(a) SF-PPR .....	0970-0334	06/30/2009	57	44	2,508
1386.22(c) P&A SGP Reinstatement .....	0980-0270	11/30/2009	57	44	2,508
1386.30(c) Council State Plan .....	0980-0162	05/31/2009	55	80	4,400
1386.32(b) Council PPR Reinstatement .....	0980-0172	02/28/2009	55	44	2,420
1386 32(a) Council Financial Status Report (ADD-02B):					
ADD-02 Council .....	0980-0212	05/31/2009	55	8	440
1388.5(b) UCEDD Annual Report .....	0970-0289	08/31/2008	67	200	13,400

The Administration for Developmental Disabilities will

consider comments by the public on

these collections of information in the following areas:

(a) Evaluating whether the proposed collection(s) is (are) necessary for the proper performance of the functions of ADD, including whether the information will have practical utility;

(b) Evaluating the accuracy of the ADD's estimate of the burden of the proposed collection(s) of information, including the validity of the methodology and assumptions used;

(c) Enhancing the quality, usefulness and clarity of the information to be collected; and

(d) Minimizing the burden of the collection of information on those who are to respond, including through the use of appropriate automated, electronic, mechanical, or other technology, e.g., permitting electronic submission of responses.

OMB is required to make a decision concerning the collection(s) of information contained in these proposed regulations between 30 and 60 days after publication of this document in the **Federal Register**. Therefore, a comment is best assured of having its full effect if OMB receives it within 30 days of publication. This does not affect the deadline for the public to comment to the Department on the NPRM. Written comments to OMB for the proposed information collection should be sent directly to OMB either by FAX to 202-395-6974 or by e-mail to [OIRA\\_submission@omb.eop.gov](mailto:OIRA_submission@omb.eop.gov), attn: desk officer for the Administration for Children and Families.

#### *Unfunded Mandates Reform Act*

Section 202 of the Unfunded Mandates Reform Act of 1995 (Unfunded Mandates Act) requires that a covered agency prepare a budgetary impact statement before promulgating a rule that includes any Federal mandate that may result in expenditures by State, local and Tribal governments, in the aggregate, or by the private sector, of \$100 million, adjusted for inflation, or more in any one year.

If a covered agency must prepare a budgetary impact statement, section 205 further requires that it select the most cost-effective and least burdensome alternatives that achieves the objectives of the rule and consistent with the statutory requirements. In addition, section 203 requires a plan for informing and advising any small government that may be significantly or uniquely impacted by a proposed rule.

We have determined that this rule does not result in the expenditure by State, local, and Tribal government in the aggregate, or by the private sector of more than \$100 million in any one year.

#### *Congressional Review*

*This rule is not a major rule as defined in 5 U.S.C. § 804(2).*

#### *Assessment of Federal Regulations and Policies on Families*

Section 654 of the Treasury and General Government Appropriations Act of 1999 requires Federal agencies to determine whether a policy or regulation may affect family well being. If the agency's conclusion is affirmative, then the agency must prepare an impact assessment addressing seven criteria specified in the law. These regulations do not have an impact on family well being as defined in the legislation.

#### *Executive Order 13132*

Executive Order 13132 on "federalism" was signed August 4, 1999. The purposes of the Order are: ". . . to guarantee the division of governmental responsibilities between the national government and the States that was intended by the Framers of the Constitution, to ensure that the principles of federalism established by the Framers guide the executive departments and agencies in the formulation and implementation of policies, and to further the policies of the Unfunded Mandates Reform Act. . . ."

The Department certifies that this rule does not have a substantial direct effect on States, on the relationship between the Federal government and the States, or on the distribution of power and responsibilities among the various levels of government.

ADD is not aware of any specific State laws that would be preempted by the adoption of the regulation in subpart C of 45 CFR part 1386. ADD would welcome comments from any State whose laws would be in conflict with the requirements of the proposed regulation or whose laws require modification to establish compliance with requirements of the proposed regulation. States should alert ADD in their comments of the specific provisions of the NPRM that would require delay in the effective dates in order to bring State laws into conformance. ADD will consider delaying the effective date of some provisions in the final regulation if States must modify legislation or enact new legislation to bring their laws into conformance with the new regulation. The rule does not impose unfunded mandates.

This proposed rule does contain regulatory policies with federalism implications that require specific consultation with State or local elected

officials. For example, compliance with the indicators of progress is mandatory for State programs. However, prior to the development of the rule, the Administration on Developmental Disabilities consulted with State Developmental Disabilities Councils, P&As, and UCEDDs to minimize any substantial direct effect on them and indirectly on States.

#### **List of Subjects**

##### *45 CFR Part 1385*

Disabled, Grant programs/education, Grant programs/social programs, Reporting and recordkeeping requirements.

##### *45 CFR Part 1386*

Disabled, Administrative practice and procedures, Grant programs—education, Grant programs—social programs, Reporting and recordkeeping requirements.

##### *45 CFR Part 1387*

Administrative practice and procedure, Grant programs—education, Grant programs—social programs, Individuals with disabilities.

##### *45 CFR Part 1388*

Colleges and Universities, Grant programs/education, Grant programs/social programs/University Centers for Excellence in Developmental Disabilities Education, Research and Services.

(Catalog of Federal Domestic Assistance Program, Nos. 93.630 Developmental Disabilities Basic Support and 93.632 Developmental Disabilities—University Centers for Excellence)

Dated: November 20, 2007.

**Daniel C. Schneider,**

*Acting Assistant Secretary for Children and Families.*

Approved: November 26, 2007.

**Michael O. Leavitt,**

*Secretary, Department of Health and Human Services.*

**Editorial Note:** This document was received at the Office of the Federal Register on April 3, 2008.

For reasons set forth in the preamble, The Department of Health and Human Services proposes to amend subchapter I, chapter XIII, of title 45 of the Code of Federal Regulations as set forth below.

1. Revise part 1385 to read as follows:

#### **PART 1385—REQUIREMENTS APPLICABLE TO THE DEVELOPMENTAL DISABILITIES PROGRAM**

**Section Contents**  
Sec.

- 1385.1 General.
- 1385.2 Purpose of the regulations.
- 1385.3 Definitions.
- 1385.4 Rights of individuals with developmental disabilities.
- 1385.5 Program accountability and indicators of progress.
- 1385.6 Employment of individuals with disabilities.
- 1385.7 Reports to the Secretary.
- 1385.8 Formula for determining allotments.
- 1385.9 Grants administration requirements.

**Authority:** 42 U.S.C. 15001 *et seq.*

#### **§ 1385.1 General.**

Except as specified in §§ 1385.4 and 1385.5, the requirements in this part are applicable to the following programs and projects:

- (a) Federal Assistance to State Councils on Developmental Disabilities;
- (b) Protection and Advocacy of Individual Rights;
- (c) Projects of National Significance; and
- (d) National Network of University Centers for Excellence in Developmental Disabilities Education, Research, and Service.

#### **§ 1385.2 Purpose of the regulations.**

These regulations implement the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (42 U.S.C. 15001 *et seq.*).

#### **§ 1385.3 Definitions.**

The following definitions apply:

**ACF.** The term “ACF” means the Administration for Children and Families within the Department of Health and Human Services.

**Act.** The term “Act” means the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (42 U.S.C. 15001 *et seq.*).

**Accessibility.** The term “Accessibility” means that programs funded under the DD Act of 2000 and facilities which are used in those programs meet applicable requirements of 45 CFR part 84 and the Americans with Disabilities Act of 1990.

**ADD.** “ADD” means the Administration on Developmental Disabilities, within the Administration for Children and Families.

**ADD Network.** “ADD Network” means the State Councils on Developmental Disabilities, the Protection and Advocacy System, and the University Centers for Excellence in Developmental Disabilities Education, Research, and Service.

**Advocacy activities.** The term “Advocacy activities” means active support of policies and practices that promote self-determination and inclusion in the community and workforce for individuals with

developmental disabilities and their families.

**Areas of emphasis.** The term “areas of emphasis” means the areas related to quality assurance activities, education activities and early intervention activities, child care-related activities, health-related activities, employment-related activities, housing-related activities, transportation-related activities, recreation-related activities, and other services available or offered to individuals in a community, including formal and informal community supports that affect their quality of life.

**Assistive technology device.** The term “assistive technology device” means any item, piece of equipment, or product system, whether acquired commercially, modified or customized, that is used to maintain, increase amount of or improve quality of the functional capabilities of individuals with developmental disabilities.

**Assistive technology service.** The term “assistive technology service” means any service that directly assists an individual with a developmental disability in the selection, acquisition, or use of an assistive technology device. Such term includes: conducting an evaluation of the needs of an individual with a developmental disability, including a functional evaluation of the individual in the individual’s environment; purchasing, leasing, or otherwise providing for the acquisition of an assistive technology device by an individual with a developmental disability; selecting, designing, fitting, customizing, adapting, applying, maintaining, repairing or replacing an assistive technology device; coordinating and using another therapy, intervention, or service with an assistive technology device, such as a therapy, intervention, or service associated with an education or rehabilitation plan or program; providing training or technical assistance for an individual with a developmental disability, or, where appropriate, a family member, guardian, advocate, or authorized representative of an individual with a developmental disability; and providing training or technical assistance for professionals (including individuals providing education and rehabilitation services), employers, or other individuals who provide services to, serve, employ, or are otherwise substantially involved in the major life functions of an individual with developmental disabilities.

**Capacity building activities.** The term “capacity building activities” means a system for sustaining and expanding the successful delivery of services, support and other assistance to individuals with

developmental disabilities and their families.

**Center.** The term “Center” means a University Center for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD) established under subtitle D of the DD Act of 2000.

**Child care-related activities.** The term “child care-related activities” means advocacy, capacity building, and systemic change activities that result in families of children with developmental disabilities having access to and use of child care services, including before-school, after-school, and out-of-school services, in their communities.

**Collaboration.** The term “collaboration” means the use of interagency agreements and similar mechanisms by agencies under the Act (State Developmental Disabilities Councils, the Protection and Advocacy agencies and the University Centers for Excellence in Developmental Disabilities Education Research, and Service). These agencies may work among themselves and with private individuals, groups, and organizations and State and local government agencies to foster cooperation in achieving the purposes of the Act.

**Commissioner.** The term “Commissioner” means the Commissioner of the Administration on Developmental Disabilities, Administration for Children and Families, Department of Health and Human Services, or his or her designee.

**Culturally competent.** The term “culturally competent,” means that services, supports, or other assistance that are conducted or provided in a manner that is responsive to the beliefs, interpersonal styles, attitudes, language, and behaviors of individuals who are receiving the services, supports or other assistance, and in a manner that has the greatest likelihood of ensuring their maximum participation in the program involved.

**Department.** The term “Department” means the U.S. Department of Health and Human Services.

**Developmental disability.** The term “developmental disability,” as determined on a case by case basis, means a severe, chronic disability of an individual that—

- (1) Is attributable to a mental or physical impairment or combination of mental and physical impairments;
- (2) Is manifested before the individual attains age 22;
- (3) Is likely to continue indefinitely;
- (4) Results in substantial functional limitations in three or more of the following areas of major life activity—
  - (i) Self-care;

(ii) Receptive and expressive language;  
 (iii) Learning;  
 (iv) Mobility;  
 (v) Self-direction;  
 (vi) Capacity for independent living;  
 and

(vii) Economic self-sufficiency.

(5) Reflects the individual's need for a combination and sequence of special, interdisciplinary or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.

(6) An individual from birth to age nine, inclusive, who has a substantial developmental delay or specific congenital or acquired condition, may be considered to have a developmental disability without meeting three or more of the criteria described in (A)(1) through (5), if the individual, without services and supports, has a high probability of meeting those criteria later in life.

*Early intervention activities.* The term "early intervention activities" means advocacy, capacity building, and systemic change activities provided to infants and young children described in the definition of "developmental disability" and their families to enhance the development of the individuals to maximize their potential, and the capacity of families to meet the special needs of the individuals.

*Education activities.* The term "education activities" means advocacy, capacity building, and systemic change activities that result in individuals with developmental disabilities being able to access appropriate supports and modifications when necessary, to maximize their educational potential, to benefit from lifelong educational activities, and to be integrated and included in all facets of student life.

*Employment-related activities.* The term "employment-related activities" means advocacy, capacity building, and systemic change activities that result in individuals with developmental disabilities acquiring, retaining, or advancing in paid employment, including supported employment or self-employment, in integrated settings in a community.

*Family support services.* The term "family support services" means services, supports, and other assistance, provided to families with a member or members who have developmental disabilities, that are designed to: strengthen the family's role as primary caregiver; prevent inappropriate out-of-the-home placement of the members and maintain family unity; and reunite, whenever possible, families with

members who have been placed out of the home. This term includes respite care, provision of rehabilitation technology and assistive technology, personal assistance services, parent training and counseling, support for families headed by aging caregivers, vehicular and home modifications, and assistance with extraordinary expenses associated with the needs of individuals with developmental disabilities.

*Fiscal year.* The term "fiscal year" means the Federal fiscal year unless otherwise specified.

