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45 CFR Parts 1385, 1386, 1387, et al.  
Developmental Disabilities Program; Final Rule

## DEPARTMENT OF HEALTH AND HUMAN SERVICES

### 45 CFR Parts 1385, 1386, 1387, and 1388

RIN 0970-AB11

#### Developmental Disabilities Program

**AGENCY:** Administration on Intellectual and Developmental Disabilities (AIDD), Administration for Community Living, HHS.

**ACTION:** Final rule.

**SUMMARY:** This rule implements the Developmental Disabilities Assistance and Bill of Rights Act of 2000. The previous regulations were completed in 1997 before the current law was passed. The rule will align the regulations and current statute and will provide guidance to AIDD grantees.

**DATES:** These final regulations are effective August 26, 2015.

**FOR FURTHER INFORMATION CONTACT:** Andrew Morris, Administration on Intellectual and Developmental Disabilities, telephone (202) 357-3424 (Voice). This is not a toll-free number. This document will be made available in alternative formats upon request. Written correspondence can be sent to Administration on Intellectual and Developmental Disabilities, U.S. Department of Health and Human Services, One Massachusetts Ave, Washington, DC 20201.

#### 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”.<sup>1</sup> 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).

Key changes in the DD Act of 2000 include:

- The DD Act of 2000 requires State Councils on Developmental Disabilities (“Councils” or “SCDDs”) 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)(3)).

- The DD Act of 2000 strengthens provisions regarding access to records of individuals with developmental disabilities that service providers hold, in order to investigate potential abuse and neglect. Also, the State must now provide information to a Protection and Advocacy (P&A) agency about the adequacy of health care and other services, supports, and assistance that individuals with developmental disabilities receive through home and community-based waivers. The DD Act of 2000 also defines the P&A governing board. The governing board is subject to section 144 of the Act.

- 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, AIDD, subject to availability of appropriations, awards 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 must be targeted to states or populations that are underserved or underserved (section 152(d)).

- The DD Act of 2000 authorizes the Projects of National Significance (section 161) 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.

- Finally, 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. Titles II and III of the DD Act of 2000 have not had funds appropriated by Congress and are not addressed in this rule.

##### II. Grantees of the Administration on Intellectual and Developmental Disabilities (AIDD) Under the Act

###### A. Federal Assistance to State Councils on Developmental Disabilities

As stated in section 121 of the DD Act, formula grants are made to each State and other eligible jurisdictions to

support a State Council on Developmental Disabilities (SCDD) 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. These grants provide assistance that promotes self-determination, independence, productivity, and integration and inclusion in all facets of community living. Activities contribute to a coordinated, person and family-centered, person 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.

It is noted that section 143 of the Act requires that a state have a functioning P&A system in order for the SCDD to receive funds.

###### B. Protection and Advocacy for Individuals With Developmental Disabilities

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

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

Under subtitle E of title I of the Act, AIDD may award grants, contracts or cooperative agreements for Projects of National Significance (PNS) to create opportunities for individuals with developmental disabilities to directly and fully contribute to, and participate in, all facets of community life. Generally, projects are to support the development of national and state policies that reinforce and promote self-

<sup>1</sup> While developmental disability is the preferred contemporary language, mental retardation was the term used in 1963.

determination, independence, productivity, integration, and inclusion in all facets of community living.

*D. National Network of University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDDs)*

Grants are awarded to entities designated as University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDDs) in the States and other eligible jurisdictions to provide leadership; advise federal, state, and community policymakers; and promote self-determination, independence, productivity, and full integration of individuals with developmental disabilities. The UCEDDs 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 Final Rule

A Notice of Proposed Rule Making (NPRM) to address the requirements of the DD Act of 2000 was published on April 10, 2008 (73 FR 19708) and a subsequent document published on July 29, 2008 (73 FR 43904) reopened the comment period through September 29, 2008. This rule finalizes many of the policies that were included in the NPRM, as well as reorganizes some provisions based on court rulings and to provide clarity.

The majority of comments received supported the focus on individuals with developmental disabilities living and participating in all aspects of community living. The following discusses issues raised in the NPRM:

a. The NPRM substantially reorganized the regulatory text of 45 CFR chapter XIII, subchapter I, the Administration on Developmental Disabilities, Developmental Disabilities Program in full. To this end we have revised citations and made technical changes as necessary. The Administration on Developmental Disabilities became the Administration on Intellectual and Developmental Disabilities (AIDD) (as published in the **Federal Register** on April 18, 2012 (77 FR 23250)).

b. AIDD has made technical changes to make the rule consistent with the statute and related to the delegations of

authorities published in the **Federal Register** on March 15, 2013 (78 FR 16511). These technical revisions further implement the Secretary's recent reorganization of the functions of the U.S. Department of Health and Human Services that created the Administration for Community Living (ACL). The new terminology "Secretary, or his or her designee," is used to replace such terms as "Assistant Secretary" (referring to the Assistant Secretary of the Administration on Children and Families) and "Commissioner" (referring to the Administration on Disabilities Commissioner).

c. The NPRM requested comment on "whether the current process involving class action lawsuits provides adequate protection for individuals with developmental disabilities," and specifically, "on the procedures used to reach decisions on whether to pursue class action lawsuits and the method of informing/obtaining consent." AIDD received many comments, both raising concerns about the use of class actions by P&As and expressing support for the outcomes P&As have accomplished via their legal advocacy generally, and the use of class action lawsuits specifically. Many commenters suggested that request for such comments deals with issues beyond the scope of AIDD's authority. AIDD considered the comments received and has chosen not to adopt new rules specifically governing the process for P&A's pursuing class action lawsuits.

Some commenters recommended adding requirements for notification of ICF/IID<sup>2</sup> residents, families and legal guardians/representatives where applicable, as well as a specific "opt out" provision for this population. As explained above, we determined not to adopt new rules governing class action lawsuits. Class action lawsuits are governed by the Federal Rules of Civil Procedure, which already include notice provisions and we do not believe additional rules specific to P&A's pursuing class actions are required. The DD Act has as its mission protecting people with developmental disabilities from abuse and neglect, and class action lawsuits are an essential tool for such protection. Additional requirements creating procedural obstacles that do not exist for other civil rights enforcement

<sup>2</sup> In keeping with the rule from the Centers for Medicare and Medicaid Services, "Medicare and Medicaid Program; Regulatory Provisions to Promote Program Efficiency, Transparency, and Burden Reduction CMS-9070-F," which took effect on July 12, 2012, this rule substitutes the term Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID) for the former term Intermediate Care Facilities for Persons with Mental Retardation (ICF/MR).

actions may impede litigation that protects and enhances the rights of people with developmental disabilities. These suggested "opt out" and notice provisions singular to these types of cases may create additional hurdles and undermine the purposes of the DD Act, the Americans with Disabilities Act, and the Supreme Court decision in *Olmstead*.

In addition, as many commenters noted, P&As utilize the tool of class actions lawsuits judiciously. For example see the 2003 report from GAO, "P&A Involvement in Deinstitutionalization Lawsuits on Behalf of Individuals with Developmental Disabilities," available at <http://www.gao.gov/new.items/d031044.pdf>.

The DD Act is clear in prioritizing full integration and inclusion of people with developmental disabilities, promoting self-determination, independence, productivity and integration and inclusion in all facets of community life. P&As have a central role in protecting the rights of individuals with developmental disabilities. Additional provisions beyond what is required in the Federal Rules of Civil Procedure could prevent P&As from fulfilling their mandate to enforce the rights of individuals with disabilities in the most effective manner.

d. Many of the comments asked AIDD to define what a UCEDD is. The previous term "University Affiliated Program" was defined in previous regulations, but the new term "UCEDD" was not defined in the 2008 NPRM. We reviewed the comments and concurred that a clear definition for the UCEDD is necessary. To that end, part 1388 has been reorganized from what was in the NPRM, and language for Governance and Administration (which defines the structure of a UCEDD) has been restored from the previously published regulations to reflect the change from University Affiliated Programs to University Centers of Excellence in Developmental Disabilities.

e. The NPRM invited comment on the question of activities to "advise," "inform," and/or "educate" federal, state, and local policymakers. The NPRM sought comment on the possible distinction between lobbying and the educational activities included in the statute. Sections 125(c)(5)(J), 143(a)(2)(L), and 153(a)(1), of the DD Act authorize the State Councils, P&As, and UCEDDs to engage in education, advising, and support of policymakers. Additionally, section 102(27)(E) defines the term "self-determination activities," to envision self-advocacy, whereby individuals with developmental disabilities, themselves, educate

policymakers and play a role in the development of public policies that affect them. Section 161(2)(D)(iii) also states that one of the purposes of the Projects of National Significance is to support the development of national and State policies that reinforce and promote such self-determination and inclusion through projects that provide education for policymakers. The majority of commenters stated support for educational activities while recognizing the restrictions with federal funds.

AIDD issued guidance (ADD-01-1 dated September 20, 2001) on lobbying activities. AIDD grantees should continue to present information in a balanced and non-partisan manner that is consistent with the principles of the DD Act. Grantees may use non-federal funds for other policy related activities in accordance with relevant federal and state laws.

We understand that grantees may have questions regarding the practice of advocacy. Many provisions of the DD Act specifically require grantees to engage in such activities as advocacy, capacity building, and/or systems change activities (sections 101(b)(1); 104(a)(3)(D)(ii)(I-III); 121(1); 124(c)(4); 124(c)(4)(L); 125(c)(2); 143(a)(2)(A)(i); 161(2)). AIDD may work with stakeholders to issue new or revised guidance on the subject to address these issues.

Below is a section-by-section discussion of changes made between the NPRM and final rule:

### **Part 1385—Requirements Applicable to the Developmental Disabilities Programs**

#### *Section 1385.1 General*

Commenters suggested that the term “Protection and Advocacy of Individual Rights” (PAIR) be changed to “Protection and Advocacy for Individuals with Developmental Disabilities” (PADD) throughout the regulation. Though the term “Protection and Advocacy of Individual Rights” is used in the DD Act, the name is identical to a similar program administered by the Department of Education. For the sake of clarity, and as the term “Protection and Advocacy for Individuals with Developmental Disabilities” (PADD) is already regularly used to refer to the P&A program under the DD Act, we have substituted this terminology throughout the regulations.