*Governor.* The term "Governor" means the chief executive officer of a State, as that term is defined in the Act, or his or her designee who has been formally designated to act for the Governor in carrying out the requirements of the Act and the regulations.

*Health-related activities.* The term "health-related activities" means advocacy, capacity building, and systemic change activities that result in individuals with developmental disabilities having access to and use of coordinated health, dental, mental health, and other human and social services, including prevention activities, in their communities.

*Housing-related activities.* The term "housing-related activities" means advocacy, capacity building, and systemic change activities that result in individuals with developmental disabilities having access to and use of housing and housing supports and services in their communities, including assistance related to renting, owning, or modifying an apartment or home.

*Inclusion.* The term "inclusion," means the acceptance and encouragement of the presence and participation of individuals with developmental disabilities by individuals without disabilities in social, educational, work, and community activities that enable individuals with developmental disabilities to have friendships and relationships with individuals of their own choice; live in homes close to community resources with regular contact with individuals without disabilities in their communities; enjoy full access and active participation in the same community activities and types of employment as individuals without disabilities; and take full advantage of their integration into the same community as individuals without disabilities, living, learning, working, and enjoying life in regular contact with individuals without disabilities.

*Indicators of progress.* The term "indicators of progress" means the grantee's compliance with its own self-

selected, ADD approved, measures of progress.

*Individualized supports.* The term "individualized supports" means supports that: Enable an individual with a developmental disability to exercise self-determination, be independent, be productive, and be integrated and included in all facets of community life; designed to enable such individual to control such individual's environment, permitting the most independent life possible; and prevent placement into a more restrictive living arrangement than is necessary and enable such individual to live, learn, work, and enjoy life in the community; and include early intervention services, respite care, personal assistance services, family support services, supported employment services support services for families headed by aging caregivers of individuals with developmental disabilities, and provision of rehabilitation technology and assistive technology, and assistive technology services.

*Integration.* The term "integration," means exercising the equal rights of individuals with developmental disabilities to access and use the same community resources as are used by and available to other individuals.

*Measures of progress.* The term "measures of progress" means the grantee's standards of performance that they have developed pursuant to section 1385.5.

*Not-for-profit.* The term "not-for-profit," used with respect to an agency, institution or organization, means an agency, institution, or organization that is owned or operated by one or more corporations or associations, no part of the net earnings of which inures, or may lawfully inure, to the benefit of any private shareholder or individual.

*Personal assistance services.* The term "personal assistance services" means a range of services provided by one or more individuals designed to assist an individual with a disability to perform daily activities, including activities on or off a job that such individual would typically perform if such individual did not have a disability. Such services shall be designed to increase such individual's control in life and ability to perform everyday activities, including activities on or off a job.

*Prevention activities.* The term "prevention activities" means activities that address the causes of developmental disabilities and the exacerbation of functional limitation, such as activities that: Eliminate or reduce the factors that cause or predispose individuals to developmental disabilities or that

increase the prevalence of developmental disabilities; increase the early identification of problems to eliminate circumstances that create or increase functional limitations; and mitigate against the effects of developmental disabilities throughout the lifespan of an individual.

**Productivity.** The term “productivity” means engagement in income-producing work that is measured by increased income, improved employment status, or job advancement, or engagement in work that contributes to a household or community.

**Protection and Advocacy Agency.** The term “Protection and Advocacy Agency” means the organization or agency designated in a State to administer and operate a protection and advocacy (P&A) system for individuals with developmental disabilities. A P&A system is authorized to investigate incidents of abuse and neglect regarding persons with developmental disabilities and the rights of such individuals. The P&A may provide information and referral to programs and services addressing the needs of such individuals. The Protection and Advocacy agency also shall provide advocacy services under other Federal programs and undertake the other activities authorized therein, except when participation in such program is inconsistent with its duties under the Act.

**Quality assurance activities.** The term “quality assurance activities” means advocacy, capacity building, and systemic change activities that result in improved consumer and family-centered quality assurance and that result in systems of quality assurance and consumer protection that include monitoring of services, supports, and assistance provided to an individual with developmental disabilities that ensures that the individual will not experience abuse, neglect, sexual or financial exploitation, or violation of legal or human rights; and will not be subject to the inappropriate use of restraints or seclusion; include training in leadership, self-advocacy, and self-determination for individuals with developmental disabilities, their families, and their guardians to ensure that those individuals will not experience abuse, neglect, sexual or financial exploitation, or violation of legal or human rights; and will not be subject to the inappropriate use of restraints or seclusion; or include activities related to interagency coordination and systems integration that result in improved and enhanced services, supports, and other assistance that contribute to and protect the self-

determination, independence, productivity, and integration and inclusion in all facets of community life of individuals with developmental disabilities.

**Recreation-related activities.** The term “recreation-related activities” means advocacy, capacity building, and systemic change activities that result in individuals with developmental disabilities having access to and use of recreational, leisure, and social activities, in their communities.

**Rehabilitation technology.** The term “rehabilitation technology” means the systematic application of technologies, engineering methodologies, or scientific principles to meet the needs of, and address the barriers confronted by individuals with developmental disabilities in areas that include education, rehabilitation, employment, transportation, independent living, and recreation. Such terms include rehabilitation engineering, and the provision of assistive technology devices and assistive technology services.

**Required planning documents.** The term “required planning documents” means the State plans required by § 1386.30 of this part for the State Council on Developmental Disabilities; the Annual Statement of Goals and Priorities required by § 1386.22(c) for P&As; and the Five-Year plan required by § 1388.5(a)(4) for UCEDDs.

**Secretary.** The term “Secretary” means the Secretary of Health and Human Services.

**Self-determination activities.** The term “self-determination activities” means activities that result in individuals with developmental disabilities, with appropriate assistance, having the ability and opportunity to communicate and make personal decisions; the ability and opportunity to communicate choices and exercise control over the type and intensity of services, supports, and other assistance the individuals receive; the authority to control resources to obtain needed services, supports, and other assistance; opportunities to participate in, and contribute to, their communities; and support, including financial support, to advocate for themselves and others to develop leadership skills through training in self-advocacy to participate in coalitions, to educate policymakers, and to play a role in the development of public policies that affect individuals with developmental disabilities.

**State.** The term “State”, includes, in addition to each of the several States of the United States, the District of Columbia, the Commonwealth of Puerto Rico, the United States Virgin Islands,

Guam, American Samoa, and the Commonwealth of the Northern Mariana Islands.

**State Council on Developmental Disabilities.** The term “State Council on Developmental Disabilities” means a Council established under Section 125 of the DD Act.

**Supported employment services.** The term “supported employment services” means services that enable individuals with developmental disabilities to perform competitive work in integrated work settings or work for individuals for whom competitive employment has been interrupted or intermittent as a result of significant disabilities, and who, because of the nature and severity of their disabilities, need intensive supported employment services or extended services in order to perform such work.

**Systemic change activities.** The term “systemic change activities” means a sustainable, transferable and replicable change in some aspect of service or support availability, design or delivery that promotes positive or meaningful outcomes for individuals with developmental disabilities and their families.

**Transportation-related activities.** The term “transportation-related activities” means advocacy, capacity building, and systemic change activities that result in individuals with developmental disabilities having access to and use of transportation.

**UCEDDs.** The term “UCEDD” means University Centers for Excellence in Developmental Disabilities Education, Research, and Service, also known by the term “Center” under Section 102(5) of the Act.

**Unserviced and underserved.** The term “unserved and underserved” includes populations such as individuals from racial and ethnic minority backgrounds, disadvantaged individuals, individuals with limited English proficiency, individuals from underserved geographic areas (rural or urban) and specific groups of individuals within the population of individuals with developmental disabilities, including individuals who require assistive technology in order to participate in community life.

#### **§ 1385.4 Rights of individuals with developmental disabilities.**

(a) Section 109 of the Act, Rights of Individuals with Developmental Disabilities (42 U.S.C. 15009), is applicable to the State Councils on Developmental Disabilities.

(b) In order to comply with Section 124(c)(5)(H) of the Act (42 U.S.C. 15024(c)(5)(H)), regarding the rights of

individuals with developmental disabilities, the State participating in the Developmental Disabilities Council program must meet the requirements of 45 CFR 1386.30(f)(2).

(c) Applications from UCEDDs also must contain an assurance that the human rights of individuals assisted by this program will be protected consistent with Section 101(c) (see Section 154(a)(3)(D) of the Act).

**§ 1385.5 Program accountability and indicators of progress.**

(a) *Program Accountability Process.*

(1) The required planning document and updates must classify under one or more areas of emphasis (as defined in section 1385.3 of this part) each of the goals related to advocacy, capacity building, and systemic change activities the State Council on Developmental Disabilities, P&A, or UCEDD will be pursuing during each of the years covered by the document. For UCEDDs, goal activities also must be classified in terms of mandated core functions.

(2) State Councils on Developmental Disabilities, P&As and UCEDDs must state in the required planning document the measures of progress to measure consumer satisfaction, collaboration, or improvement for each established goal under each selected area of emphasis during any year covered by the planning document. The measures of progress developed by State Councils, P&As, and UCEDDs must be able to, over time, demonstrate whether the grantee has achieved progress in meeting the goals of the Act through its advocacy, capacity building, and systemic change activities.

(3) Measures of progress included in the required planning document, or in revisions to such document, shall meet the requirements under this part. In the event that one or more of the measures of progress included in the required planning document, or an amendment to the document, do not meet the requirements under this part, the Commissioner shall decline to accept the planning document, or the revision to such document, submitted by the grantee.

(4) Each State Council on Developmental Disabilities pursuant to section 1386.32(b), P&A pursuant to § 1386.22(a), and UCEDD pursuant to § 1388.5(a)(4) must report the results of the measures of progress measuring consumer satisfaction, collaboration, or improvement for each area of emphasis under which a goal has been established for the year on which it is reporting. The report must include information necessary for the Secretary to comply

with the Act and other information required by the applicable regulation.

(b) *Measures of Progress.* For each of the areas of emphasis under which a grantee has established a goal(s), it shall meet approved annual measures for successful achievement of progress.

(c) *Indicators of Progress.* For each of the areas of emphasis under which a State Council on Developmental Disabilities, a P&A, or a UCEDD has classified activities, the indicators of progress shall be the achievement of the measures of progress they have established pursuant to this section for the year on which it is reporting. Each State Council on Developmental Disabilities, P&A, and UCEDD is required to meet the indicators of progress for each of the areas of emphasis in which it has classified activities for the year on which it is reporting.

(d) *Measures of Consumer Satisfaction.* Each State Council on Developmental Disabilities, P&A, and UCEDD must:

(1) establish criteria in its planning document, or any revision, on the level of consumer satisfaction to be attained for each area of emphasis for which goals are identified, and

(2) track consumer satisfaction for each area of emphasis for which goals are identified through the end of each year. If, for any reason, a State Council on Developmental Disabilities, P&A, or UCEDD does not fully perform a planned activity related to a goal under an area of emphasis, as appropriate, the consumer satisfaction with the activity shall be measured by the grantee on the basis of the portion of the activity performed.

(e) *Measures of Collaboration.* (1) Each State Council on Developmental Disabilities, P&A, and UCEDD must identify in its planning document, and any revision, the collaborative activities that it will implement for each area of emphasis under which it has identified one or more goals. Each UCEDD also must identify the collaborative activities it will implement with UCEDDs in other States which are pursuing similar activities under the same areas of emphasis.

(2) Collaboration by each State Council on Developmental Disabilities, P&A, and UCEDD with other grantees within the State must include the following:

(i) A meeting with the other grantees in the State on the proposed collaboration and on the implementation of the agreed upon collaborative activities;

(ii) A Memorandum of Understanding on the collaboration initiative agreed

upon by each of the other grantees in the State, signed by the administering officials of the State Council, P&A, and UCEDD.

(f) *Measures of Improvement.* (1) Each State Council on Developmental Disabilities, P&A, and UCEDD must establish for each year covered by the planning document the measures of improvement it will attain in each area of emphasis for which goals have been identified by assessing the extent to which grantee activities have enabled individuals with developmental disabilities to:

(i) Make choices and exert control over the type, intensity, and timing of services, supports and assistance in the area of emphasis;

(ii) Participate in the full range of community life associated with the area of emphasis with persons of the individual's choice; and

(iii) Access services, supports and assistance in the area of emphasis in a manner that ensures that such individuals are free from abuse, neglect, sexual and financial exploitation, violation of legal and human rights, and the inappropriate use of restriction and seclusion.

(2) State Councils on Developmental Disabilities, P&As, and UCEDDs may adopt additional measures of progress to assess their performance during a year.

**§ 1385.6 Employment of individuals with disabilities.**

Each grantee which receives Federal funding under the Act must meet the requirements of Section 107 of the Act (42 U.S.C. 15007) regarding affirmative action. The grantee must take affirmative action to employ and advance in employment and otherwise treat qualified individuals with disabilities without discrimination based upon their physical or mental disability in all employment practices such as the following: advertising, recruitment, employment, rates of pay or other forms of compensation, selection for training, including apprenticeship, upgrading, demotion or transfer, and layoff or termination. This obligation is in addition to the requirements of 45 CFR part 84, subpart B, prohibiting discrimination in employment practices on the basis of disability in programs receiving assistance from the Department. Recipients of funds under the Act also may be bound by the provisions of the Americans with Disabilities Act of 1990 (Pub. L. 101-336, 42 U.S.C. 12101 *et seq.*) with respect to employment of individuals with disabilities. Failure to comply with Section 107 of the Act may result in loss of Federal funds under the

Act. If a compliance action is taken, the State will be given reasonable notice and an opportunity for a hearing as provided in subpart E of 45 CFR part 1386.

**§ 1385.7 Reports of the Secretary.**

All grantee submission of plans, applications and reports must label goals, activities and results clearly in terms of the following: area of emphasis, type of activity (advocacy, capacity building, systemic change), and categories of measures of progress.

**§ 1385.8 Formula for determining allotments.**

The Commissioner will allocate funds appropriated under the Act for the State Councils on Developmental Disabilities and the P&As on the following basis:

(a) Two-thirds of the amount appropriated will be allotted to each State according to the ratio the population of each State bears to the population of the United States. This ratio is weighted by the relative per capita income for each State. The data used to compute allotments are supplied by the U.S. Department of Commerce for the three most recent consecutive years for which satisfactory data are available.

(b) One-third of the amount appropriated will be allotted to each State on the basis of the relative need for services of persons with developmental disabilities. The relative need is determined by the number of persons receiving benefits under the Childhood Disabilities Beneficiary Program [(Section 202(d)(1)(B)(ii) of the Social Security Act), (42 U.S.C. 402(d)(1)(B)(ii)].

**§ 1385.9 Grants administration requirements.**

(a) The following parts of title 45 CFR apply to grants funded under parts 1386 and 1388 of this chapter, and to grants for Projects of National Significance under Section 162 of the Act (42 U.S.C. 15082).

45 CFR Part 16—Procedures of the Departmental Grant Appeals Board.

45 CFR Part 46—Protection of Human Subjects.

45 CFR Part 74—Administration of Grants.

45 CFR Part 76—Governmentwide Debarment and Suspension (Nonprocurement) and Governmentwide Requirements for Drug-Free Workplace.

45 CFR Part 80—Nondiscrimination under Programs Receiving Federal Assistance through the Department of Health and Human Services—Effectuation of title VI of the Civil Rights Act of 1964.

45 CFR Part 81—Practice and Procedures—Practice and Procedure for Hearings Act under Part 80 of this title.

45 CFR Part 84—Nondiscrimination on the Basis of Handicap in Programs and Activities Receiving or Benefiting from Federal Financial Assistance.

45 CFR Part 86—Nondiscrimination on the Basis of Sex in Education Programs and Activities Receiving or Benefiting from Federal Financial Assistance.

45 CFR Part 91—Nondiscrimination on the Basis of Age in Programs or Activities Receiving Federal Financial Assistance from HHS.

45 CFR Part 92—Uniform Administrative Requirements for Grants and Cooperative Agreements to State and Local Governments.

45 CFR Part 93—New restrictions on Lobbying.

(b) The Departmental Appeals Board also has jurisdiction over appeals by any grantee that has received grants under the UCEDD programs or for Projects of National Significance. The scope of the Board's jurisdiction concerning these appeals is described in 45 CFR part 16.

(c) The Departmental Appeals Board also has jurisdiction to decide appeals brought by the States concerning any disallowances taken by the Commissioner with respect to specific expenditures incurred by the States or by contractors or subgrantees of States. This jurisdiction relates to funds provided under the two formula programs—subtitle B of the Act—Federal Assistance to State Councils on Developmental Disabilities, and subtitle C of the Act—Protection and Advocacy of Individual Rights. Appeals filed by States shall be decided in accordance with 45 CFR part 16.

(d) In making audits and examination to any books, documents, papers, and transcripts of records of State Councils on Developmental Disabilities, the UCEDDs and the Projects of National Significance grantees and subgrantees, as provided for in 45 CFR part 74 and part 92, the Department will keep information about individual clients confidential to the maximum extent permitted by law and regulations.

(e)(1) The Department or other authorized Federal officials may access client and case eligibility records or other records of a P&A system for audit purposes, and for purposes of monitoring system compliance pursuant to Section 103(b) of the Act. However, such information will be limited pursuant to Section 144(c) of the Act. No personal identifying information such as name, address, and social security number will be obtained. Only eligibility information will be obtained

regarding the type and level of disability of individuals being served by the P&A and the nature of the issue concerning which the system represented an individual.

(2) Notwithstanding paragraph (e)(1) of this section, if an audit, monitoring review, evaluation, or other investigation by the Department produces evidence that the system has violated the Act or the regulations, the system will bear the burden of proving its compliance. The system's inability to establish compliance because of the confidentiality of records will not relieve it of this responsibility. The P&A may elect to obtain a release regarding personal information and privacy from all individuals requesting or receiving services at the time of intake or application. The release shall state that only information directly related to client and case eligibility will be subject to disclosure to officials of the Department.

2. Revise part 1386 to read as follows.

**PART 1386—FORMULA GRANT PROGRAMS**

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Authority: 42 U.S.C. 15001 *et seq.*

**Subpart A—Basic Requirements**

**§ 1386.1 General.**

All rules under this subpart are applicable to both the State Councils on Developmental Disabilities and the agency designated to administer the State Protection and Advocacy System (P&As).

**§ 1386.2 Obligation of funds.**

(a) Funds which the Federal Government allots under this part during a Federal fiscal year are available for obligation by States for a two-year period beginning with the first day of the Federal fiscal year in which the grant is awarded.

(b)(1) A State incurs an obligation for acquisition of personal property or for the performance of work on the date it makes a binding, legally enforceable, written commitment, or when the State Council on Developmental Disabilities enters into an Interagency Agreement with an agency of State government for

acquisition of personal property or for the performance of work.

(2) A State incurs an obligation for personal services, for services performed by public utilities, for travel or for rental of real or personal property on the date it receives the services, its personnel takes the travel, or it uses the rented property.

(c)(1) A Protection & Advocacy System may elect to treat entry of an appearance in judicial and administrative proceedings on behalf of an individual with a developmental disability as a basis for obligating funds for the litigation costs. The amount of the funds obligated must not exceed a reasonable estimate of the costs, and the way the estimate was calculated must be documented.

(2) For the purpose of this paragraph, *litigation costs* mean expenses for court costs, depositions, expert witness fees, travel in connection with a case and similar costs, and costs resulting from litigation in which the agency has represented an individual with developmental disabilities (e.g., monitoring court orders, consent decrees), but not for salaries of employees of the P&A. All funds made available for Federal assistance to State Councils on Developmental Disabilities and to the P&As obligated under this paragraph are subject to the requirement of paragraph (a) of this section. These funds, if reobligated, may be reobligated only within a two-year period beginning with the first day of the Federal fiscal year in which the funds were originally awarded.

**§ 1386.3 Liquidation of obligations.**

(a) All obligations incurred pursuant to a grant made under the Act for a specific Federal fiscal year, must be liquidated within two years of the close of the Federal fiscal year in which the grant was awarded.

(b) The Commissioner may waive the requirements of paragraph (a) of this section when State law impedes implementation or the amount of obligated funds to be liquidated is in dispute.

(c) Funds attributable to obligations which are not liquidated in accordance with the provisions of this section revert to the Federal Government.

**§ 1386.4 [Reserved]**

**Subpart B—Protection and Advocacy of Individual Rights**

**§ 1386.19 Definitions.**

As used in §§ 1386.20, 1386.21, 1386.24, and 1386.25 of this part and subpart C the following definitions apply:

*Abuse.* The term “abuse” means any act or failure to act which was performed, or which was failed to be performed, knowingly, recklessly, or intentionally, and which caused, or may have caused, injury or death to an individual with developmental disabilities, and includes but is not limited to such acts as: verbal, nonverbal, mental and emotional harassment; rape or sexual assault; striking; the use of excessive force when placing such an individual in bodily restraints; the use of bodily or chemical restraints which is not in compliance with Federal and State laws and regulations; or, any other practice which is likely to cause immediate physical or psychological harm or result in long term harm if such practices continue. In addition, the P&A may determine, in its discretion, that repeated and/or egregious violations of an individual's statutory or constitutional rights amounts to abuse, such as in a case where an individual is subject to significant financial exploitation which may prevent the individual from providing for his or her basic needs such as food and shelter.

*American Indian Consortium.* The term “American Indian Consortium” means any confederation of 2 or more recognized American Indian tribes, created through the official action of each participating tribe, that has a combined total resident population of 150,000 enrolled tribal members and a contiguous territory of Indian lands in two or more States.

*Complaint.* The term “complaint” includes, but is not limited to, any report or communication, whether formal or informal, written or oral, received by the system, including media accounts, newspaper articles, telephone calls (including anonymous calls) from any source relating to the status or treatment of an individual with a developmental disability.

*Designating Official.* The term “designating official” means the Governor or other State official, who is empowered by the State legislature or Governor to designate the State official or public or private agency to be accountable for the proper use of funds by and conduct of the agency designated to administer the State Protection and Advocacy System.

*Full Investigation.* The term “full investigation” means access to service providers, individuals with developmental disabilities and records authorized under these regulations, that are necessary for a P&A system to make a determination about whether alleged or suspected instances of abuse and neglect are taking place or have taken

place. Full investigations may be conducted independently or in cooperation with other agencies authorized to conduct similar investigations.

*Legal Guardian, conservator and legal representative.* The terms “legal guardian,” “conservator,” and “legal representative” all mean an individual appointed and regularly reviewed by a State court or agency empowered under State law to appoint and review such officers, and having authority to make all decisions on behalf of individuals with developmental disabilities. It does not include persons acting only as a representative payee, persons acting only to handle financial payments, attorneys or other persons acting on behalf of an individual with developmental disabilities only in individual legal matters, or officials or their designees responsible for the provision of treatment or habilitation services to an individual with developmental disabilities.

*Neglect.* The term “neglect” means a negligent act or omission by an individual responsible for providing services, supports or other assistance which caused or may have caused injury or death to an individual with developmental disabilities, or which placed an individual with developmental disabilities at risk of injury or death, and includes acts or omissions such as failure to: establish or carry out an appropriate individual program plan or treatment plan (including a discharge plan); provide adequate nutrition, clothing, or health care to an individual with developmental disabilities; or provide a safe environment which also includes failure to maintain adequate numbers of trained staff.

*Probable cause.* The term “probable cause” means, depending on the context, a reasonable ground for belief that an individual with developmental disabilities has been, or may be, subject to abuse or neglect, or that the health or safety of the individual is in serious and immediate jeopardy. The individual making such determination may base the decision on reasonable inferences drawn from his or her experience or training regarding similar incidents, conditions or problems that are usually associated with abuse or neglect. The P&A system is the final arbiter of probable cause between itself and the organization or individual from whom it is seeking records.

*Service provider.* The term “service provider” refers to any individual (including a family member of an individual with a developmental disability), or a public or private

organization or agency that provides, directly or through contract, brief or long-term services, supports or other assistance to one or more individuals with developmental disabilities. Service providers include, entities that provide either specialized assistance addressing the needs of persons with developmental disabilities or more general assistance such as the provision of vocational training, transportation, education or shelter, food or clothing. Service providers may include, but are not limited to, organizations such as group homes, board and care homes, individual residences and apartments, day programs, public and private residential and non-residential schools (including charter schools), juvenile detention centers, hospitals, nursing homes, homeless shelters, and jails and prisons.

*State Protection and Advocacy System.* The term “State Protection and Advocacy System” is synonymous with the term “P&A” used elsewhere in this regulation, and the terms “system” and “Protection and Advocacy System” used in this part and in part C.

**§ 1386.20 Agency Designated to Administer the State Protection and Advocacy System.**

(a) The designating official must designate the State official or public or private agency to be accountable for proper use of funds and conduct of the Protection and Advocacy System.

(b) An agency of the State or private agency providing direct services, including guardianship services, may not be designated as the agency to administer the Protection and Advocacy System.

(c) In the event that an entity outside of the State government is designated to carry out the program, the designating official or entity must assign a responsible State official to receive, on behalf of the State, notices of disallowances and compliance actions as the State is accountable for the proper and appropriate expenditure of Federal funds.

(d)(1) Prior to any redesignation of the agency which administers and operates the State Protection and Advocacy System, the designating official must give written notice of the intention to make the redesignation to the agency currently administering and operating the State Protection and Advocacy System by registered or certified mail. The notice must indicate that the proposed redesignation is being made for good cause. The designating official also must publish a public notice of the proposed action. The agency and the public shall have a reasonable period of

time, but not less than 45 days, to respond to the notice.