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

No changes were made from the NPRM.

#### *Section 1385.3 Definitions*

This section of the final rule updates definitions from the NPRM. The definitions in § 1385.3 are applicable to the rule in its entirety. Some definitions have been changed because the NPRM definitions went beyond the scope of the law.

##### **Accessibility**

The definition of accessibility has been changed to reflect the most current and up to date laws and regulations regarding section 504 of the Rehabilitation Act of 1973, and the Americans with Disabilities Act of 1990, and the Americans with Disabilities Act Amendments Act of 2008 (Pub. L. 110-325).

##### **AIDD**

This definition was added to reflect the change in organizational names from the Administration on Developmental Disabilities to the Administration on Intellectual and Developmental Disabilities in the process of the creation of the Administration for Community Living.

##### **Advocacy Activities**

AIDD received comments asking for the inclusion of systems change in the definition of “advocacy activities” and we concurred with comments. A minority of comments suggested removing “families” from the definition. AIDD disagreed with removing families from the definition as they play a key role in the lives of people with developmental disabilities and are specifically referenced throughout the statute, including in the purpose of the law. AIDD concurred with requests for a broader definition of advocacy activities, and expanded Advocacy Activities to include all aspects of community living. AIDD has revised the term “advocacy activities”.

##### **Assistive Technology Device**

AIDD received comments asking that the definition of “assistive technology device” be changed to the wording of the statute. AIDD concurred with the comments.

##### **Assistive Technology Service**

AIDD received comments asking that the definition of “assistive technology service” be changed to the wording of the statute. AIDD concurred with the comments.

##### **Capacity Building Activities**

AIDD received comments that the definition of “capacity building activities” did not include key processes and limited activities. Also, the NPRM

changed the application of capacity building activities from the UCEDDs to all DD Act programs. Based on comments received, the definition of capacity building activities has been clarified to include elements of community living, and made applicable to all the DD Act programs.

##### **Developmental Disability**

AIDD received multiple objections that the insertion of the term “determined on a case by case basis” regarding a developmental disability, with some commenting that it constituted an additional requirement not included in the statute. AIDD concurred and removed it from the definition. The definition as passed in the 2000 reauthorization did not include such language requiring that each person with a developmental disability be determined on a case by case basis. Multiple commenters opined that that phrase excessively puts a medical diagnosis on developmental disabilities.

##### **Inclusion**

We received comments asking that the definition of “inclusion” be changed to the wording of the statute. We concurred with the comments.

##### **State**

We made a technical revision that was an error in the NPRM for the definition of “State”. For the purposes of the UCEDD grants, American Samoa and the Commonwealth of the Northern Mariana Islands are not considered States. See section 155 of the DD Act, 42 U.S.C. 15065.

##### **Supported Employment Services**

We received comments asking that the definition for “supported employment services” be changed to the wording of the statute. We concurred with the comments.

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

No changes were made from the NPRM.

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

This section of the NPRM is not being developed into a final rule. We generally received unfavorable comments from stakeholders that the requirements would place an administrative and cost burden on grantees. We concurred, as AIDD does not want to place undue hardships on grantees. We have concluded that additional guidance is unnecessary at this time. Since the law was passed

AIDD has issued OMB approved reporting requirements that are consistent with the Act. See OMB approved reporting in the Impact Statement of the Preamble.

*Section 1385.6 Employment of Individuals With Disabilities*

There were no changes made to this section in the final rule from the NPRM.

*Section 1385.7 Reports of the Secretary*

There were no changes made to this section in the final rule from the NPRM.

*Section 1385.8 Formula for Determining Allotment*

To reflect the accuracy of the allotment process as defined in the statute, the final rule has been amended to replicate sections 122 and 142 of the Act.

*Section 1385.9 Grants Administration*

There were no changes made to this section in the final rule from the NPRM.

**Part 1386—Formula Grant Programs**  
**Subpart A—Basic Requirements**

*Section 1386.1 General*

The final rule makes technical changes to § 1386.1 to update the terminology.

*Section 1386.2 Obligation of Funds*

Similarly, the final rule revises § 1386.2 to update terminology.

**Subpart B—Protection and Advocacy for Individuals with Developmental Disabilities (PADD).**

We have revised the title of subpart B to read: Subpart B—Protection and Advocacy for Individuals with Developmental Disabilities (PADD).

*Section 1386.19 Definitions*

A number of comments were received on the definitions proposed in the NPRM with respect to subparts B, § 1386.19, requesting that modifications be made to the below definitions of “Abuse,” “Complaint,” “Legal Guardian, Conservator and Legal Representative,” “Neglect,” “Probable Cause,” and “Service Provider.”

**Abuse**

AIDD received numerous comments on the definition of “abuse.” Commenters recommended including the language “willful infliction of injury, unreasonable confinement, intimidation, or punishment with resulting physical harm, pain or mental anguish” in the definition. The DD Act authorizes P&As to investigate incidents of abuse and neglect, as in section

143(a)(2)(B), to protect individuals with developmental disabilities, regardless of the intent of the alleged abuser. Determining “willful infliction” may also require further information to establish such intent, which would, in turn, complicate and even potentially eliminate, a P&A’s ability to conduct an appropriate investigation. After careful consideration, AIDD did not include this recommended change in the final rule.

Some commenters suggested removing the phrase “repeated and/or egregious,” from the definition of abuse. AIDD removed “repeated and egregious,” as suggested. This change is consistent with the language of the DD Act, which states that one of its purposes is to provide individuals with developmental disabilities the opportunity and support “to live free of abuse, neglect, financial and sexual exploitation, and violations of their legal and human rights” (section 101(a)(16)(F) of the DD Act, 42 U.S.C. 15001(a)(16)(F)). Even a single instance of the aforementioned treatment is should be sufficient to constitute the type of circumstance that would give a P&A authority to initiate an investigation.

Commenters also recommended substituting “legal” for “statutory and constitutional” in the definition. AIDD made the recommended change, as P&A authority must include the ability to investigate violations of regulations and judicial precedent; P&A investigatory authority is not limited only to violations of statutory or constitutional law.

Finally, some commenters suggested deleting the phrase “which may prevent the individual from providing for his or her basic needs such as food and shelter” from the definition with respect to financial exploitation. Financial exploitation is a type of abuse which falls within the investigatory authority of P&As, and individuals with developmental disabilities can be subject to this type of abuse even when the individual is able to take care of basic food and shelter needs.

AIDD adopted the recommendation and removed the phrase “which may prevent the individual from providing for his or her basic needs such as food and shelter” from the final rule.

**Complaint**

Commenters suggested that “complaint” be defined to include “from any source relating to alleged abuse or neglect,” rather than “from any source relating to status or treatment,” as “status” and “treatment” are not defined in the proposed regulations.

The language “from any source alleging abuse or neglect,” was adopted into the final rule as it is consistent with the prior DD Act regulations, as well as with the Protection and Advocacy for Individuals with Mental Illness (PAIMI regulations, 42 CFR 51.2).

Another commenter recommended that the definition include a clarification that an individual’s residential placement does not, alone, constitute a complaint issue. Related, other commenters expressed concern that residential status in the context of the definition would lead to potentially inappropriate investigations by the P&As, and recommended that the definition include specific language stating that an individual’s residential placement, if not related to quality issues, does not constitute a complaint issue. AIDD has considered these suggestions and did not adopt the suggested change. Residential status may be a part of the determination of whether an investigation should be initiated by a P&A under the DD Act. The DD Act includes the authority to protect and advocate for the rights of individuals “who . . . are being considered for a change in living arrangements” in section 143(a)(2)(A)(i), and P&As must apply these principles in accordance with the intent of the law. An example of such principles can be found in section 109(a)(2), “treatment, services, and habitation for an individual with developmental disabilities should be designed to maximize the potential of the individual and should be provided in the setting that is least restrictive of the individual’s personal liberty.”

Commenters also suggested the term “alleging” be added to modify “abuse or neglect.” AIDD adopted this change, as the P&A may not yet have determined whether abuse or neglect has actually occurred at the complaint stage.

AIDD also included “electronic communications,” and other media to provide an additional, relevant and technologically up-to-date example of a type of communication that a P&A may receive that may fall under this definition.

**Legal Guardian, Conservator and Legal Representative**

Based on comments received, AIDD has modified the definition of “legal guardian, conservator and legal representative,” to include “a parent of a minor, unless the State has appointed another legal guardian under applicable State law,” to be consistent with the findings of the district court in *State of Connecticut Office of Protection and Advocacy for Persons with Disabilities*

*v. Hartford Bd. of Ed.*, 464 F.3d 229 (2d Cir. 2006) (holding that P&A has access to names and contact information for parents and/or guardians of certain students). Commenters also recommended adding “executors and administrators of estates,” to the list of excluded categories, a change AIDD instituted for the sake of clarity. Finally, commenters recommended substituting “services, supports and other assistance” for “treatment and habilitation services,” and AIDD made that change, to be consistent with the principles of the DD Act and to explicitly express that the DD Act covers a broad range of services.

#### Neglect

Some commenters recommended the addition of “failure to take appropriate steps to prevent harassment or assault by a peer or self-abuse” to the term “neglect.” P&As need the authority to investigate acts or omissions leading to this type of situation, which can put the health, safety and life of an individual with a developmental disability at risk. AIDD accepted the proposed change.

Another commenter recommended alternative modifications, including concerns similar to the issue raised regarding the definition of abuse, suggesting that “repeated” be part of the definition. The DD Act seeks to ensure that people with developmental disabilities “live free of . . . neglect” in section 101(a)(16)(F). AIDD did not accept the proposed change, as the DD Act does not require “repeated” incidents to qualify under this definition.

One commenter objected to the continued inclusion of the existence of a discharge plan in the definition of “neglect.” AIDD considered this comment, and rejected it. Since at least 1996, the regulations have contained language about failing to establish or carry out a discharge plan.

#### Probable Cause

Commenters suggested adding language to the body of the rule to the effect that the definition is not intended to affect the authority of the courts to review the determinations of P&As as to whether probable cause exists. However, we did not accept this change, as AIDD does not have authority over court jurisdiction.

Commenters also suggested removing the phrase “depending on the context,” as ambiguous and unnecessary. AIDD agreed and removed the phrase accordingly.

Some commenters suggested that the definition in the NPRM failed to provide constitutionally mandated due process

and was unclear. The NPRM stated 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.” We agreed that the language is unnecessary and deleted it. Where a P&A determines it has reasonable belief that an individual with developmental disabilities has been, or may be, subject to abuse or neglect, it has a legally enforceable right to access the records or individuals sought, in compliance with relevant statutes and regulatory provisions.

A commenter suggested creating an alternative process to address circumstances when a service provider wants to withhold access and challenges the standard. AIDD believes that would be excessively burdensome and did not incorporate the suggestion. Where there is controversy between the P&A and service provider, the P&A makes the relevant determination, in the interest of providing strong protection of and advocacy for people with developmental disabilities in keeping with the purpose of the DD Act. In situations regarding abuse and neglect, the court remains the “final arbiter” with respect to determining whether an adequate basis for probable cause exists.

#### Service Provider

The NPRM proposed a new definition of “Service Provider,” but has chosen not to finalize it. This is due to the rapidly changing nature of who provides services, and the tremendous variation in the delivery of supports in a broad range of settings. To define an exemplary list of “service providers” in a regulation would not allow for the broad range of entities currently providing services to be inclusively represented. The DD Act is clear that P&As have access to people with developmental disabilities, “in a location in which services, supports, and other assistance are provided . . .” (section 143(a)(2)(H)). However the law is not explicit about who might be providing such services, intentionally leaving this flexibility to evolve with systems. Twenty years ago it was common for an individual to live in a large congregate setting. Now an individual is more likely to be living in a small group home, in an adult supported living (foster) home, with his or her own family or family member, or independently in his or her own home.

AIDD received comments asking for possible types of service providers to be listed, but determined that publishing a specific list might create a perception that any list is exhaustive or potentially over-inclusive.

#### Service Recipient

Commenters recommended replacing the term “service recipient” with “individual with developmental disabilities,” where appropriate, throughout the regulations. The term “service recipient” was not defined in the proposed regulation, and it also represents passive language not in alignment with the DD Act. To reflect the fact that service recipient is not a defined term, the final rule alters terminology was altered in §§ 1386.26, 1386.27, and 1386.28 and in relevant subject headings to refer to “individuals with developmental disabilities”. This change is not intended to affect the scope of the P&A’s legal authority as outlined in the regulations.

#### *Section 1386.20 Agency Designated as the State Protection and Advocacy System*

Similar to the proposed rule, the final rule revises the heading of § 1386.20 to Agency Designated as the State Protection and Advocacy System from Designated State Protection and Advocacy Agency. Commenters recommended that the redesignation process described in paragraph (d) include an opportunity for an oral administrative hearing before an independent authority. AIDD considered this comment, but declines to make that addition to the regulations as the requested change would necessitate an undue administrative burden on the agency.

AIDD made technical changes in § 1386.20(d)(2)(vi) and (d)(3) requiring accessible formats and access for individuals with limited English proficiency. AIDD removed examples of outdated technology in § 1386.20(d)(3).

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

AIDD revised the title to include a reference to “State” in relation to the Protection and Advocacy System and updated terminology and statutory cites.

Commenters expressed support for § 1386.21(c) as written in the NPRM, which revised the regulation to include additional language regarding prohibited State actions which would diminish or interfere with the exercise of the required authority of the P&As. No changes were made to the language in this section of the final rule.

In paragraph (g), we are adding a statement indicating governing boards are also required to have a majority of individuals with disabilities or their family members. This brings the rule in alignment with the statute.

Regarding § 1386.21(j), commenters recommended the inclusion of a new subsection to allow the P&As to enter into contracts for part of their programs. AIDD agreed that this option would allow greater flexibility for monitoring in remote areas, and for entering into special initiatives. P&As have explicit oversight responsibilities to ensure the contractor organizations meets all of the standards and requirements applicable to the P&As. The language in § 1386.21(j) reflects the field's evolving understanding of legal standing in the P&A context.

#### *Section 1386.22 Periodic Reports: State Protection and Advocacy System*

The P&A system shall continue to comply with the reporting requirements of the law and applicable regulations, in accordance with OMB approved reports.

#### *Section 1386.23 Non-allowable costs for the State Protection and Advocacy System*

No changes were made in this section.

#### *Section 1386.24 Allowable litigation costs for the State Protection and Advocacy System*

No substantive changes from the NPRM were made in this section.

### **Subpart C—Access to Records, Service Providers and Individuals With Developmental Disabilities**

As noted above, the terminology in the title of subpart C of part 1386—Formula Grant Programs was changed from “Service Recipients” to “Individuals with Developmental Disabilities,” to be consistent with changes made in response to comments received, emphasizing clearer and more active language.

#### **General Context—Subpart C**

As explained in the NPRM, this rule addresses key provisions in Subtitle C of the Act (42 U.S.C. 15043)(a)(1); (2)(A), (H), (I), (J); and (c)) on Protection and Advocacy for Individuals with Developmental Disabilities. These provisions of the DD Act pertain to P&A access to service providers, access to individuals with developmental disabilities, and access to records. The rule also offers some examples of records to which a P&A shall have access. Given the obligation of P&As to conduct investigations of incidences of abuse and neglect, as well as the statutory authority under section 143(a)(2)(I) to, in certain circumstances, contact an individual's guardian, conservator or legal representative, AIDD has taken the position that a P&A shall have prompt access to contact

information of such individuals. AIDD's determination also is supported by law by the Second Circuit Court decision in the case, *State of Conn. Office of Protection and Advocacy for Persons with Disabilities v. Hartford Board of Education*, 464 F.3d 229 (2nd Cir. 2006) (holding that the P&A had the right to access a learning academy to investigate complaints of abuse and neglect at the school and to obtain the directory of students with contact information for parents and guardians).

AIDD notes the importance of accessing records of individuals with developmental disabilities in order for the P&A system to investigate suspected cases of abuse and neglect. As discussed in the NPRM, many of the changes in this subpart reflect the access authority language contained in sections 143(a)(2)(I) and (J) of the Act (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 P&A's authority to investigate abuse and neglect and to ensure the protection of rights. This broad interpretation of available records and reports also is consistent with the requirements of the PAIMI regulations (42 CFR 51.41). Ensuring that interpretations of statutory authority are included in regulation also allows P&As to minimize the amount of resources spent on determining the standards for access, in service of protecting and advocating for the legal and human rights of individuals with developmental disabilities.

The DD Act and this rule 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 must be provided no later than within 24 hours (42 U.S.C. 15043(a)(2)(J)(ii)).

AIDD recognizes that P&As are charged with engaging in a range of activities that necessitate access to people with developmental disabilities. Examples of such activities include but are not limited to protecting the legal and human rights of individuals with developmental disabilities, monitoring for incidents of abuse or neglect, and monitoring health and safety.

The DD Act requires 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 neither the DD Act, nor this rule, makes a distinction on the basis of age with regard to access of an individual with a developmental disability by the P&A.

### **Specific Changes/Additions to Subpart C**

#### *Section 1386.25 Access to Records*

Regarding § 1386.25(a)(1), commenters recommended replacing the term “client” with “individual with a developmental disability.” AIDD considered that comment and rejected it. The term “client” connotes a specific relationship, which implies certain duties between the client and the P&A system. Though P&A access authority is not limited to clients, the term “client,” is not interchangeable with “individual with a developmental disability.” The term client is also used in the Act in section 143(a)(2)(I)(i).

Regarding § 1386.25(a)(2)(iii), commenters recommended removing “about his or her status or treatment,” as the term “complaint” is adequately defined in § 1386.19. For clarity, the phrase has been removed. Commenters also recommended removal of “by any other individual or has subjected him or herself to self-abuse,” to modify “neglect.” This language was removed, as it is now included in the definition of neglect in § 1386.19.

In § 1386.25(a)(3), AIDD removed “by any other individual or has subjected him or herself to self-abuse,” as this language has been added to the definition of neglect in § 1386.19.

Regarding § 1386.25(a)(3)(i), we added a requirement for disclosure of the name and address of a representative be given to the P&A promptly. In response to comments and to improve clarity, AIDD has added “telephone number(s)” of the legal guardian, conservator, or other legal representative, to be consistent with proposed § 1386.26, and “within the timelines set forth in § 1386.25(c),” to be consistent with the express time periods established in that section.

Regarding § 1386.25(a)(3)(iii), commenters suggested replacing “act” with “provide consent” and AIDD made this change to clarify the intent of the provision, in accordance with judicial interpretation and the intent of the law. AIDD finds the DD Act encourages the broad applicability of access authority to records when there is a complaint or probable cause of abuse and neglect. For example, a P&A may need to access records in a situation where the guardian is allegedly abusing or neglecting his/her ward. A majority of courts have recognized that P&As should be permitted to access records in

these situations when a guardian has refused to consent to their release.<sup>3</sup> AIDD had included this change in language to reflect an interpretation weighted toward the protection of individuals with developmental disabilities.

For the final rule, AIDD also added § 1386.25(a)(4) and (5) to include language from commenters, regarding P&A access authority to records without consent in cases where an individual with developmental disabilities has died, or if the P&A has probable cause to believe that the health or safety of an individual with developmental disabilities is in serious and immediate jeopardy, consistent with the DD Act, 42 U.S.C. 15043(a)(2)(J)(ii)(I) and (II).

Regarding § 1386.25(b)(1), commenters suggested adding language to include records that were not prepared by the service provider, but received by the service provider from other service providers. AIDD amended the section accordingly, per the authority of the DD Act, that a P&A be able to access “all records” of an individual with a developmental disability, 42 U.S.C. 15043(a)(2)(I), to the extent allowed by law. Such records may include information that is relevant to the P&A’s work, and shall be accessible to P&A’s.