(2) The public notice must include:

(i) The Federal requirements for the State Protection and Advocacy System for individuals with developmental disabilities (Section 143 of the Act); and where applicable, the requirements of other Federal advocacy programs administered by the State Protection and Advocacy System;

(ii) The goals and function of the State’s Protection and Advocacy System including the current Statement of Goals and Priorities;

(iii) The name and address of the agency currently designated to administer and operate the State Protection and Advocacy System, and an indication of whether the agency also operates other Federal advocacy programs;

(iv) A description of the current agency operating and administering the Protection and Advocacy System including, as applicable, descriptions of other Federal advocacy programs it operates;

(v) A clear and detailed explanation of the good cause for the proposed redesignation;

(vi) A statement suggesting that interested persons may wish to write the current agency operating and administering the State Protection and Advocacy System at the address provided in paragraph (d)(2)(iii) of this section to obtain a copy of its response to the notice required by paragraph (d)(1) of this section. Copies shall be provided in accessible formats to individuals with disabilities upon request;

(vii) The name of the new agency proposed to administer and operate the State Protection and Advocacy System under the Developmental Disabilities program. This agency will be eligible to administer other Federal advocacy programs;

(viii) A description of the system which the new agency would administer and operate, including a description of all other Federal advocacy programs the agency would operate;

(ix) The timetable for assumption of operations by the new agency and the estimated costs of any transfer and start-up operations; and

(x) A statement of assurance that the proposed new designated State Protection and Advocacy System will continue to serve existing clients and cases of the current P&A System or refer them to other sources of legal advocacy as appropriate, without disruption.

(3) The public notice as required by paragraph (d)(1) of this section, must be

in a format accessible to individuals with developmental disabilities or their representatives, e.g., tape, diskette. The designating official must provide for publication of the notice of the proposed redesignation using the State register, statewide newspapers, public service announcements on radio and television, or any other legally equivalent process. Copies of the notice must be made generally available to individuals with developmental disabilities and mental illness who live in residential facilities through posting or some other means.

(4) After the expiration of the public comment period required in paragraph (d)(1) of this section, the designating official must conduct a public hearing on the redesignation proposal. After consideration of all public and agency comments, the designating official must give notice of the final decision to the currently designated agency and the public through the same means used under paragraph (d)(3) of this section. This notice must include a clear and detailed explanation of the good cause finding. If the notice to the currently designated agency states that the redesignation will take place, it also must inform the agency of its right to appeal this decision to the Assistant Secretary for Children and Families, who has been delegated the authority to hear appeals by the Secretary, and provide a summary of the public comments received in regard to the notice of intent to redesignate and the results of the public hearing and its responses to those comments. The redesignation shall not be effective until 10 working days after notifying the current agency that administers and operates the State Protection and Advocacy System or, if the agency appeals, until the Assistant Secretary has considered the appeal.

(e)(1) Following notification as indicated in paragraph (d)(4) of this section, the agency that administers and operates the State Protection and Advocacy System which is the subject of such action, may appeal the redesignation to the Assistant Secretary. To do so, the agency that administers and operates the State Protection and Advocacy System must submit an appeal in writing to the Assistant Secretary within 20 days of receiving official notification under paragraph (d)(4) of this section, with a separate copy sent by registered or certified mail to the designating official who made the decision concerning redesignation.

(2) In the event that the agency subject to redesignation does exercise its right to appeal under paragraph (e)(1) of this section, the designating official must

give public notice of the Assistant Secretary's final decision regarding the appeal through the same means utilized under paragraph (d)(3) of this section within 10 working days of receipt of the Assistant Secretary's final decision under paragraph (e)(6) of this section.

(3) The designating official within 10 working days from the receipt of a copy of the appeal must provide written comments to the Assistant Secretary (with a copy sent by registered or certified mail to the Protection and Advocacy agency appealing under paragraph (e)(1) of this section), or withdraw the redesignation. The comments must include a summary of the public comments received in regard to the notice of intent to redesignate and the results of the public hearing and its responses to those comments.

(4) In the event that the designating official withdraws the redesignation while under appeal pursuant to paragraph (e)(1) of this section, the designating official must notify the Assistant Secretary, and the current agency, and must give public notice of his or her decision through the same means utilized under paragraph (d)(3) of this section.

(5) As part of their submission under paragraph (e)(1) or (e)(3) of this section, either party may request, and the Assistant Secretary may grant, an opportunity for an informal meeting with the Assistant Secretary at which representatives of both parties will present their views on the issues in the appeal. The meeting will be held within 20 working days of the submission of written comments by the designating official under paragraph (e)(2) of this section. The Assistant Secretary will promptly notify the parties of the date and place of the meeting.

(6) Within 30 days of the informal meeting under paragraph (e)(5) of this section, or, if there is no informal meeting under paragraph (e)(5) of this section, within 30 days of the submission under paragraph (e)(3) of this section, the Assistant Secretary will issue to the parties a final written decision on whether the redesignation was for good cause as defined in paragraph (d)(1) of this section. The Assistant Secretary will receive comments on the record from agencies administering the Federal advocacy programs that will be directly affected by the proposed redesignation. The P&A and the designating official will have an opportunity to comment on the submissions of the Federal advocacy programs. The Assistant Secretary shall consider the comments of the Federal programs, the P&A and the designating

official in making his final decision on the appeal.

(f)(1) Within 30 days after the redesignation becomes effective under paragraph (d)(4) of this section, the designating official must submit an assurance to the Assistant Secretary that the newly designated agency that will administer and operate the State Protection and Advocacy System meets the requirements of the statute and the regulations.

(2) In the event that the agency administering and operating the State Protection and Advocacy System subject to redesignation does not exercise its rights to appeal within the period provided under paragraph (e)(1) of this section, the designating official must provide to the Assistant Secretary documentation that the agency was redesignated for good cause. Such documentation must clearly demonstrate that the Protection and Advocacy agency subject to redesignation was not redesignated for any actions or activities which were carried out under section 143 of the Act, this regulation or any other Federal advocacy program's legislation or regulations.

#### **§ 1386.21 Requirements and authority of the State Protection and Advocacy System.**

(a) In order for a State to receive Federal funding for Protection and Advocacy activities under this subpart, as well as for the State Council on Developmental Disabilities activities (subpart D of this part), the Protection and Advocacy System (P&A) must meet the requirements of Section 143 and 144 of the Act (42 U.S.C. 15043 and 42 U.S.C. 15044) and that system must be operational.

(b) Allotments must be used to supplement and not to supplant the level of non-Federal funds available in the State for activities under the Act, which shall include activities on behalf of individuals with developmental disabilities to remedy abuse, neglect, and violations of rights as well as information and referral activities.

(c) A P&A shall not implement a policy or practice restricting the remedies that may be sought on the behalf of individuals with developmental disabilities or compromising the authority of the P&A to pursue such remedies through litigation, legal action or other forms of advocacy. Under this requirement, States may not establish a policy or practice, which requires the P&A to: obtain the State's review or approval of the P&A's plans to undertake a particular advocacy initiative, including specific litigation (or to pursue litigation

rather than some other remedy or approach); refrain from representing individuals with particular types of concerns or legal claims, or refrain from otherwise pursuing a particular course of action designed to remedy a violation of rights, such as educating policymakers about the need for modification or adoption of laws or policies affecting the rights of individuals with developmental disabilities; restrict the manner of the P&A's investigation in a way that is inconsistent with the system's required authority under the DD Act; or similarly interfere with the P&A's exercise of such authority. The requirements of this paragraph shall not prevent P&As, including those functioning as agencies within State governments, from developing case or client acceptance criteria as part of the annual priorities identified by the P&A as described in section 1386.23(c) of this part. Clients must be informed at the time they apply for services of such criteria.

(d) A Protection and Advocacy System shall be free from hiring freezes, reductions in force, prohibitions on staff travel, or other policies, imposed by the State, to the extent that such policies would impact system program staff or functions funded with Federal funds, and would prevent the system from carrying out its mandates under the Act.

(e) A Protection and Advocacy System shall have sufficient staff, qualified by training and experience, to carry out the responsibilities of the system in accordance with the priorities of the system and requirements of the Act. These responsibilities include the investigation of allegations of abuse, neglect and representations of individuals with developmental disabilities regarding rights violations.

(f) A Protection and Advocacy System may exercise its authority under State law where the State authority exceeds the authority required by the Developmental Disabilities Assistance and Bill of Rights Act of 2000. However, State law must not diminish the required authority of the Protection and Advocacy System as set by the Act.

(g) Each Protection and Advocacy System that is a public system without a multimember governing or advisory board must establish an advisory council in order to provide a voice for individuals with developmental disabilities. The Advisory Council shall advise the Protection and Advocacy System on program policies and priorities. The Advisory Council shall be comprised of a majority of individuals with developmental disabilities who are eligible for services, or have received or are receiving

services or parents or family members (including those representing individuals with developmental disabilities who live in institutions and home and community based settings), guardians, advocates, or authorized representatives of such individuals.

(h) Prior to any Federal review of the State program, a 30-day notice and an opportunity for public comment must be published in the **Federal Register**. Reasonable effort shall be made by the appropriate Regional Office to seek comments through notification to major disability advocacy groups, the State Bar, disability law resources, the State Councils on Developmental Disabilities and the University Centers for Excellence in Developmental Disabilities Education, Research, and Service, for example, through newsletters and publication of those organizations. The findings of public comments may be consolidated if sufficiently similar issues are raised and they shall be included in the report of the onsite visit.

(i) Before the Protection and Advocacy System releases information to individuals not otherwise authorized to receive it, the Protection and Advocacy System must obtain written consent from the client requesting assistance, if competent, or his or her guardian.

#### **§ 1386.22 Periodic reports: State Protection and Advocacy System.**

(a) By January 1 of each year, each State Protection and Advocacy System shall submit to ADD, an Annual Program Performance Report. In order to be accepted, the Report must meet the requirements of Section 144(e) of the Act (42 U.S.C. 15044), the applicable regulation and include information on the System's program necessary for the Secretary to comply with section 105(1), (2), and (3) of the Act (42 U.S.C. 15005). The Report shall describe the activities, accomplishments, and expenditures of the system during the preceding fiscal year, including a description of the system's goals, the extent to which the goals were achieved, barriers to their achievement, the process used to obtain public input, the nature of such input, and how such input was used, the extent to which unserved or underserved individuals or groups, particularly from ethnic or racial groups or geographic regions (e.g., rural or urban areas), were the target of assistance or service, and other such information on the Protection and Advocacy System's activities requested by ADD. In addition, each System must report on its achievement of the measures of progress for the preceding

year pursuant to § 1385.5(a) (4) of this part.

(b) Financial status reports (standard form 269) must be submitted by the agency administering and operating the State Protection and Advocacy System semiannually.

(c) By January 1 of each year, the State Protection and Advocacy System shall submit to ADD, an Annual Statement of Goals and Priorities, (SGP), for the coming fiscal year as required under Section 143(a)(2)(C) of the Act (42 U.S.C. 15043). In order to be accepted by ADD, an SGP must meet the requirements of the Act and the applicable regulation, including § 1385.5(a)(3).

(1) The SGP is a description and explanation of the system's goals and priorities for its activities, selection criteria for its individual advocacy and training activities, and the outcomes it strives to accomplish. The SGP is developed through data driven strategic planning. For each goal in an area of emphasis the indicators of progress (measures of consumer satisfaction, improvement, and collaboration) will apply as provided under section 1385.5 of this part. If changes are made to the goals or the indicators of progress established for a year, the SGP must be amended to reflect those changes. The SGP must include a description of how the Protection and Advocacy System operates, and where applicable, how it coordinates the State Protection and Advocacy program for individuals with developmental disabilities with other Protection and Advocacy programs administered by the State Protection and Advocacy System. This description must include the System's processes for intake, internal and external referrals, and streamlining of advocacy services. If the System will be requesting or requiring fees or donations from clients as part of the intake process, the SGP must state that the system will be doing so. The description also must address collaboration, the reduction of duplication and overlap of services, the sharing of information on service needs, and the development of statements of goals and priorities for the various advocacy programs.

(2) Priorities as established through the SGP serve as the basis for the Protection and Advocacy System to determine which cases are selected in a given fiscal year. Protection and Advocacy Systems have the authority to turn down a request for assistance when it is outside the scope of the SGP, but they must inform individuals when this is the basis for turning them down.

(d) Each fiscal year, the Protection and Advocacy System shall:

(1) Obtain formal public input on its Statement of Goals and Priorities;

(2) At a minimum, provide for a broad distribution of the proposed Statement of Goals and Priorities for the next fiscal year in a manner accessible to individuals with developmental disabilities and their representatives, allowing at least 45 days from the date of distribution for comment;

(3) Provide to the State Councils on Developmental Disabilities and the University Centers for Excellence in Developmental Disabilities Education, Research and Service a copy of the proposed Statement of Goals and Priorities for comment concurrently with the public notice;

(4) Incorporate or address any comments received through public input and any input received from the State Councils on Developmental Disabilities and the University Centers for Excellence in Developmental Disabilities Education, Research and Service in the final Statement submitted; and

(5) Address how the Protection and Advocacy System; State Councils on Developmental Disabilities and University Centers for Excellence in Developmental Disabilities Education Research and Service will collaborate with each other and with other public and private entities.