A commenter recommended deleting § 1386.25(b)(1), describing this section as providing “inappropriate access to records” because it would give P&As too broad of access to records and be duplicative of existing requirements for providers with oversight by the Centers for Medicare and Medicaid Services. Congress intended to ensure access to records consistent with the P&A’s authority to investigate abuse or neglect and ensure the protection of rights. AIDD did not accept the suggested change.

Regarding § 1386.25(b)(2), commenters suggested removing: “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.” AIDD eliminated the sentence, as “human services system” is undefined,

<sup>3</sup> See, e.g., *Pennsylvania Protection & Advocacy, Inc. v. Royer-Greaves Sch. for the Blind*, 1999 WL 179797, \*8 (E.D. Pa., March 25, 1999) (permitting P&A to access records even when guardian expressly refused to consent to release of records); *Disability Law Center v. Reil*, 130 F. Supp. 2d 294 (D. Ma. 2001) (court ordered service provider to release records notwithstanding the guardian’s good faith refusal to do so). But see, *Disability Law Center v. Millcreek Health Center*, 339 F.Supp.2d 1280 (D. Utah 2004), vacated, 428 F.3d 992 (10th Cir. 2005) (court denied P&A’s access to records because an actively involved guardian refused to give consent).

potentially unclear, and this phrase may serve to unduly limit the types of reports P&As can receive.

Commenters also recommended numerous additions to this section regarding the organizations whose reports are subject to this requirement. AIDD included various additional examples that may be helpful for clarifying the types of facilities and organizations providing services, supports and other assistance to individuals with developmental disabilities from which P&As have access to records. These additions are clarifying examples and are not intended to limit the types of organizations whose reports are subject to this requirement.

With respect to the reports subject to this requirement, commenters recommended adding “or by medical care evaluation or peer review committees, regardless of whether they are protected by federal or state law” to § 1386.25(b)(2). AIDD has adopted the recommended change because this addition facilitates the P&As fulfilling their responsibilities under the DD Act, maximizes the most efficient use of resources, and is consistent with court decisions allowing P&As access to all records of an individual.<sup>4</sup> Peer review records shall be handled in accordance with the confidentiality requirements as described in § 1386.28 of this rule.

Regarding § 1386.25(b)(4), commenters recommended adding “information in professional, performance building, or other safety standards, demographic and statistical information relating to a service provider.” AIDD restored the language that the NPRM deleted, as found in § 1386.22(c)(2) of the 1997 regulations. This is consistent with the DD Act provision, 42 U.S.C. 15043(a)(2)(I), that a P&A be able to access “all records” of an individual with a developmental disability, 42 U.S.C 15043(a)(2)(J), and we have substituted “service provider” for “facility,” as discussed previously.

<sup>4</sup> See, e.g., *Pennsylvania Protection and Advocacy, Inc. v. Houstoun*, 228 F.3d 423, 428 (3rd Cir. 2000); *Center for Legal Advocacy v. Hammons*, 323 F.3d 1262, 1270 (10th Cir. 2003); *Protection & Advocacy for Persons with Disabilities v. Mental Health & Addiction Services*, 448 F.3d 119 (2d Cir. 2006); *Missouri Prot. & Advocacy Servs. v. Missouri Dep’t of Mental Health*, 447 F.3d 1021, 1023–1024 (8th Cir. 2006); *Protection & Advocacy for Persons with Disabilities, Conn. v. Mental Health & Addiction Servs.*, 448 F.3d 119, 128 (2d Cir. 2006); *Indiana Prot. & Advocacy Servs. v. Indiana Family & Social Servs. Admin.*, 603 F.3d 365, 382–383 (7th Cir. 2010) (en banc), petition for cert. pending, No. 10–131 (filed July 21, 2010); *Disability Law Center of Alaska v. North Star Behavioral Health*, 3:07-cv-00062 JWS, 2008 WL 853639 (D. Alaska, March 27, 2008).

Commenters suggested reformulation of the NPRM § 1386.25(c) regarding time periods. AIDD added additional § 1386.25(a)(4) and (5), regarding access to records without consent when a P&A determines there is probable cause to believe the health and safety of an individual is in serious or immediate jeopardy, and in the case of death of an individual with a developmental disability. With the additions of § 1386.25(a)(4) and (5), AIDD has removed the NPRM language defining access to records in the case of death. AIDD has retained § 1386.25(c)(1) from the NPRM, to address circumstances where access to records must be provided within 24 hours of receipt of a written request from P&As. AIDD has also retained § 1386.25(c)(2), specifying access within three business days from receipt of written request in all other cases. AIDD considered recommended revisions, and determined that the current formulation best captures the specifics of section 143(a)(2)(J)(i) and (ii) of the DD Act.

Section 1386.25(d) addresses the remaining provisions regarding sharing and copying of records, consistent with the corresponding PAIMI regulation, (42 CFR 51.41) which states that the P&A system may not be charged for copies more than is “reasonable” according to prevailing local rates, 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. Regarding § 1386.25(d), commenters recommended adding a specific monetary cap to the amount charged by a service provider or its agents to copy records for the P&A system. AIDD added a provision linking the amount charged in these circumstances to the amount customarily charged other non-profit or State government agencies for reproducing documents, to avoid prohibitive charges as a barrier to accessing appropriate records. AIDD recognizes that many records are now being transitioned and maintained electronically. To that end, when records are kept or maintained electronically they shall be provided electronically to the P&A.

Regarding § 1386.25(e), commenters recommended adding a provision making explicit that the Health Insurance Portability and Accountability Act (HIPAA) permits the disclosure of protected health information (PHI) without the authorization of the individual to a P&A system to the extent that such disclosure is required by law and the disclosure complies with the requirements of that law. This provision accords with the



HIPAA Privacy Rule,<sup>5</sup> and AIDD has included it in this rule. Readers may refer to sections 143(a)(2), (A)(i), (B), (I) and (J) of the DD Act for provisions governing disclosure required by law. We consider a disclosure to be required by law under the DD Act where the access is required under 45 CFR 1386.25 and the disclosure is in accordance with such regulation.

Regarding § 1386.25(f), commenters recommended the addition of a provision specifying the authority of P&As to access records of schools, educational agencies, etc. An amicus brief submitted by the Department of Justice (DOJ), on behalf of the Department of Education and the Department of Health and Human Services, took the position that a school must provide a P&A with the name and contact information for the parent or guardian of a student for whom the P&A has the requisite degree of probable cause to obtain records under the DD Act (*State of Connecticut Office of Protection and Advocacy for Persons with Disabilities v. Hartford Bd. of Ed.*, 464 F.3d 229 (2nd Cir. 2006)). DOJ also asserted that a P&A may interview a minor student suspected of being subject to abuse or neglect without prior consent from a parent or guardian. In addition, “[i]f the P&A has probable cause ‘to believe that the health and safety of the individual is in serious and immediate jeopardy,’ it shall have access to records immediately without notice to or consent from a parent or guardian.” The Second Circuit adopted DOJ’s position on both of these issues.

DOJ also asserted the government’s position that the Court should “construe the DD Act [and PAIMI Act] as an override of the Family Educational Rights and Privacy Act (FERPA) non-disclosure requirements, in the narrow context where those statutes require that a P&A have authority to obtain student records held by an institution servicing disabled and/or mentally ill students.” However, after the government submitted its brief, Appellants abandoned their FERPA arguments. Consequently, the Court did not issue an opinion with respect to the interplay of FERPA and the PAIMI and DD Acts.

Additionally, in 2009 the Ninth Circuit Court ruled in *Disability Law Center of Alaska, Inc. v. Anchorage School District* that P&As have an

override of FERPA to have access to contact information for parents, guardians, or representatives of student. 581 F. 3d 936 (9th Cir. 2009).

It remains AIDD’s position that the role of P&As as established in the DD Act provides for an override of FERPA to permit a P&A to access names and contact information for the parents or guardians of students with developmental disabilities, where the P&A’s determination of probable cause satisfies the substantive standards for record access.

#### *Section 1386.26 Denial or Delay of Access to Records*

P&As must be able to obtain the identities of individuals with developmental disabilities from service providers (who have control of this information). In emergency situations or in the case of the death of an individual with developmental disabilities receiving services, section 143(a)(2)(J)(ii) of the DD Act requires that P&As have access to records of individuals with developmental disabilities receiving services within 24 hours after written request is made and without consent. AIDD believes that establishing a deadline for providing the written justification denying access is necessary in recognition of the consequences of not accessing relevant information quickly. This is particularly necessary 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.

Some commenters expressed the need for a specific penalty in cases of denial or delay if a service provider fails to provide a written statement giving reason for denial of access to records. AIDD considered the comment, but is not attempting to impose penalties via these regulations, as AIDD does not have the authority to do so.

Commenters also recommended the inclusion of [individuals with] “intellectual disabilities.” That term is not included in the DD Act nor defined with respect to the scope of individuals included in that category for the purposes of these regulations; we have not included it in this section.

AIDD modified the section to clarify that § 1386.26 is applicable specifically to access to records, to effectuate the purposes of Sec. 143(a)(2)(J)(ii) of the DD Act and to address comments submitted regarding possible confusion of timing implications of these denial or delay of access provisions, and the provisions for access in § 1386.27.

#### *Section 1386.27 Access to Service Providers and Individuals With Developmental Disabilities*

AIDD again notes the change from the term “service recipients” to “individuals with developmental disabilities” in the heading and throughout the section, with the same justification as in § 1386.22. Under this section, the term “service provider” is substituted throughout for the term “facility.” The term “programs” is undefined in the regulations, and the final language more precisely expresses the parties and items with respect to whom the P&As seek access, with more active language than “recipients.”

Section 143(a)(2)(H) of the DD Act (42 U.S.C. 15043) requires that P&As “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 an individual.” P&A systems must not be required to provide advance notice to a service provider when investigating 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. To serve the monitoring function described in section 143(a)(2)(I) of the Act, P&As must also have the ability to make unannounced visits to check for compliance regarding the health and safety of individuals with developmental disabilities. Immediate access may also be necessary, for example, to prevent interested parties from concealing situations involving abuse or neglect or taking actions that may compromise evidence related to such incidents (such as intimidating staff or individuals with developmental disabilities who are receiving services). Thus, AIDD added the following provision, in keeping with the recommendation from commenters: “Service providers shall provide such access without advance notice from the P&A.”

Some commenters recommended creating separate sections for access to “locations” and access to “individuals with developmental disabilities and other individuals.” To minimize confusion, AIDD maintained the original structure from the proposed regulations, with modifications and reordering where needed for clarity.

Regarding § 1386.27(c) in the NPRM, commenters suggested adding the following language to the section on consent to attend treatment planning meetings, “except that no consent is required if (1) the individual, due to his or her mental or physical condition, is

<sup>5</sup> See Dep’t of Health and Human Services, Health Information Privacy, Frequently Asked Questions, at [http://www.hhs.gov/ocr/privacy/hipaa/faq/disclosures\\_required\\_by\\_law/909.html](http://www.hhs.gov/ocr/privacy/hipaa/faq/disclosures_required_by_law/909.html) (last visited March 1, 2012) (“May a covered entity disclose protected health information to a Protection and Advocacy system where the disclosure is required by law? Answer: Yes.”).

unable to authorize the system to have access to a treatment planning meeting, and (2) 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).” The proposed language addresses potential conflicts of interest regarding consent to P&A access to attend a treatment planning meeting. AIDD adopted this change and included parallel language to the similar provisions regarding state guardians in records access provisions § 1386.25(a)(2)(i).

AIDD received a comment asking that a physician note be required if the service provider denies the P&A access to an individual. We concurred with the comment and added language setting forth the specific process to be followed in situations where access is denied based on the justification that it would interfere with an individual's treatment, this was done to minimize confusion and to underscore section 143(a)(2)(H) of the Act. Section 143(a)(2)(H) gives P&As access at reasonable times to any individual with a developmental disability in a location in which services, supports and other assistances are provided in order to carry out the purposes of P&As under the DD Act. AIDD included 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 individuals with developmental disabilities receiving services.

AIDD also explained in the proposed rule that the regulations are 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). To assure consistency with the PAIMI program, P&As are authorized to attend treatment team meetings, which serve some of the same purposes as discharge planning sessions. The DD Act supports broad access to individuals to monitor conditions relating to safety and health.

With respect to § 1386.27(c)(3) in the NPRM, commenters suggested a number of modifications. In response to such comments, AIDD has specified that access is “including but not limited to” inspecting, viewing, and photographing all areas of a service provider's premises. We have also added the phrase “or under the service provider's supervision or control,” to more clearly specify the areas covered under this

section. Commenters suggested including “video recording” to the list of access activities: inspecting, viewing, and photographing. AIDD adopted this change as a helpful clarification. AIDD also included the following carve out, to safeguard the privacy and preferences of individuals with developmental disabilities, in keeping with the values of choice and self-determination in the DD Act: “but shall not include photographing or video recording individuals with developmental disabilities unless they consent or state laws allow such activities.”

Commenters suggested replacing the NPRM language, “at reasonable times” in the introductory portion of § 1386.27(c) with “at all times.” AIDD did not make the change, as the DD Act provision regarding access to an individual with a developmental disability states a P&A shall have access at “reasonable times” 42 U.S.C. 15043(a)(2)(H).

With respect to § 1386.27(d) in the NPRM, commenters recommended adding provisions on the specifics of the ability of P&As to access individuals with developmental disabilities. AIDD added language with specifics on the P&A's access authority for these individuals. This includes protection of P&As against compulsion to disclose the identity of such individuals to the service provider, except as required by law. The P&As were established under the DD Act to protect and advocate for the legal and human rights of people with developmental disabilities. That purpose would be defeated if individuals with developmental disabilities or their guardians, conservators, or other legal representatives become subject to retribution for reaching out to a P&A seeking information about a P&A and their services, or to report a suspected incident of abuse or neglect.

A few commenters recommended that § 1386.27 should clarify that P&A access to service providers and “recipients” must be based on substantial allegations of wrongdoing and should only involve individuals with developmental disabilities that are the subject of wrongdoing. AIDD carefully considered these comments and determined that the DD Act expresses a broader intent, that includes, e.g., the authority to “have access . . . to any individual with a developmental disability in a location in which services, supports, and other assistance are provided to such an individual,” section 143(a)(2)(H). This includes a P&A role of monitoring, as well as, “providing information . . . and referral,” as stated in section 143(a)(2)(A)(ii) which allows

for access in circumstances beyond where there is a pre-existing substantial allegation of wrongdoing.

Commenters suggested adding a section on access to Individuals with Developmental Disabilities and Locations for the purpose of providing information, training, and referral for programs. The recommended language includes the following: “P&As shall have access to individuals with disabilities and the locations in which they are receiving services, supports and other assistance for the purpose of 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. Service providers shall post, in an area which is used by individuals with developmental disabilities, a poster which states the protection and advocacy services available from the P&A system, including the name, address, and telephone number of the P&A system.” AIDD agrees that for P&As to accomplish the goal of protecting the legal and human rights of individuals with developmental disabilities, the people who need these services should be aware that such services are available, as well as how to access this resource. AIDD has included a clarification that P&As may have access for purposes of providing such information at § 1327(c)(2)(i).

Finally, § 1386.27 has been reorganized and renumbered to clarify the access requirements and authorities when P&As investigate incidents of abuse and neglect of individuals with developmental disabilities, as well as in implementing their additional responsibilities under the DD Act. This addresses conflicting comments suggesting that the access authority as identified in this section is both overbroad and too limited. AIDD carefully considered the input, and revised the section to reflect the agency's understanding of P&A access authority to protect the legal and human rights of individuals with developmental disabilities under the DD Act.

#### *Section 1386.28 Confidentiality of Protection and Advocacy System Records*

Similar to the approach used in the PAIMI regulation at 42 CFR 51.45, AIDD, in the NPRM, incorporated a new section at § 1386.28, Confidentiality of

Protection and Advocacy Systems Records. This section will replace the current AIDD regulation in 45 CFR 1386.22(e), Access to Records, Facilities and Individuals that deals with P&A access authority.

Some commenters recommended an essential rewriting of § 1386.28, stating that some provisions of these regulations could be interpreted to “thwart the fundamental P&A mandate of protecting individuals with [developmental] disabilities from abuse or neglect while maintaining appropriate confidentiality.” However, the commenters were not specific with problems that an essential rewrite would resolve. AIDD did not accept wholesale language commenters proposed; however AIDD did make the following changes below.

Commenters recommended new language with respect to confidentiality provisions. AIDD included the following § 1386.28(a), as it explicitly articulates existing applicable duties: “A P&A shall, at minimum, comply with the confidentiality provisions of all applicable Federal and State laws.”

Commenters also requested additions clarifying circumstances where information can be disclosed, citing shortcomings in the NPRM, but without offering specific examples of the problems raised by the proposed language. AIDD has maintained the language from the NPRM (renumbered where necessary), for the sake of consistency with the PAIMI confidentiality provisions, at 42 CFR 51.45, to ensure strong confidentiality protections and certainty of integrity are maintained.

In addition, one commenter suggested that the regulations must make clear that the DD Act funding shall not be used to advocate against and in any way undermine, downsize or close a Medicaid certified and licensed facility [ICF/IDD]. The purpose of the Act clearly articulated, in 42 U.S.C. 15001(b), “to assure that individuals with developmental disabilities and their families participate in the design of and have access to needed community services, 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 authorized under this title . . .” applies broadly. The law makes no provision to carve out a category of care facilities to which the provisions of the Act do not apply, and AIDD does not do so here.

A commenter also stated that “the regulations must clearly state that a P&A

is not permitted to access private homes, unless accompanied by the existing state authorities which evaluate accusations of abuse and neglect of children and vulnerable adults.” AIDD considered this comment, but notes that other government oversight entities may not be able to investigate instances of abuse/neglect in a timely fashion as a result of limited resources. For example, Congress created the P&A system, to, among other responsibilities, investigate abuse and neglect and to take appropriate steps to protect and advocate for individuals with developmental disabilities, 42 U.S.C. 15043(a)(2)(A), (B) and (G). Congress has also explicitly recognized that P&As may learn of abuse and neglect by monitoring service providers, 42 U.S.C. 15043(a)(2)(L)(ii)(III). Again, the DD Act does not carve out exceptions for a category of care facilities or service providers, even in cases where services may be provided in a private home. P&As must not be constrained in carrying out their statutory mandate to protect individuals with developmental disabilities from abuse or neglect, and must not have their investigation and monitoring efforts hampered based on the responsiveness and timeliness of other government agencies or authorities.

With respect to § 1386.28(b)(2), AIDD added the term “disposal” to the list of required written policies regarding information from client records to help ensure the protection of confidentiality and help ensure the prevention of inappropriate or unintentional disclosure of such information. The addition of “disposal” conforms to prudent modern data management practices.

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

The final rule 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.

#### *Section 1386.30 State Plan Requirements*

The NPRM placed a five year time limit on demonstration projects to coincide with the State Plan submission and approval process, as well as to ensure consistency with the Act (42 U.S.C. 125(c)(5)(K)(i) and (ii)). A number of commenters relayed concerns that a five year time limit on demonstration projects would have unintended consequences. For example, Web sites, employment activities, self-

advocacy activities and programs such as Partners in Policymaking could be impacted. Therefore, AIDD has modified paragraphs (e) and (f) so that States desiring to receive assistance beyond five years, under this subtitle, shall include, in the State plan, the estimated period for the project’s continued duration, justification of why the project cannot be funded by the State, other public or private sources of funding, justification as to why a project receive continued funding, and intention to provide data outcomes showing evidence of success. Councils must also develop and include strategies to locate on-going funding from other sources after five years. AIDD clarified in paragraphs (e) that it reserves the right as the overseeing agency to deny the continuation of demonstration projects past five years.

Although no adverse comments were received on paragraph (f), AIDD has amended this section to make it consistent with section 124(a)(5) of the Act (42 U.S.C. 15024).