**§ 1386.23 Non-allowable costs for the State Protection and Advocacy System.**

(a) Federal financial participation is not allowable for:

(1) Costs incurred for activities on behalf of individuals with developmental disabilities to solve problems not directly related to their disabilities and which are faced by the general populace. Such activities include but are not limited to: preparation of wills, divorce decrees, and real estate proceedings. Allowable costs in such cases would include the Protection and Advocacy System providing disability-related technical assistance information and referral to appropriate programs and services; and

(2) Costs not allowed under other applicable statutes, Departmental regulations and issuances of the Office of Management and Budget.

(b) Attorneys' fees are considered program income pursuant to part 74-Administration of Grants and part 92-Uniform Administrative Requirements for Grants and Cooperative Agreements to State and Local Governments and must be added to the funds committed to the program and used to further the objectives of the program. This requirement shall apply to all attorneys' fees, including those earned by

contractors and those received after the project period in which they were earned.

**§ 1386.24 Allowable litigation costs for the State Protection and Advocacy System.**

Allotments may be used to pay the otherwise allowable costs incurred by a Protection and Advocacy System in bringing lawsuits in its own right to redress incidents of abuse or neglect, discrimination and other rights violations impacting on individuals with developmental disabilities to obtain access to records and when it appears on behalf of named plaintiffs or a class of plaintiff for such purposes.

**Subpart C—Access to Records, Service Providers and Service Recipients**

**§ 1386.25 Access to records.**

(a) Pursuant to sections 143(a)(2), (A)(i), (B), (I) and (J) of the Act, and subject to the provisions of this section, a Protection and Advocacy (P&A) System, and all of its authorized agents, shall have access to the records of individuals with developmental disabilities under the following circumstances:

(1) If authorized by an individual who is a client of the system, or who has requested assistance from the system, or by such individual's legal guardian, conservator or other legal representative.

(2) In the case of an individual, including an individual whose whereabouts are unknown, to whom all of the following conditions apply:

(i) The individual, due to his or her mental or physical condition, is unable to authorize the system to have access;

(ii) The individual does not have a legal guardian, conservator or other legal representative, or the individual's guardian is the State (or one of its political subdivisions); and

(iii) The individual has been the subject of a complaint to the P&A system about his or her status or treatment, or the P&A system has probable cause (which can be the result of monitoring or other activities including media reports and newspaper articles) to believe that such individual has been subject to abuse and neglect by any other individual or has subjected him or herself to self-abuse.

(3) In the case of an individual, who has a legal guardian, conservator, or other legal representative, about whom a complaint has been received by the system or, as a result of monitoring or other activities, the system has determined that there is probable cause to believe that the individual with

developmental disabilities has been subject to abuse or neglect by any other individual or has subjected him or herself to self-abuse, whenever the following conditions exist:

(i) The P&A system has made a good faith effort to contact the legal guardian, conservator, or other legal representative upon prompt receipt of the name and address of the legal guardian, conservator, or other legal representative;

(ii) The system has offered assistance to the legal guardian, conservator, or other legal representative to resolve the situation; and

(iii) The legal guardian, conservator, or other legal representative has failed or refused to act on behalf of the individual.

(b) Individual records to which P&A systems must have access under Section 143(a)(2), (A)(i), (B), (I) and (J) of the Act (whether written or in another medium, draft, preliminary or final, including handwritten notes, electronic files, photographs or video or audiotape records) shall include, but shall not be limited to:

(1) Individual records prepared or received in the course of providing intake, assessment, evaluation, education, training and other services, supports or assistance, including medical records, financial records, and monitoring and other reports prepared or received by a service provider. This includes records stored or maintained at sites other than the service provider.

(2) Reports prepared by a Federal, State or local governmental agency, or a private organization charged with investigating incidents of abuse or neglect, injury or death. The reports subject to this requirement include, but are not limited to, those prepared or maintained by agencies with responsibility for overseeing human services systems. The organizations whose reports are subject to this requirement include, but are not limited to, agencies in the foster care systems, developmental disabilities systems, and prison and jail systems, criminal and civil law enforcement agencies such as police departments, State and Federal licensing and certification agencies, and private accreditation organizations such as the Joint Commission on the Accreditation of Health Care Organizations. The reports subject to this requirement describe any or all of the following:

(i) The incidents of abuse, neglect, injury, and/or death;

(ii) The steps taken to investigate the incidents;

(iii) Reports and records, including personnel records, prepared or

maintained by the service provider in connection with such reports of incidents; or,

(iv) Supporting information that was relied upon in creating a report including all information and records that describe persons who were interviewed, physical and documentary evidence that was reviewed, and the related investigative findings; and

(3) Discharge planning records.

(c) The time period in which the P&A system must be given access to records of individuals with developmental disabilities under sections 143(a)(2)(A)(i), (B), (I), and (J) of the Act, and subject to the provisions of this section, varies depending on the following circumstances:

(1) If the P&A system determines that there is probable cause to believe that the health or safety of the individual with a developmental disability is in serious and immediate jeopardy, or in any case of the death of an individual with a developmental disability, access to the records of the individual with a developmental disability, as described in paragraph (b) of this section shall be provided (including the right to inspect and copy records as specified in paragraph (d) of this section) to the P&A system within 24 hours of receipt of the P&A system's written request for the records without the consent of another party. In the case of an inquiry regarding a death of an individual with a developmental disability, probable cause to believe the individual with a developmental disability's death resulted from abuse or neglect or any other specific cause is not required for the P&A system to obtain access to the records. Any individual who dies in a situation in which services, supports, or other assistance are, have been, or may customarily be provided to individuals with developmental disabilities shall, for purposes of the P&A system's obtaining access to the individual's records, be deemed an individual with a developmental disability.

(2) In all other cases, access to records of individuals with developmental disabilities shall be provided to the P&A system within three business days after the receipt of such a written request from the P&A system.

(d) A system shall be permitted to inspect and copy information and records, subject to a reasonable charge to offset duplicating costs. If the organization or agency having possession of the records copies them for the P&A system, it may not charge the P&A system an amount that would exceed the amount it customarily charged other non-profit or State government agencies for reproducing

documents. At its option, the P&A may make written notes when inspecting information and records, and may use its own photocopying equipment to obtain copies. If a party other than the P&A system performs the photocopying or other reproduction of records, it shall provide the photocopies or reproductions to the P&A system within the time frames specified in paragraph (c) of this section.

**§ 1386.26 Denial or delay of access.**

If a P&A system's access to service providers, programs, service recipients or records is denied or delayed beyond the deadlines specified in §§ 1386.25 and 1386.27 of this part, the P&A system shall be provided, within one business day after the expiration of such deadline with a written statement of reasons for the denial or delay. In the case of a denial for alleged lack of authorization, the name, address and telephone number of individual service recipients and legal guardians, conservators, or other legal representative will be included in the aforementioned response. All of the above information shall be provided whether or not the P&A has probable cause to suspect abuse or neglect, or has received a complaint.

**§ 1386.27 Access to service providers and service recipients.**

(a) Access to service providers and service recipients shall be extended to all authorized agents of a P&A system.

(b) A P&A system shall have reasonable unaccompanied access to public and private service providers, programs in the State, and to all areas of the service provider's premises which are used by service recipients or are accessible to them. Such access shall be provided without advance notice and made available immediately upon request. The P&A system shall have reasonable unaccompanied access to service recipients at all times necessary to conduct a full investigation of an incident of abuse or neglect. This authority shall include the opportunity to interview any service recipient, employee, or other persons, including the person thought to be the victim of such abuse, who might be reasonably believed by the system to have knowledge of the incident under investigation. The P&A may not be required to provide the name or other identifying information regarding the service recipient or staff with whom it plans to meet; neither may the P&A be required to justify or explain its interaction with such persons. Such access shall be afforded upon request, by the P&A system when:

(1) An incident is reported or a complaint is made to the P&A system;

(2) The P&A system determines that there is probable cause to believe that an incident has or may have occurred; or

(3) The P&A system determines that there is or may be imminent danger of serious abuse or neglect of an individual with a developmental disability.

(c) In addition to the access required under paragraph (b) of this section, a P&A system shall have reasonable unaccompanied access to service providers for routine circumstances. This includes areas which are used by service recipients and are accessible to service recipients at reasonable times which at a minimum shall include normal working hours and visiting hours. A P&A also shall be permitted to attend treatment planning meetings concerning individual service recipients with the consent of the individual or his or her guardian, conservator or other legal representative. Access to service providers shall be afforded immediately upon an oral or written request by the P&A system. Except where complying with the P&A's request would interfere with treatment or therapy to be provided, service providers shall provide access to individuals for the purpose covered by this paragraph within 24 hours of the system's making a request. If the P&A's access to an individual must be delayed beyond 24 hours to allow for the provision of treatment or therapy, the P&A shall receive access as soon as possible thereafter. Service recipients subject to the requirements in this paragraph include adults or minors who have legal guardians or conservators. P&A activities shall be conducted so as to minimize interference with service provider programs, respect service recipients' privacy interests, and honor a recipient's request to terminate an interview. This access is for the purpose of:

(1) Providing information, training, and referral for programs addressing the needs of individuals with developmental disabilities, and information and training about individual rights, and the protection and advocacy services available from the P&A system, including the name, address, and telephone number of the P&A system;

(2) Monitoring compliance with respect to the rights and safety of service recipients; and

(3) Inspecting, viewing and photographing all areas of a service provider's premises which are used by service recipients or are accessible to them.

(d) Unaccompanied access to service recipients shall include the opportunity to meet and communicate privately with individuals regularly, both formally and informally, by telephone, mail and in person.

**§ 1386.28 Confidentiality of protection and advocacy systems records.**

(a) Records maintained by the P&A system are the property of the P&A system which must protect them from loss, damage, tampering or use by unauthorized individuals. The P&A system must:

(1) Except as provided elsewhere in this section, keep confidential all records and information, including information contained in any automated electronic database pertaining to:

(i) Clients;

(ii) Individuals who have been provided general information or technical assistance on a particular matter;

(iii) The identity of individuals who report incidents of abuse or neglect, or who furnish information that forms the basis for a determination that probable cause exists; and

(iv) Names of individuals who have received services, supports or other assistance, and who provided information to the P&A for the record.

(2) Have written policies governing the access, storage, duplication and release of information from client records.

(3) Obtain written consent from the client, if competent, or from his or her legal representative; individuals who have been provided general information or technical assistance on a particular matter; and individuals who furnish reports or information that form the basis for a determination of probable cause, before releasing information concerning such individuals to individuals not otherwise authorized to receive it.

(b) Nothing in this subpart shall prevent the P&A system from issuing a public report of the results of an investigation which maintains the confidentiality of the individuals listed in paragraph (a)(1) of this section, or reporting the results of an investigation in a manner which maintains the confidentiality of such individuals, to responsible investigative or enforcement agencies should an investigation reveal information concerning the service provider, its staff, or employees warranting possible sanctions or corrective action. This information may be reported to agencies responsible for service provider licensing or accreditation, employee discipline,

employee licensing or certification, or criminal investigation or prosecution.

(c) Notwithstanding the confidentiality requirements of this section, the P&A may make a report to investigative or enforcement agencies, as described in paragraph (b), which reveals the identity of an individual service recipient, and information relating to his or her status or treatment:

(1) When the system has received a complaint that the individual has been or may be subject to abuse and neglect, or has probable cause (which can be the result of monitoring or other activities including media reports and newspaper articles) to believe that such individual has been or may be subject to abuse or neglect;

(2) When the system determines that there is probable cause to believe the health or safety of the individual is in serious and immediate jeopardy; or

(3) In any case of the death of an individual whom the system believes may have had a developmental disability.

**Subpart D—Federal Assistance to State Councils on Developmental Disabilities**

**§ 1386.30 State plan requirements.**

(a) In order to receive Federal funding under this subpart, each State Developmental Disabilities Council must prepare and submit a State plan which meets the requirements of Sections 124 and 125 of the Act (42 U.S.C. 15024 and 15025), and the applicable regulation. Development of the State plan and its periodic updating are the responsibility of the State Council on Developmental Disabilities. As provided in Section 124(d) of the Act, the Council shall provide opportunities for public input and review, and will consult with the Designated State Agency to determine that the plan is consistent with applicable State laws, and obtain appropriate State plan assurances.

(b) Failure to comply with the State plan requirements may result in the loss of Federal funds as described in Section 127 of the Act (42 U.S.C. 15027). The Secretary must provide reasonable notice and an opportunity for a hearing to the Council and the Designated State Agency before withholding any payments for planning, administration, and services.

(c) The State plan must be submitted through the Electronic Data Submission system which is used to collect quantifiable and qualifiable information from the State Councils on Developmental Disabilities. The plan must:

(1) Identify the agency or office in the State designated to support the Council in accordance with Section 124(c)(2) and 125(d). The Designated State Agency shall provide required assurances and support services requested from and negotiated with the Council.

(2) For a year covered by the State plan, include for each area of emphasis under which a goal or goals have been identified, the measures of progress (measures of consumer satisfaction, collaboration, and improvement) the Council has established or is required to apply pursuant to section 1385.5 of this part to measure its progress in furthering the purpose of the Developmental Disabilities Assistance and Bill of Rights Act through advocacy, capacity building, and systemic change activities.

(3) Provide for the establishment and maintenance of a Council in accordance with Section 125 and describe the membership of such Council. The non-State agency members of the Council shall be subject to term limits to ensure rotating membership.

(d) The State plan must be updated during the five-year period when substantive changes are contemplated in plan content, including changes under paragraph (c)(2).

(e)(1) The State plan may provide for funding projects to demonstrate new approaches to direct services that enhance the independence, productivity, and integration and inclusion into the community of individuals with developmental disabilities. Direct service demonstrations must be short-term, no longer than five years, and include a strategy to locate on-going funding from other sources. For each demonstration funded, the State plan must include an estimated period of the project's duration and a brief description of how the services will be continued without Federal developmental disabilities program funds. Council funds may not be used to fund on-going services that should be paid for by the State or other sources.

(2) The State plan may provide for funding of other demonstration projects or activities, including but not limited to outreach, training, technical assistance, supporting and educating communities, interagency collaboration and coordination, coordination with related councils, committees and programs, barrier elimination, systems design and redesign, coalition development and citizen participation, and informing policymakers. Awards for these demonstrations should be no longer than five years.

(f) The State plan must contain assurances that:

(1) The State will comply with all applicable Federal statutes and regulations in effect during the time that the State is receiving formula grant funding;

(2) The human rights of individuals with developmental disabilities will be protected consistent with Section 109 of the Act (42 U.S.C. 15009).

(3) Buildings used in connection with activities assisted under the plan must meet all applicable provisions of Federal and State laws pertaining to accessibility, fire, health and safety standards.

(4) The State Council on Developmental Disabilities shall follow the requirements of Section 125(c)(8), (9) and (10) of the Act regarding budgeting, staff hiring, supervision, and assignment. Budget expenditures must be consistent with applicable State laws and policies regarding grants, contracts, and accounting, and bookkeeping practices and procedures. In relation to staff hiring, the clause "consistent with State law" in Section 125(c)(9) means that the hiring of State Council on Developmental Disabilities staff must be done in accordance with State personnel policies and procedures except that a State shall not apply hiring freezes, reductions in force, prohibitions on staff travel, or other policies, to the extent that such policies would impact staff or functions funded with Federal funds, and would prevent the Council from carrying out its functions under the Act.

**§ 1386.31 State plan submittal and approval.**

(a) The Council shall issue a public notice about the availability of the proposed State plan or State plan amendment(s) for comment. The Notice shall be published in formats accessible to individuals with developmental disabilities and the general public (*e.g.*, tape, diskette, public forums, and newspapers) and shall provide a 45-day period for public review and comment. The Council shall take into account comments submitted within that period, and respond in the State plan to significant comments and suggestions. A summary of the Council's responses to State plan comments shall be submitted with the State plan and made available for public review. This document shall be made available in accessible formats upon request.

(b) The State plan or amendment must be submitted to ADD 45 days prior to the fiscal year for which it is applicable. The State plan or amendment must be

approved by the entity or individual authorized to do so under State law.

(c) Failure to submit an approvable State plan or amendment prior to the Federal fiscal year for which it is applicable may result in the loss of Federal financial participation. Plans received during a quarter of the Federal fiscal year are approved back to the first day of the quarter so costs incurred from that point forward are approvable. Costs resulting from obligations incurred during the period of the fiscal year for which an approved plan is not in effect are not eligible for Federal financial participation.

(d) The Commissioner must approve any State plan or plan amendment provided it meets the requirements of the Act and this regulation.

**§ 1386.32 Periodic reports: Federal assistance to State Councils on Developmental Disabilities.**

(a) The Governor or appropriate State financial officer must submit financial status reports (standard form 269) on the programs funded under this Subpart semiannually.

(b) By January 1 of each year, the State Council on Developmental Disabilities shall submit to ADD, an Annual Program Performance Report through the system established by ADD. In order to be accepted by ADD, reports must meet the requirements of Section 125(c)(7) of the Act (42 U.S.C. 15025) and the applicable regulations, include the information on its program necessary for the Secretary to comply with Section 105(1), (2), and (3) of the Act (42 U.S.C. 15005), and any other information requested by ADD. Each Report shall contain information about the progress made by the Council in achieving its goals including:

- (1) A description of the extent to which the goals were achieved;
- (2) A description of the strategies that contributed to achieving the goals;
- (3) To the extent to which the goals were not achieved, a description of factors that impeded the achievement;
- (4) Separate information on the self-advocacy goal described in Section 124(c)(4)(A)(ii) of the Act (42 U.S.C. 15024);

(5) As appropriate, an update on the results of the comprehensive review and analysis of the extent to which services, supports, and other assistance are available to individuals with developmental disabilities and their families, including the extent of unmet needs for services, supports, and other assistance for those individuals and their families, in the State as required in Section 124(c)(3) of the Act (42 U.S.C. 15024);

(6) Information on consumer satisfaction with Council supported or conducted activities;

(7) A description of the adequacy of health care and other services, supports, and assistance that individuals with developmental disabilities in Intermediate Care Facilities (Mental Retardation) receive;

(8) To the extent available, a description of the adequacy of health care and other services, supports, and assistance received by individuals with developmental disabilities served through home and community-based waivers (authorized under Section 1915(c) of the Social Security Act);

(9) An accounting of the funds paid to the State awarded under the DD Council program;

(10) A description of resources made available to carry out activities to assist individuals with developmental disabilities directly attributable to Council actions;

(11) A description of resources made available for such activities that are undertaken by the Council in collaboration with other entities; and

(12) A description of the method by which the Council will widely disseminate the annual report to affected constituencies and the general public and will assure that the report is available in accessible formats.

(c) Each Council must include in its Annual Program Performance Report information on its achievement of the measures of progress established pursuant to § 1385.5 for the year covered by the Report (OMB Clearance 0980-0172).

**§ 1386.33 Protection of employee's interests.**

(a) Based on Section 124(c)(5)(J) of the Act (42 U.S.C.15024(c)(5)(J)), the State plan must assure fair and equitable arrangements to protect the interest of all institutional employees affected by actions under the plan to provide community living activities. The State must inform employees of the State's decision to provide for community living activities. Specific arrangements for the protection of affected employees must be developed through negotiations between the appropriate State authorities and employees or their representatives.

(b) Fair and equitable arrangements must include procedures that provide for the impartial resolution of disputes between the State and an employee concerning the interpretation, application, and enforcement of protection arrangements. To the maximum extent practicable, these

arrangements must include provisions for:

- (1) The preservation of rights and benefits;
- (2) Guaranteeing employment to employees affected by action under the plan to provide alternative community living arrangements; and
- (3) Employee training and retraining programs.

**§ 1386.34 Designated State Agency.**

(a) The Designated State Agency shall provide the required assurances and other support services as requested and negotiated by the Council. These include:

- (1) Provision of financial reporting and other services as provided under Section 125(d)(3)(D) of the Act; and
- (2) Information and direction, as appropriate, on procedures on the hiring, supervision, and assignment of staff in accordance with State law.

(b) If the State Council on Developmental Disabilities requests a review by the Governor (or State legislature, if applicable) of the Designated State Agency, the Council must provide documentation of the reason for change, and recommend a new preferred Designated State Agency by the Governor (or State legislature, if applicable).

(c) After the review is completed by the Governor (or State legislature, if applicable), and if no change is made, a majority of the non-State agency members of the Council may appeal to the Assistant Secretary for the Administration for Children and Families for a review of the Designated State Agency if the Council's independence as an advocate is not assured because of the actions or inactions of the Designated State agency.

(d) The following steps apply to the appeal of the Governor's (or State legislature, if applicable) designation of the Designated State Agency.

(1) Prior to an appeal to the Assistant Secretary, the State Council on Developmental Disabilities must give a 30 day written notice, by certified mail, to the Governor (or State legislature, if applicable) of the majority of non-State members' intention to appeal the designation of the Designated State Agency.

(2) The appeal must clearly identify the grounds for the claim that the Council's independence as an advocate is not assured because of the action or inactions of the Designated State Agency.

(3) Upon receipt of the appeal from the State Council on Developmental Disabilities, the Assistant Secretary will

notify the State Council on Developmental Disabilities and the Governor (or State legislature, if applicable), by certified mail, that the appeal has been received and will be acted upon within 60 days. The Governor (or State legislature, if applicable) shall within 10 working days from the receipt of the Assistant Secretary's notification provide written comments to the Assistant Secretary (with a copy sent by registered or certified mail to the Council) on the claims in the Council's appeal. Either party may request, and the Assistant Secretary may grant, an opportunity for an informal meeting with the Assistant Secretary at which representatives from both parties will present their views on the issues in the appeal. The meeting will be held within 20 working days of the submission of written comments by the Governor (or State legislature, if applicable). The Assistant Secretary will promptly notify the parties of the date and place of the meeting.

(4) The Assistant Secretary will review the issue(s) and provide a final written decision within 60 days following receipt of the appeal from the State Council on Developmental Disabilities. If the determination is made that the Designated State Agency should be redesignated, the Governor (or State legislature, if applicable) must provide written assurance of compliance within 45 days from receipt of the decision.

(5) Anytime during this appeals process the State Council on Developmental Disabilities may withdraw such request if resolution has been reached with the Governor (or State legislature, if applicable) on the Designated State Agency. The Governor (or State legislature, if applicable) must notify the Assistant Secretary in writing of such a decision.

(e) The Designated State Agency may authorize the Council to contract with State agencies other than the Designated State Agency to perform functions of the Designated State Agency.

**§ 1386.35 Allowable and non-allowable costs for Federal Assistance to State Councils on Developmental Disabilities.**

(a) Under this subpart, Federal funding is available for costs resulting from obligations incurred under the approved State plan for the necessary expenses of administering the plan, which may include the establishment and maintenance of the State Council, and all programs, projects, and activities carried out under the State plan.

(b) Expenditures which are not allowable for Federal financial participation are:

(1) Costs incurred by institutions or other residential or non-residential programs which do not comply with the Congressional findings with respect to the rights of individuals with developmental disabilities in Section 109 of the Act (42 U.S.C. 15009).

(2) Costs incurred for activities not provided for in the approved State plan; and

(3) Costs not allowed under other applicable statutes, Departmental regulations, or issuances of the Office of Management and Budget.

(c) Expenditure of funds that supplant State and local funds are not allowed. Supplanting occurs when State or local funds previously used to fund activities under the State plan are replaced by Federal funds for the same purpose. However, supplanting does not occur if State or local funds are replaced with Federal funds for a particular activity or purpose in the approved State plan if the replaced State or local funds are then used for other activities or purposes in the approved State plan.

(d) For purposes of determining aggregate minimum State share of expenditures, there are three categories of expenditures:

(1) Expenditures for projects or activities undertaken directly by the Council and Council staff to implement State plan activities, as described in Section 126(a)(3) of the Act, require no non-Federal aggregate of the necessary costs of such activities.

(2) Expenditures for projects whose activities or products target individuals with developmental disabilities who live in urban or rural poverty areas, as determined by the Secretary, but not carried out directly by the Council and Council staff, as described in Section 126(a)(2) of the Act, shall have non-Federal funding of at least 10 percent in the aggregate of the necessary costs of such projects.

(3) All other projects not directly carried out by the Council and Council staff shall have non-Federal funding of at least 25 percent in the aggregate of the necessary costs of such projects.

(e) The Council may vary the non-Federal funding required on a project-by-project, activity-by-activity basis (both poverty and non-poverty activities), including requiring no non-Federal funding from particular projects or activities as the Council deems appropriate so long as the requirement for aggregate non-Federal funding is met.

**§ 1386.36 Final disapproval of the State plan or plan amendments.**

The Department will disapprove any State plan or plan amendment only after

the following procedures have been complied with:

(a) The State plan has been submitted to ADD Central Office for review. If after contacting the State on issues with the plan with no resolution, a detailed written analysis of the reasons for recommending disapproval shall be prepared and provided to the State Council and State Designated Agency.

(b) Once the Commissioner has determined that the State plan, in whole or in part, is not approvable, notice of this determination shall be sent to the State with appropriate references to the records, provisions of the statute and regulations, and all relevant interpretations of applicable laws and regulations. The notification of the decision must inform the State of its right to appeal in accordance with 45 CFR part 1386, subpart E.

(c) The Commissioner's decision has been forwarded to the State Council and its Designated State Agency by certified mail with a return receipt requested.

(d) A State has filed its request for a hearing with the Assistant Secretary within 21 days of the receipt of the decision. The request for a hearing must be sent by certified mail to the Assistant Secretary. The date of mailing the request is considered the date of filing if it is supported by independent evidence of mailing. Otherwise the date of receipt shall be considered the date of filing.

### Subpart E—Practice and Procedure for Hearings Pertaining to State's Conformity and Compliance With Developmental Disabilities State Plans, Reports and Federal Requirements

#### General

##### § 1386.80 Definitions.

For purposes of this Subpart:

*Act.* The term "Act" means the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (42 U.S.C. 15001 *et seq.*).

*ADD.* The term "ADD" means the Administration on Developmental Disabilities within the Administration for Children and Families.

*Assistant Secretary.* The term "Assistant Secretary" means the Assistant Secretary for Children and Families (ACF), Department of Health and Human Services.

*Department.* The term "Department" means the Department of Health and Human Services.