#### *Section 1386.31 State Plan Submittal and Approval*

Although we received no adverse comments on paragraph (a), we are making technical changes to the proposed regulation to provide examples of formats accessible to individuals with developmental disabilities and the general public to reflect current technology.

AIDD chose not to finalize the requirement in § 1386.31(b) that, “the State plan or amendment must be approved by the entity or individual authorized to do so under State law.” We did not finalize this because it is not a requirement under the Act and could potentially create conflict with the law in section 124(c)(5)(L) that requires a State not interfere with the State plan development or implementation.

#### *Section 1386.33 Protection of Employee Interests*

Commenters requested clarification that the State would be responsible for the protection of employees who are displaced by institutional closures rather than the operator of the institution. AIDD has not made any changes to this section as the NPRM clearly states that specific arrangements for the protection of affected employees must be developed through negotiations between the State authorities and employees or their representatives.

### *Section 1386.34 Designated State Agency*

No comments were received however technical changes we made to reflect the move of AIDD to ACL.

### *Section 1386.35 Allowable and Non-Allowable Costs for Federal Assistance to State Councils on Developmental Disabilities*

Some respondents requested that § 1386.35 be revised to allow for State Councils on Developmental Disabilities' rapid response to the emergency needs of impacted citizens such as those affected by a national disaster or time of war. While we appreciate the comments received, AIDD does not find it necessary to make changes to this section. Under the existing law, the State Councils on Developmental Disabilities can use their funding to work with emergency responders to assist them with planning for the support needs of individuals with developmental disabilities in the event of a national disaster or time of war.

### *Section 1386.36 Final Disapproval of the State Plan or Plan Amendments*

No comments were received however AIDD has made technical changes to reflect the move of AIDD to ACL.

### *Sections 1386.80 through 1386.112 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*

No comments were received; however, AIDD has made technical changes to reflect the move of AIDD to ACL and related delegations.

## **Part 1387—Projects of National Significance**

### *Section 1387.1 General Requirements*

No comments were received on this section of the NPRM. However, AIDD made an administrative change and removed § 1387.1(b) as PNS program announcements are not required by the Act to be published in the **Federal Register**.

## **Part 1388—National Network of University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDDS)**

Significant changes were made to part 1388 from the NPRM based on comments received. Section 153(a)(1) of the Act directed the Secretary to define the term "UCEDD". The NPRM removed language from previous regulations that defined the term University Affiliated

Program, which was the previous name of the program.

Many of the comments asked AIDD to define what a UCEDD is. The previous term "University Affiliated Program" was defined in previous regulations, but the new term "UCEDD" was not defined in the 2008 NPRM. We reviewed the comments and concurred that a clear definition for the UCEDD is necessary. To that end, part 1388 has been reorganized, and language for Governance and Administration has been restored from the previously published regulations.

### *Section 1388.1 Definitions*

As a technical correction AIDD added the definition of "State" to part 1388 so that it matches the statute. Under Subtitle D, section 155, the statutory definition of "State" that applies to UCEDDs differs from the definition of "State" in the rest of the Act.

### *Section 1388.2 Purpose*

In paragraph (a)(2), the wording "(as defined by the Secretary)" was removed because AIDD has defined a UCEDD, in § 1388.6, in response to comments received.

### *Section 1388.3 Core Functions*

This section was renumbered from § 1388.2 to § 1388.3. No other changes were made.

### *Section 1388.4 National Training Initiatives on Critical and Emerging Needs*

This section was renumbered from § 1388.3 to § 1388.4. No other changes were made.

### *Section 1388.5 Applications*

This section was renumbered from § 1388.4 to § 1388.5. Additional technical changes were made.

### *Section 1388.6 Governance and Administration*

In the NPRM, this language had been deleted. Many commenters disagreed with the deletion, expressing concern that the elimination of this language would undermine the effectiveness of the UCEDD programs and allow for diversion of funds for inappropriate purposes.

AIDD concurred with the commenters and has restored the original regulatory language prescribing the governance and administration of UCEDDs.

### *Section 1388.7 Five-Year Plan and Annual Report*

This section was renumbered from § 1388.5 to § 1388.7.

Amended regulations: 45 CFR parts 1385, 1386, 1387, and 1388.

In 2008, a Notice of Proposed Rulemaking was promulgated by the Administration on Intellectual and Developmental Disabilities. This final rule presents 45 CFR parts 1385, 1386, 1387, and 1388 as amended in their entirety.

## **IV. Impact Analysis**

### *A. 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 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 rule implements the Developmental Disabilities Act of 2000. In developing the final rule, we considered input we received from the public including stakeholders.

### *B. 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 (SCDDs), State Protection and Advocacy Systems (P&As), and University Centers of Excellence in Developmental Disabilities (UCEDDs). This final rule will support the work of the P&As in investigating potential abuse and neglect by providing guidance regarding access to service providers and records of individuals. 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 and operation standards of the programs. The regulation does not have a significant economic impact on these entities. AIDD estimates an impact of less than \$100,000 across the DD entities.

### *C. Paperwork Reduction Act of 1995*

Sections 1386.22, 1386.32, and 1388.5 contain information collection requirements. In part 1386 of the NPRM, the State Council on Developmental Disabilities Program Performance Report and the Protection and Advocacy Statement of Goals and Priorities required renewal from OMB.

## REPORTING AND RECORDKEEPING REQUIREMENTS IN PART 1386 AND 1388 OF THE FINAL RULE

	Expires	Annual # of respondents	Ave. burden response	Annual burden hours
1386.23(a) SF-PPR 0980-0027 .....	08/31/2017	57	44 hours .....	2,508
1386.23(c) P&A SGP Reinstatement 0980-0270 .....	11/30/2015	57	44 hours .....	2,508
1386.30(c) Council State Plan 0980-0029 .....	11/30/2017	56	367 hours .....	20,552
1386.32(b) Council PPR Reinstatement 0980-0172 .....	08/31/2015	56	138 hours .....	7,728
1386.32(a) Council Financial Status Report (AIDD-02B).				
AIDD-02 Council 0985-0026 .....	11/30/2015	56	8 hours .....	842
1388.5(b) UCEDD Annual Report 0970-0289 .....	09/30/2016	67	1,412 hours .....	94,604

*D. 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, or 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 is 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 rule.

AIDD has 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.

*E. Congressional Review*

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

*F. 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.

*G. 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.

AIDD 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.

This rule does contain regulatory policies with federalism implications that require specific consultation with State or local elected officials. However, prior to the development of the rule, the Administration on Intellectual and Developmental Disabilities consulted with SCDDs, 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 program—social programs, Reporting and recordkeeping requirements

*45 CFR Part 1386*

Administrative practice and procedures, Grant programs—education, Grant programs—social programs, Individuals with disabilities, Reporting and recordkeeping requirements.

*45 CFR Part 1387*

Administration practice and procedures, Grant programs—education, Grant programs—social programs, Individuals with disabilities.

*45 CFR Part 1388*

Colleges and universities, Grant programs—education, Grant programs—social programs, Individuals with disabilities, Research.

Dated: July 16, 2015.

**Kathy Greenlee,**

*Administrator, Administration for Community Living, Assistant Secretary for Aging, Administration on Aging.*

Approved: July 17, 2015.

**Sylvia M. Burwell,**  
*Secretary.*

**Regulation Text**

For reasons set forth in the preamble, under the authority of 42 U.S.C. 15001 *et seq.*, the Department of Health and Human Services revises subchapter I, chapter XIII, of title 45 of the Code of Federal Regulations to read as set forth below:

**CHAPTER XIII—OFFICE OF HUMAN DEVELOPMENT SERVICES, DEPARTMENT OF HEALTH AND HUMAN SERVICES****Subchapter I—The Administration on Intellectual and Developmental Disabilities, Developmental Disabilities Program****PART 1385—REQUIREMENTS APPLICABLE TO THE DEVELOPMENTAL DISABILITIES PROGRAM****1386—FORMULA GRANT PROGRAMS**  
**1387—PROJECTS OF NATIONAL SIGNIFICANCE****1388—THE NATIONAL NETWORK OF UNIVERSITY CENTERS FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES, EDUCATION, RESEARCH, AND SERVICE****Subchapter I—The Administration on Intellectual and Developmental Disabilities, Developmental Disabilities Program****PART 1385—REQUIREMENTS APPLICABLE TO THE DEVELOPMENTAL DISABILITIES PROGRAM**

Sec.

1385.1 General.

1385.2 Purpose of the regulations.

1385.3 Definitions.

1385.4 Rights of individuals with developmental disabilities.

1385.5 [Reserved]

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, 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 for Individuals with Developmental Disabilities;
- (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.**

For the purposes of parts 1385 through 1388 of this chapter, the following definitions apply:

**ACL.** The term “ACL” means the Administration for Community Living within the U.S. Department of Health and Human Services.

**Act.** The term “Act” means the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD 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 section 504 of the Rehabilitation Act of 1973 (Pub. L. 93–112), its implementing regulation, 45 CFR part 84, the Americans with Disabilities Act of 1990, as amended, Title VI of the Civil Rights Act of 1964 (Pub. L. 88–352), and its implementing regulation, 45 CFR part 80.

(1) For programs funded under the DD Act of 2000, information shall be provided to applicants and program participants in plain language and in a manner that is accessible and timely to:

- (i) Individuals with disabilities, including accessible Web sites and the provision of auxiliary aids and services at no cost to the individual; and
- (ii) Individuals who are limited English proficient through the provision of language services at no cost to the individual, including:
  - (A) Oral interpretation;
  - (B) Written translations; and
  - (C) Taglines in non-English languages indicating the availability of language services.

**AIDD.** The term “AIDD” means the Administration on Intellectual and

Developmental Disabilities, within the Administration for Community Living at the U.S. Department of Health and Human Services.

**Advocacy activities.** The term “advocacy activities” means active support of policies and practices that promote systems change efforts and other activities that further advance self-determination and inclusion in all aspects of community living (including housing, education, employment, and other aspects) 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 increase, maintain, or improve 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 customary 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, 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 activities (*e.g.* training and technical assistance) that expand and/or improve the ability of individuals with developmental disabilities, families, supports, services and/or systems to promote, support and enhance self-determination, independence, productivity and inclusion in community life.