*Payment or Allotment.* The term "payment" or "allotment" means an amount provided under part B or C of the Developmental Disabilities Assistance and Bill of Rights Act of

2000. This term includes Federal funds provided under the Act irrespective of whether the State must match the Federal portion of the expenditure. This term shall include funds previously covered by the terms "Federal financial participation," "the State's total allotment," "further payments," "payments," "allotment" and "Federal funds."

*Presiding officer.* The term "presiding officer" means anyone designated by the Assistant Secretary to conduct any hearing held under this subpart. The term includes the Assistant Secretary if the Assistant Secretary presides over the hearing.

##### § 1386.81 Scope of rules.

(a) The rules of procedures in this subpart govern the practice for hearings afforded by the Department to States pursuant to Sections 124, 127 and 143 of the Act (42 U.S.C. 15024, 15027 and 15043).

(b) Nothing in this part is intended to preclude or limit negotiations between the Department and the State, whether before, during, or after the hearing to resolve the issues that are, or otherwise would be, considered at the hearing. Negotiation and resolution of issues are not part of the hearing, and are not governed by the rules in this subpart, except as otherwise provided in this subpart.

##### § 1386.82 Records to the public.

All pleadings, correspondence, exhibits, transcripts of testimony, exceptions, briefs, decisions, and other documents filed in the docket in any proceeding are subject to public inspection.

##### § 1386.83 Use of gender and number.

As used in this subpart, words importing the singular number may extend and be applied to several persons or things, and vice versa. Words importing either gender may be applied to the other gender or to organizations.

##### § 1386.84 Suspension of rules.

Upon notice to all parties, the Assistant Secretary may modify or waive any rule in this subpart, unless otherwise expressly provided, upon determination that no party will be unduly prejudiced and justice will be served.

##### § 1386.85 Filing and service of papers.

(a) All papers in the proceedings must be filed with the designated individual in an original and two copies. Only the originals of exhibits and transcripts of testimony need be filed.

(b) Copies of papers in the proceedings must be served on all

parties by personal delivery or by mail. Service on the party's designated representative is deemed service upon the party.

#### Preliminary Matters—Notice and Parties

##### § 1386.90 Notice of hearing or opportunity for hearing.

Proceedings are commenced by mailing a notice of hearing or opportunity for hearing from the Assistant Secretary to the State Council on Developmental Disabilities and the Designated State Agency, or to the State Protection and Advocacy System or designating official. The notice must state the time and place for the hearing, and the issues that will be considered. The notice must be published in the **Federal Register**.

##### § 1386.91 Time of hearing.

The hearing must be scheduled not less than 30 days, nor more than 60 days after the notice of the hearing is mailed to the State.

##### § 1386.92 Place.

The hearing must be held on a date and at a time and place determined by the Assistant Secretary with due regard for convenience, and necessity of the parties or their representatives. The site of the hearing shall be accessible to individuals with disabilities.

##### § 1386.93 Issues at hearing.

(a) Prior to a hearing, the Assistant Secretary may notify the State in writing of additional issues which will be considered at the hearing. That notice must be published in the **Federal Register**. If that notice is mailed to the State less than 20 days before the date of the hearing, the State or any other party, at its request, must be granted a postponement of the hearing to a date 20 days after the notice was mailed or such later date as may be agreed to by the Assistant Secretary.

(b) If any issue is resolved in whole or in part, but new or modified issues are presented, the hearing must proceed on the new or modified issues.

(c)(1) If at any time, whether prior to, during, or after the hearing, the Assistant Secretary finds that the State has come into compliance with Federal requirements on any issue in whole or in part, he or she must remove the issue from the proceedings in whole or in part as may be appropriate. If all issues are removed the Assistant Secretary must terminate the hearing.

(2) Prior to the removal of an issue, in whole or in part, from a hearing involving issues relating to the conformity with Federal requirements

under part B of the Act, of the State plan or the activities of the State's Protection and Advocacy System, the Assistant Secretary must provide all parties other than the Department and the State (see § 1386.94(b) of this part) with the statement of his or her intention to remove an issue from the hearing and the reasons for that decision. A copy of the proposed State plan provision or document explaining changes in the activities of the State's Protection and Advocacy System on which the State and the Assistant Secretary have settled must be sent to the parties. The parties must have an opportunity to submit in writing within 15 days their views as to, or any information bearing upon, the merits of the proposed provision and the merits of the reasons for removing the issue from the hearing.

(d) In hearings involving questions of noncompliance of a State's operation of its program under part B of the Act, with the State plan or with Federal requirements, or compliance of the State's Protection and Advocacy System with Federal requirements, the same procedure set forth in paragraph (c)(2) of this section must be followed with respect to any report or evidence resulting in a conclusion by the Assistant Secretary that a State has achieved compliance.

(e) The issues considered at the hearing must be limited to those issues of which the State is notified as provided in § 1386.90 and paragraph (a) of this section, and new or modified issues described in paragraph (b) of this section, and may not include issues or parts of issues removed from the proceedings pursuant to paragraph (c) of this section.

#### **§ 1386.94 Request to participate in hearing.**

(a) The Department, the State, the State Council on Developmental Disabilities, the Designated State Agency, and the State Protection and Advocacy System, as appropriate, are parties to the hearing without making a specific request to participate.

(b)(1) Other individuals or groups may be recognized as parties if the issues to be considered at the hearing have caused them injury and their interests are relevant to the issues in the hearing.

(2) Any individual or group wishing to participate as a party must file a petition with the designated individual within 15 days after notice of the hearing has been published in the **Federal Register**, and must serve a copy on each party of record at that time in accordance with § 1386.85(b) of this part. The petition must concisely state:

- (i) Petitioner's interest in the proceeding;
- (ii) Who will appear for petitioner;
- (iii) The issues the petitioner wishes to address; and
- (iv) Whether the petitioner intends to present witnesses.

(c)(1) Any interested person or organization wishing to participate as amicus curiae must file a petition with the designated individual before the commencement of the hearing. The petition must concisely state:

- (i) The petitioner's interest in the hearing;
- (ii) Who will represent the petitioner; and
- (iii) The issues on which the petitioner intends to present argument.

(2) The presiding officer may grant the petition if he or she finds that the petitioner has a legitimate interest in the proceedings and that such participation will not unduly delay the outcome and may contribute materially to the proper disposition of the issues.

(3) An amicus curiae may present a brief oral statement at the hearing at the point in the proceedings specified by the presiding officer. It may submit a written statement of position to the presiding officer prior to the beginning of a hearing and must serve a copy on each party. It also may submit a brief or written statement at such time as the parties submit briefs and must serve a copy on each party.

#### **Hearing Procedures**

##### **§ 1386.100 Who presides.**

(a) The presiding officer at a hearing must be the Assistant Secretary or someone designated by the Assistant Secretary.

(b) The designation of a presiding officer must be in writing. A copy of the designation must be served on all parties and amici curiae.

##### **§ 1386.101 Authority of presiding officer.**

(a) The presiding officer has the duty to conduct a fair hearing, avoid delay, maintain order, and make a record of the proceedings. The presiding officer has all powers necessary to accomplish these ends, including, but not limited to, the power to:

- (1) Change the date, time, and place of the hearing, upon notice to the parties. This includes the power to continue the hearing in whole or in part;
- (2) Hold conferences to settle or simplify the issues in a proceeding, or to consider other matters that may aid in the expeditious disposition of the proceedings;
- (3) Regulate participation of parties and amici curiae and require parties and

amici curiae to state their positions with respect to the issues in the proceeding;

- (4) Administer oaths and affirmations;
- (5) Rule on motions and other procedural items on matters pending before him or her, including issuance of protective orders or other relief to a party against whom discovery is sought;
- (6) Regulate the course of the hearing and conduct of counsel therein;
- (7) Examine witnesses;
- (8) Receive, rule on, exclude, or limit evidence or discovery;
- (9) Fix the time for filing motions, petitions, briefs, or other items in matters pending before him or her;
- (10) Make a final decision; and
- (11) Take any action authorized by the rules in this subpart or 5 U.S.C. 551–559.

(b) The presiding officer does not have authority to compel the production of witnesses, papers, or other evidence by subpoena.

(c) If the presiding officer is a person other than the Assistant Secretary, he or she shall certify the entire record, including recommended findings and proposed decision, to the Assistant Secretary. His or her authority is to render a recommended decision with respect to program requirements which are to be considered at the hearing. In case of any noncompliance, he or she shall recommend whether payments or allotments should be withheld with respect to the entire State plan or the activities of the State's Protection and Advocacy System, or whether the payments or allotments should be withheld only with respect to those parts of the program affected by such noncompliance.

##### **§ 1386.102 Rights of parties.**

All parties may:

- (a) Appear by counsel, or other authorized representative, in all hearing proceedings;
- (b) Participate in any prehearing conference held by the presiding officer;
- (c) Agree to stipulations of facts which will be made a part of the record;
- (d) Make opening statements at the hearing;
- (e) Present relevant evidence on the issues at the hearing;
- (f) Present witnesses who then must be available for cross-examination by all other parties;
- (g) Present oral arguments at the hearing; and
- (h) Submit written briefs, proposed findings of fact, and proposed conclusions of law, after the hearing.

##### **§ 1386.103 Discovery.**

The Department and any party named in the Notice issued pursuant to

§ 1386.90 of this part has the right to conduct discovery (including depositions) against opposing parties as provided by the Federal Rules of Civil Procedure. There is no fixed rule on priority of discovery. Upon written motion, the presiding officer must promptly rule upon any objection to discovery action. The presiding officer also has the power to grant a protective order or relief to any party against whom discovery is sought and to restrict or control discovery so as to prevent undue delay in the conduct of the hearing. Upon the failure of any party to make discovery, the presiding officer may issue any order and impose any sanction other than contempt orders authorized by Rule 37 of the Federal Rules of Civil Procedure.

**§ 1386.104 Evidentiary purpose.**

The hearing is directed to receiving factual evidence and expert opinion testimony related to the issues in the proceeding. Argument will not be received in evidence; rather, it must be presented in statements, memoranda, or briefs, as directed by the presiding officer. Brief opening statements, which shall be limited to a statement of the party's position and what it intends to prove, may be made at hearings.

**§ 1386.105 Evidence.**

(a) *Testimony.* Testimony by witnesses at the hearing is given orally under oath or affirmation. Witnesses must be available at the hearing for cross-examination by all parties.

(b) *Stipulations and exhibits.* Two or more parties may agree to stipulations of fact. Such stipulations, or any exhibit proposed by any party, must be exchanged at the prehearing conference or at a different time prior to the hearing if the presiding officer requires it.

(c) *Rules of evidence.* Technical rules of evidence do not apply to hearings conducted pursuant to this subpart, but rules or principles designed to assure production of the most credible evidence available and to subject testimony to test by cross-examination are applied where reasonably necessary by the presiding officer. A witness may be cross-examined on any matter material to the proceeding without regard to the scope of his or her direct examination. The presiding officer may exclude irrelevant, immaterial, or unduly repetitious evidence. All documents and other evidence offered or taken for the record is open to examination by the parties and opportunity must be given to refute facts and arguments advanced on either side of the issues.

**§ 1386.106 Exclusion from hearing for misconduct.**

Disrespectful, disorderly, or rebellious language or contemptuous conduct, refusal to comply with directions, or continued use of dilatory tactics by any person at the hearing before a presiding officer shall constitute grounds for immediate exclusion of such person from the hearing by the presiding officer.

**§ 1386.107 Un-sponsored written material.**

Letters expressing views or urging action and other un-sponsored written material regarding matters in issue in a hearing is placed in the correspondence section of the docket of the proceeding. This material is not deemed part of the evidence or record in the hearing.

**§ 1386.108 Official transcript.**

The Department will designate the official reporter for all hearings. The official transcript of testimony taken, together with any stipulations, exhibits, briefs, or memoranda of law filed with them is filed with the Department. Transcripts of testimony in hearings may be obtained from the official reporter by the parties and the public at rates not to exceed the maximum rates fixed by the contract between the Department and the reporter. Upon notice to all parties, the presiding officer may authorize corrections to the transcript which involve matters of substance. Transcripts must be taken by stenotype machine and not be voice recording devices, unless otherwise agreed by all of the parties and the presiding officer.

**§ 1386.109 Record for decision.**

The transcript of testimony, exhibits, and all papers and requests filed in the proceedings, except the correspondence section of the docket, including rulings and any recommended or initial decision, constitute the exclusive record for decision.

**Posthearing Procedures, Decisions**

**§ 1386.110 Posthearing briefs.**

The presiding officer must fix the time for filing posthearing briefs. This time may not exceed 30 days after termination of the hearing and receipt of the transcript. Briefs may contain proposed findings of fact and conclusions of law. If permitted, reply briefs may be filed no later than 15 days after filing of the posthearing briefs.

**§ 1386.111 Decisions following hearing.**

(a) If the Assistant Secretary is the presiding officer, he or she must issue a decision within 60 days after the time

for submission of posthearing briefs has expired.