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

**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.

**Culturally competent.** The term “culturally competent,” used with respect to services, supports, and other assistance 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” 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

(viii) 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 paragraphs (1) through (5) of this definition, 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", used with respect to individuals with developmental disabilities, 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 and families of their own choice; live in homes close to community resources, with regular contact with individuals without disabilities in their communities; enjoy full access to 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 resources as individuals without disabilities, living, learning, working, and enjoying life in regular contact with individuals without disabilities.

*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.

*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 (P&A) Agency.* The term “Protection and Advocacy (P&A) Agency” means a protection and advocacy system established in accordance with section 143 of 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.

*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 term includes 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 chapter for the State Council on Developmental Disabilities, the Annual Statement of Goals and Priorities required by § 1386.22(c) of this chapter for P&As, and the five-year

plan and annual report required by § 1388.7 of this chapter for UCEDDs.

*Secretary.* The term “Secretary” means the Secretary of the U.S. Department 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”:

(1) Except as applied to the University Centers of Excellence in Developmental Disabilities Education, Research and Service in section 155 of the Act, includes 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.

(2) For the purpose of UCEDDs in section 155 of the Act and part 1388 of this chapter, “State” means each of the several States of the United States, the District of Columbia, the Commonwealth of Puerto Rico, the United States Virgin Islands, and Guam.

*State Council on Developmental Disabilities (SCDD).* The term “State Council on Developmental Disabilities (SCDD)” 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, in the case of individuals with developmental disabilities for whom competitive employment has not traditionally occurred; or 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.

*UCEDD.* 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.

*Unerved and underserved.* The term “unerved 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 SCDD.

(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 SCDD program must meet the requirements of 45 CFR 1386.30(f).

(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 [Reserved]**

#### **§ 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: 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 to 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 Secretary, or his or her designee, will allocate funds appropriated under the Act for the State Councils on Developmental Disabilities and the P&As as directed in sections 122 and 142 of the Act (42 U.S.C. 15022 and 15042).

#### § 1385.9 Grants administration requirements.

(a) The following parts of this title and title 2 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):

(1) 45 CFR part 16—Procedures of the Departmental Grant Appeals Board.

(2) 45 CFR part 46—Protection of Human Subjects.

(3) 45 CFR part 75—Uniform Administrative Requirements, Cost Principles, and Audit Requirements for HHS Award.

(4) 2 CFR part 376—Nonprocurement Debarment and Suspension.

(5) 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.

(5) 45 CFR part 81—Practice and Procedure for Hearings under part 80 of this title.

(6) 45 CFR part 84—Nondiscrimination on the Basis of Handicap in Programs and Activities Receiving Federal Financial Assistance.

(7) 45 CFR part 86—Nondiscrimination on the Basis of Sex in Education Programs and Activities Receiving Federal Financial Assistance.

(8) 45 CFR part 91—Nondiscrimination on the Basis of Age in Programs or Activities Receiving Federal Financial Assistance from HHS.

(9) 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 Secretary, or his or her designee, with respect to specific expenditures incurred by the States or by contractors or sub grantees 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 for Individuals with Developmental Disabilities. 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 SCDDs, the P&As, the UCEDDs and the Projects of National Significance grantees and sub grantees, as provided for in 45 CFR part 75, 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.

### PART 1386—FORMULA GRANT PROGRAMS

#### Subpart A—Basic Requirements

Sec.

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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 as the State Protection and Advocacy (P&As) System.

**§ 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 (c), *litigation costs* means 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 (c) 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 Secretary, or his or her designee, 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 for Individuals With Developmental Disabilities (PADD)**

**§ 1386.19 Definitions.**

As used in this subpart and subpart C of this part, 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 a violation of an individual’s legal rights amounts to abuse, such as if an individual is subject to significant financial exploitation.

*American Indian Consortium.* The term “American Indian Consortium” means any confederation of 2 or more recognized American Indian Tribes, created through the official 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 P&A system, including media accounts, newspaper articles, electronic communications, telephone calls (including anonymous calls) from any source alleging abuse or neglect 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 P&A 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 a parent of a minor, unless the State has appointed another legal guardian under applicable State law, or 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, executors and administrators of estates, 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 services, supports, and other assistance 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 a developmental disability(ies) or which placed an individual with developmental disability(ies) 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 or failure to take appropriate steps to prevent self-abuse, harassment, or assault by a peer.

*Probable cause.* The term “probable cause” means a reasonable ground for belief that an individual with developmental disability(ies) 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.

*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 subpart C of this part.

**§ 1386.20 Agency designated as 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 must be in a format accessible to individuals with

disabilities (including plain language), and language assistance services will be provided to individuals with limited English proficiency, such as translated materials or interpretation, 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 disabilities, and language assistance services will be provided to individuals with limited English proficiency, such as translated materials or interpretation, upon request to individuals with developmental disabilities or their representatives. 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 Secretary, or his or her designee, the authority to hear appeals by the Secretary, or his or her designee, 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 Secretary, or his or her designee, 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 Secretary, or his or her designee. To do so, the agency that administers and operates the State Protection and Advocacy System must submit an appeal in writing to the Secretary, or his or her designee, 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 Secretary's, or his or her designated person'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 Secretary's, or his or her designee'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 Secretary, or his or her designee, (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 Secretary, or his or her designee, 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 (3) of this section, either party may request, and the Secretary, or his or her designee, may grant an opportunity for a meeting with the Secretary, or his or her designee, 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 Secretary, or his or her designee, 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 Secretary, or his or her designee, 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 Secretary, or his or her designee, 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 Secretary, or his or her designee, 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 Secretary, or his or her designee, 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 Secretary, or his or her designee, 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 must meet the requirements of section 143 and 144 of the Act (42 U.S.C. 15043 and 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 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 (c) 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 § 1386.23(c). 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 and Governing Board shall be comprised of a majority of individuals with disabilities who are eligible for services, have received or are receiving services, parents, family members, 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 AIDD 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 or his or her guardian.

(j) *Contracts for program operations.*

(1) An eligible P&A system may contract for the operation of part of its program with another public or private nonprofit organization with demonstrated experience working with individuals with developmental disabilities, provided that:

(i) The eligible P&A system institutes oversight and monitoring procedures which ensure that any and all subcontractors will be able to meet all applicable terms, conditions and obligations of the Federal grant, including but not limited to the ability to pursue all forms of litigation under the DD Act;

(ii) The P&A exercises appropriate oversight to ensure that the contracting organization meets all applicable responsibilities and standards which apply to P&As, including but not limited to, the confidentiality provisions in the DD Act and regulations, ethical responsibilities, program accountability and quality controls;

(2) Any eligible P&A system should work cooperatively with existing advocacy agencies and groups and, where appropriate, consider entering into contracts for protection and advocacy services with organizations already working on behalf of individuals with developmental disabilities.

#### **§ 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 AIDD, 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, or his or her designee, 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. Reports shall include a description of the system's goals and 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 AIDD.

(b) Financial status reports (standard form 425) 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 AIDD, 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 AIDD, an SGP must meet the requirements of section 143 of the Act.

(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. 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 45 CFR part 75 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.**

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 the ability of

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 Individuals With Developmental Disabilities**

**§ 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 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, 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.

(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 disability has been subject to abuse or neglect, 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 (within the timelines set forth in paragraph (c) of this section) of the contact information (which is required to include but not limited to name, address, telephone numbers, and email 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 provide consent on behalf of the individual.

(4) If the P&A determines there is probable cause to believe that the health or safety of an individual is in serious and immediate jeopardy, no consent from another party is needed.

(5) In the case of death, no consent from another party is needed. Probable cause to believe that the death of an individual with a developmental disability 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 the purposes of the P&A system obtaining access to the individual's records, be deemed an "individual with a developmental disability."

(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 that of the service provider, as well as records that were not prepared by the service provider, but received by the service provider from other service providers.

(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 organizations whose reports are subject to this requirement include, but are not limited to, agencies in the foster care systems, developmental disabilities systems, prison and jail systems, public and private educational systems, emergency shelters, criminal and civil law enforcement agencies such as police departments, agencies overseeing juvenile justice facilities, juvenile detention facilities, all pre- and post-

adjudication juvenile facilities, State and Federal licensing and certification agencies, and private accreditation organizations such as the Joint Commission on the Accreditation of Health Care Organizations or by medical care evaluation or peer review committees, regardless of whether they are protected by federal or state law. 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;
- (3) Discharge planning records; and
- (4) Information in professional, performance, building or other safety standards, and demographic and statistical information relating to a service provider.

(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.

(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 P&A shall be permitted to inspect and copy information and records, subject to a reasonable charge to offset duplicating costs. If the service provider or its agents copy the records

for the P&A system, it may not charge the P&A system an amount that would exceed the amount 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. In addition, where records are kept or maintained electronically they shall be provided to the P&A electronically.

(e) The Health Insurance Portability and Accountability Act Privacy Rule permits the disclosure of protected health information (PHI) without the authorization of the individual to a P&A system to the extent that such disclosure is required by law and the disclosure complies with the requirements of that law.

(f) Educational agencies, including public, private, and charter schools, as well as, public and private residential and non-residential schools, must provide a P&A with the name of and contact information for the parent or guardian of a student for whom the P&A has probable cause to obtain records under the DD Act.

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

If a P&A system's access is denied or delayed beyond the deadlines specified in § 1386.25, 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 individuals with developmental disabilities 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 individuals with developmental disabilities.**

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

(b) The P&A system shall have reasonable unaccompanied access to individuals with developmental disabilities at all times necessary to

conduct a full investigation of an incident of abuse or neglect.

(1) Such access shall be afforded upon request, by the P&A system when:

- (i) An incident is reported or a complaint is made to the P&A system;
- (ii) The P&A system determines that there is probable cause to believe that an incident has or may have occurred; or
- (iii) 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.

(2) 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 that are used by individuals with developmental disabilities or are accessible to them. Such access shall be provided without advance notice and made available immediately upon request. This authority shall include the opportunity to interview any individual with developmental disability, 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 individual with developmental disability or staff with whom it plans to meet; neither may the P&A be required to justify or explain its interaction with such persons.