(b)(1) If the presiding officer is a person designated by the Assistant Secretary, he or she must, within 30 days after the time for submission of posthearing briefs has expired, certify the entire record to the Assistant Secretary including the recommended findings and proposed decision.

The Assistant Secretary must serve a copy of the recommended findings and proposed decision upon all parties and amici.

(2) Any party may, within 20 days, file exceptions to the recommended findings and proposed decision and supporting brief or statement with the Assistant Secretary.

(3) The Assistant Secretary must review the recommended decision and, within 60 days of its issuance, issue his or her own decision.

(c) If the Assistant Secretary concludes:

(1) In the case of a hearing pursuant to Sections 124, 127, or 143 of the Act, that a State plan or the activities of the State's Protection and Advocacy System does not comply with Federal requirements, he or she shall also specify whether the State's payment or allotment for the fiscal year will not be authorized for the State or whether, in the exercise of his or her discretion, the payment or allotment will be limited to the parts of the State plan or the activities of the State's Protection and Advocacy System not affected by the noncompliance.

(2) In the case of a hearing pursuant to Section 127 of the Act that the State is not complying with the requirements of the State plan, he or she also must specify whether the State's payment or allotment will be made available to the State or whether, in the exercise of his or her discretion, the payment or allotment will be limited to the parts of the State plan not affected by such noncompliance. The Assistant Secretary may ask the parties for recommendations or briefs or may hold conferences of the parties on these questions.

(d) The decision of the Assistant Secretary under this section is the final decision of the Secretary and constitutes "final agency action" within the meaning of 5 U.S.C. 704 and the "Secretary's action" within the meaning of Section 128 of the Act (42 U.S.C. 15028). The Assistant Secretary's decision must be promptly served on all parties and amici.

**§ 1386.112 Effective date of decision by the Assistant Secretary.**

(a) If, in the case of a hearing pursuant to Section 124 of the Act, the Assistant Secretary concludes that a State plan does not comply with Federal requirements, and the decision provides that the payment or allotment will be authorized but limited to parts of the State plan not affected by such noncompliance, the decision must specify the effective date for the authorization of the payment or allotment.

(b) In the case of a hearing pursuant to Sections 127 or 143 of the Act, if the Assistant Secretary concludes that the State is not complying with the requirements of the State plan or if the activities of the State's Protection and Advocacy System do not comply with Federal requirements, the decision that further payments or allotments will not be made to the State, or will be limited to the parts of the State plan or activities of the State Protection and Advocacy System not affected, must specify the effective date for withholding payments or allotments.

(c) The effective date may not be earlier than the date of the decision of the Assistant Secretary and may not be later than the first day of the next calendar quarter.

(d) The provision of this section may not be waived pursuant to § 1386.84.

3. Revise part 1387 to read as follows.

**PART 1387—PROJECTS OF NATIONAL SIGNIFICANCE****Section Contents**

Sec.

1387.1 General requirements.

**Authority:** 42 U.S.C. 15001 *et seq.*

**§ 1387.1 General requirements.**

(a) All projects funded under this part must be of national significance and serve or relate to individuals with developmental disabilities to comply with subtitle E of the Act, Sections 161–162 (42 U.S.C. 15081–15083).

(b) The requirements concerning format and content of the application, submittal procedures, eligible applicants, and final priority areas will be published in program announcements in the **Federal Register**.

(c) In general, Projects of National Significance provide technical assistance, collect data, demonstrate exemplary and innovative models, disseminate knowledge at the local and national levels, and otherwise meet the goals of Projects of National Significance Section 161 (42 U.S.C. 15081).

(d) Projects of National Significance may engage in one or more of the types of activities provided in Section 161(2) of the statute.

(e) In general, eligible applicants for PNS funding are public and private non-profit entities, 42 U.S.C. 15082, such as institutions of higher learning, State and local governments, and tribal governments. The program announcements will specifically state any further eligibility requirements for the priority areas in the fiscal year.

(f) Faith-based organizations are eligible to apply for PNS funding, providing that the faith-based organizations meet the specific eligibility criteria contained in the program announcement for the fiscal year.

4. Revise part 1388 to read as follows.

**PART 1388—THE NATIONAL NETWORK OF UNIVERSITY CENTERS FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES EDUCATION, RESEARCH, AND SERVICE****Section Contents**

Sec.

1388.1 Purpose.

1388.2 Core functions.

1388.3 National Training Initiatives on Critical and Emerging Needs.

1388.4 Applications.

1388.5 Five-year plan and annual report.

**Authority:** 42 U.S.C. 15001 *et seq.*

**§ 1388.1 Purpose.**

(a) The Administration on Developmental Disabilities awards grants to eligible entities designated as Centers in each State to pay for the Federal share of the cost of the administration and operation of the Centers. Centers shall:

(1) Provide leadership in, advise Federal, State, and community policymakers about, and promote opportunities for individuals with developmental disabilities to exercise self-determination, be independent, be productive, and be integrated and included in all facets of community life.

(2) Be interdisciplinary education, research, and public service units of universities (as defined by the Secretary) or public or not-for-profit entities associated with universities that engage in core functions, described in § 1388.2 of this part, addressing, directly or indirectly, one or more of the areas of emphasis, as defined in § 1385.3.

(b) To conduct National Training Initiatives on Critical and Emerging Needs as described in § 1388.3.

**§ 1388.2 Core functions.**

The Centers described in § 1388.1(a)(1) and (2) must engage in the core functions referred to in § 1388.1(a)(2), which shall include—

(a) Provision of interdisciplinary pre-service preparation and continuing education of students and fellows, which may include the preparation and continuing education of leadership, direct service, clinical, or other personnel to strengthen and increase the capacity of States and communities to achieve the purpose of the DD Act of 2000.

(b) *Provision of community services.*

(1) That provide training or technical assistance for individuals with developmental disabilities, their families, professionals, paraprofessionals, policymakers, students, and other members of the community; and

(2) That may provide services, supports, and assistance for the persons listed in (b)(1) through demonstration and model activities.

(c) Conduct of research, which may include basic or applied research, evaluation, and the analysis of public policy in areas that affect or could affect, either positively or negatively, individuals with developmental disabilities and their families.

(d) Dissemination of information related to activities undertaken to address the purpose of the DD Act of 2000, especially dissemination of information that demonstrates that the network authorized under subtitle D is a national and international resource that includes specific substantive areas of expertise that may be accessed and applied in diverse settings and circumstances.

**§ 1388.3 National Training Initiatives on Critical and Emerging Needs.**

(a) Supplemental grant funds for National Training Initiatives (NTIs) on Critical and Emerging Needs will be reserved when each Center described in Section 152 of the DD Act has received a grant award of at least \$500,000, adjusted for inflation.

(b) The grants shall be awarded to Centers to pay for the Federal share of the cost of training initiatives related to the unmet needs of individuals with developmental disabilities and their families.

(c) The grants shall be awarded on a competitive basis, and for periods of not more than 5 years.

**§ 1388.4 Applications.**

(a) To be eligible to receive a grant under § 1388.1 for a Center, an entity shall submit to the Secretary, and obtain

approval of, an application at such time, in such manner, and containing such information, as the Secretary may require.

(b) Each application shall describe a five-year plan, that must include—

(1) Projected goal(s) related to one or more areas of emphasis described in § 1385.3 for each of the core functions.

(2) Measures of progress (measures of consumer satisfaction, improvement, and collaboration) it has established, pursuant to § 1385.5.

(c) The application shall contain or be supported by reasonable assurances that the entity designated as the Center will—

(1) Meet the measures of progress (measures of consumer satisfaction, improvement, and collaboration); and

(2) Address the projected goals, and carry out goal-related activities, based on data driven strategic planning and in a manner consistent with the objectives of subtitle D, that—

(i) Are developed in collaboration with the consumer advisory committee established pursuant to paragraph (5);

(ii) Are consistent with, and to the extent feasible complement and further, the Council goals contained in the State plan submitted under Section 124 of the DD Act of 2000 and the goals of the P&A System established under Section 143 of the DD Act of 2000; and

(iii) Will be reviewed and revised annually as necessary to address emerging trends and needs.

(3) Use the funds made available through the grant to supplement, and not supplant, the funds that would otherwise be made available for activities described in § 1388.1(a)(1) and (2) of this part.

(4) Protect, consistent with the policy specified in Section (101)(c) of the DD Act of 2000 (U.S.C. 15001) (relating to rights of individuals with developmental disabilities), the legal and human rights of all individuals with developmental disabilities (especially those individuals under State guardianship who are involved in activities carried out under programs assisted under subtitle D).

(5) Establish a consumer advisory committee—

(i) Of which a majority of the members shall be individuals with developmental disabilities and family members of such individuals;

(ii) That is comprised of—

(A) Individuals with developmental disabilities and related disabilities;

(B) Family members of individuals with developmental disabilities;

(C) A representative of the State Protection and Advocacy System;

(D) A representative of the State Council on Developmental Disabilities;

(E) A representative of a self-advocacy organization described in Section 124(c)(4)(A)(ii)(I) of the DD Act of 2000 (42 U.S.C. § 15024(c)(4)(A)(ii)(I)); and

(F) Representatives of organizations that may include parent training and information centers assisted under Section 671 or 672 of the Individuals with Disabilities Education Act (20 U.S.C. 1471, 1472), entities carrying out activities authorized under Section 104 or 105 of the Assistive Technology Act of 1998 (29 U.S.C. 3003, 3004), relevant State agencies, and other community groups concerned with the welfare of individuals with developmental disabilities and their families.

(iii) That reflects the racial and ethnic diversity of the State;

(iv) That shall—

(A) Consult with the Director of the Center regarding the development of the five-year plan;

(B) Participate in an annual review of, and comment on, the progress of the Center in meeting the projected goals contained in the plan;

(C) Make recommendations to the Director of the Center regarding any proposed revisions of the plan that might be necessary; and

(v) Meet as often as necessary to carry out the role of the committee, but at a minimum twice during each grant year.

(6) To the extent possible, utilize the infrastructure and resources obtained through funds made available under the grant to leverage additional public and private funds to successfully achieve the projected goals developed in the five-year plan;

(7)(i) Have a director with appropriate academic credentials, demonstrated leadership, expertise regarding developmental disabilities, significant experience in managing grants and contracts, and the ability to leverage public and private funds; and

(ii) Allocate adequate staff time to carry out activities related to each of the core functions described in § 1388.2.

(8) Educate, and disseminate information related to the purpose of the DD Act of 2000 to the legislature of the State in which the Center is located, and to Members of Congress from such State.

(d)(1) All applications submitted under this section shall be subject to technical and qualitative review by peer review groups as described under § 1388.4(c)(2) of this part.

(2) Each peer review group shall include such individuals with disabilities and parents, guardians, or advocates of or for individuals with developmental disabilities, as are necessary to carry out this section.

(e)(1) The Federal share of the cost of administration or operation of a Center,

or the cost of carrying out a training initiative, supported by a grant made under this subtitle D may not be more than 75 percent of the necessary cost of such project, as determined by the Secretary.

(2) In the case of a project whose activities or products target individuals with developmental disabilities who live in an urban or rural poverty area, as determined by the Secretary, the Federal share of the cost of the project may not be more than 90 percent of the necessary costs of the project, as determined by the Secretary.

(3) For the purpose of determining the Federal share with respect to the project, expenditures on that project by a political subdivision of a State or by a public or private entity shall be subject to the provisions of 45 CFR part 93 New Restrictions on Lobbying (also see § 1385.9 Grants administration) and must be considered as an expenditure of the Center under subtitle D.

#### § 1388.5 Five-year plan and annual report.

(a) As required by Section 154(a)(2) of the DD Act of 2000, (42 U.S.C. 15064), the application for core funding for a UCEDD shall describe a five-year plan, including a projected goal or goals related to one or more areas of emphasis for each of the core functions in Section 153(a)(2) of the DD Act of 2000 (42 U.S.C. 15063).

(1) For each area of emphasis under which a goal has been identified, the UCEDD must state in its application the measures of progress (consumer satisfaction, improvement and collaboration) it has established, pursuant to § 1385.5 of this part.

(2) If changes are made to the measures of progress established for a year, the five-year plan must be amended to reflect those changes.

(3) By July 31 of each year, a UCEDD shall submit an Annual Report, using the system established by ADD. In order to be accepted by ADD, an Annual Report must meet the requirements of Section 154(e) of the Act (42 U.S.C. 15064) and, the applicable regulations, and include the information necessary for the Secretary to comply with Section 105(1), (2), and (3) of the Act (42 U.S.C. 15005) and any other information requested by ADD. The Report shall include information on progress made in achieving the UCEDDs goals for the previous year, including:

(i) The extent to which the goals were achieved;

(ii) a description of the strategies that contributed to achieving the goals;

(iii) to the extent to which the goals were not achieved, a description of

factors that impeded the achievement;  
and

(iv) an accounting of the manner in which funds paid to the UCEDD for a fiscal year were expended.

(4) The Report also must include information on proposed revisions to the goals and a description of successful efforts to leverage funds, other than funds under the Act, to pursue goals consistent with the UCEDD program.

(5) Each UCEDD must include in its Annual Report information on its achievement of the measures of progress established in § 1385.5 of this part.

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