(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 individuals with developmental disabilities and are accessible to individuals with developmental disabilities 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 individuals with developmental disabilities with the consent of the individual or his or her guardian, conservator or other legal representative, except that no consent is required if the individual, due to his or mental or physical condition, is unable to authorize the system to have access to a treatment planning meeting; and 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).

(1) 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. If the P&As 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. In cases where a service provider denies a P&A access to an individual with a developmental disability on the grounds that such access would interfere with the individual's treatment or therapy, the service provider shall, no later than 24 hours of the P&A's request, provide the P&A with a written statement from a physician stating that P&A access to the individual will interfere with the individual's treatment and therapy, and the time and circumstances under which the P&A can interview the individual. If the physician states that the individual cannot be interviewed in the next 24 hours, the P&A and the service provider shall engage in a good faith interactive process to determine when and under what circumstances the P&A can interview the individual. If the P&A and the service provider are unable to agree upon the time and circumstance, they shall select a mutually agreeable independent physician who will determine when and under what circumstances the individual may be interviewed. The expense of the independent physician's services shall be paid for by the service provider. Individuals with developmental disabilities subject to the requirements in this paragraph include adults and minors who have legal guardians or conservators.

(2) P&A activities shall be conducted so as to minimize interference with service provider programs, respect individuals with developmental disabilities' privacy interests, and honor a recipient's request to terminate an interview. This access is for the purpose of:

(i) Providing information, training, and referral for programs addressing the needs of individuals with developmental disabilities, 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. P&As shall be permitted to post, in an area which individuals with developmental disabilities receive services, a poster which states the protection and advocacy services available from the P&A system,

including the name, address and telephone number of the P&A system.

(ii) Monitoring compliance with respect to the rights and safety of individuals with developmental disabilities; and

(iii) Access including, but is not limited to inspecting, viewing, photographing, and video recording all areas of a service provider's premises or under the service provider's supervision or control which are used by individuals with developmental disabilities or are accessible to them. This authority does not include photographing or video recording individuals with developmental disabilities unless they consent or State laws allow such activities.

(d) Unaccompanied access to individuals with developmental disabilities including, but not limited to, the opportunity to meet and communicate privately with individuals regularly, both formally and informally, by telephone, mail and in person. This authority shall also include the opportunity to meet, communicate with, or interview any individual with a developmental disability, including a person thought to be the subject of abuse, who might be reasonably believed by the P&A system to have knowledge of an incident under investigation or non-compliance with respect to the rights and safety of individuals with developmental disabilities. Except as otherwise required by law the P&A shall not be required to provide the name or other identifying information regarding the individual with a disability with whom it plans to meet; neither may the P&A be required to justify or explain its interaction with such persons.

**§ 1386.28 Confidentiality of State Protection and Advocacy System records.**

(a) A P&A shall, at minimum, comply with the confidentiality provisions of all applicable Federal and State laws.

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

(v) Peer review records.

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

(3) Obtain written consent from the client, 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 those not otherwise authorized to receive it.

(c) 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.

(d) Notwithstanding the confidentiality requirements of this section, the P&A may make a report to investigative or enforcement agencies, as described in paragraph (b) of this section, which reveals the identity of an individual with developmental disability, 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 (in accessible formats and plain language requirements), 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, or his or her designee, 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 designated system by AIDD 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) of the Act. 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 the Council has established or is required to apply in 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 of the Act 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) of this section.

(e) 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, with a strategy to locate on-going funding from other sources after five years. Any State desiring to receive assistance beyond five years, under this subtitle, shall include in the State plan the information listed in paragraphs (e)(1) through (3) of this section, and AIDD reserves the right as the overseeing agency to deny the continuation of the demonstration project beyond five years.

(1) The estimated period for the project's continued duration;

(2) Justifications of why the project cannot be funded by the State or other sources and should receive continued funding; and

(3) Provide data outcomes showing evidence of success.

(f) 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. Demonstrations must be short-term, with a strategy to locate on-going funding from other sources after five years. Any State desiring to receive assistance beyond five years, under this subtitle, shall include in the State plan the information listed in paragraphs (f)(1) through (3) of this section, and AIDD reserves the right as the overseeing agency to deny the continuation of the demonstration project beyond five years.

(1) The estimated period for the project's continued duration;

(2) Justifications on why the project cannot be funded by the State or other resources and should receive continued funding; and

(3) Provide data showing evidence of success.

(g) The State plan must contain assurances that are consistent with section 124 of the Act (42 U.S.C. 15024).

##### **§ 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. public forums, Web sites, newspapers, and other current technologies) 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 AIDD 45 days prior to the fiscal year for which it is applicable.

(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 Secretary, or his or her designee, 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 (AIDD-02B) on the programs funded under this subpart semiannually.

(b) By January 1 of each year, the State Council on Developmental Disabilities shall submit to AIDD, an Annual Program Performance Report through the system established by AIDD. In order to be accepted by AIDD, 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, or his or her designee, to comply with section 105(1),

(2), and (3) of the Act (42 U.S.C. 15005), and any other information requested by AIDD. 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 individual 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 for Individuals with Intellectual Disabilities (ICF/IID) 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.

### **§ 1386.33 Protection of employees 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 Secretary, or his or her designee, 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 Secretary, or his or her designee, 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 Secretary, or his or her designee, 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 Secretary's, or his or her designated person's, notification provide written comments to the Secretary, or his or her designee, (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 Secretary, or his or her designee, may grant, an opportunity for an informal meeting with the Secretary, or his or her designee, 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 Secretary, or his or her designee, will promptly notify the parties of the date and place of the meeting.

(4) The Secretary, or his or her designee, 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 Secretary, or his or her designee, 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, or his or her designee, 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 AIDD 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 Secretary, or his or her designee, 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 subpart E of this part.

(c) The Secretary's, or his or her designee'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 Secretary, or his or her designee, within 21 days of the receipt of the decision. The request for a hearing must be sent by certified mail to the Secretary, or his or her designee. 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 States' Conformity and Compliance With Developmental Disabilities State Plans, Reports, and Federal Requirements**

**General**

**§ 1386.80 Definitions.**

For purposes of this subpart:

*Payment or allotment.* The term "payment" or "allotment" means an amount provided under part B or C of the Developmental Disabilities Assistance and Bill or 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 Secretary to conduct any hearing held under this subpart. The term includes the Secretary, or the Secretary's designee, if the Secretary or his or her designee presides over the hearing. For purposes of this subpart the Secretary's "designee" refers to a person, such as the Administrator of ACL, who has been delegated broad authority to carry out all or some of the authorizing statute. The term designee does not refer to a presiding officer designated only to conduct a particular hearing or hearings.

**§ 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 Secretary or the Secretary's designee 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 Secretary, or his or her designee, 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 Secretary, or his or her designee 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 Secretary or his or her designee 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 Secretary or his or her designee.

(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 Secretary, or his or her designee, 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 Secretary, or his or her designee, 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 Protection and Advocacy System, the Secretary, or his or her designee, must provide all parties other than the Department and the State (see § 1386.94(b)) 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 Secretary, or his or her designee, 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 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 Secretary, or his or her designee, 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). 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 Secretary, his or her designee, or another person specifically designated for a particular hearing or hearings.

(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) If the presiding officer is the Secretary, or his or her designee, make a final decision;

(11) If the presiding officer is a person other than the Secretary or his or her designee, the presiding officer shall certify the entire record, including recommended findings and proposed decision, to the Secretary or his or her designee; and

(12) 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 Secretary or his or her designee, 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 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 Unsponsored written material.

Letters expressing views or urging action and other unsponsored 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.

**Post-Hearing Procedures, Decisions**

**§ 1386.110 Post-hearing briefs.**

The presiding officer must fix the time for filing post-hearing 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 post-hearing briefs.

**§ 1386.111 Decisions following hearing.**

(a) If the Secretary, or his or her designee, is the presiding officer, he or she must issue a decision within 60 days after the time for submission of post-hearing briefs has expired.

(b)(1) If the presiding officer is another person designated for a particular hearing or hearings, he or she must, within 30 days after the time for submission of post-hearing briefs has expired, certify the entire record to the Secretary (or his or her designee) including the recommended findings and proposed decision.

(2) The Secretary, or his or her designee, must serve a copy of the recommended findings and proposed decision upon all parties and amici.

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

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

(c) If the Secretary, or his or her designee, 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 Secretary, or his or her designee, may ask the parties for recommendations or briefs or may hold conferences of the parties on these questions.

(d) The decision of the Secretary, or his or her designee, 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 Secretary's, or his or her designee's, decision must be promptly served on all parties and amici.

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

(a) If, in the case of a hearing pursuant to section 124 of the Act, the Secretary, or his or her designee, 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 Secretary, or his or her designee, 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 Secretary, or his or her designee,

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.

**PART 1387—PROJECTS OF NATIONAL SIGNIFICANCE**

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 161–163 (42 U.S.C. 15081–15083).

(b) In general, Projects of National Significance (PNS) 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).

(c) Projects of National Significance may engage in one or more of the types of activities provided in section 161(2) of the Act.

(d) 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.

(e) 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.

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

Sec.

1388.1 Definitions.

1388.2 Purpose.

1388.3 Core functions.

1388.4 National training initiatives on critical and emerging needs.

1388.5 Applications.

1388.6 Governance and administration.

1388.7 Five-year plan and annual report.

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

**§ 1388.1 Definitions.**

*States.* For the purpose of this part, "State" means each of the several States of the United States, the District of

Columbia, the Commonwealth of Puerto Rico, the United States Virgin Islands, and Guam.

**§ 1388.2 Purpose.**

(a) The Secretary, or his or her designee awards grants to eligible entities designated as University Centers for Excellence in Developmental Disabilities Education, Research, and Service (“UCEDDs”, or “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 or public not-for-profit entities associated with universities that engage in core functions, described in § 1388.3, addressing, directly or indirectly, one or more of the areas of emphasis, as defined in § 1385.3 of this chapter.

(b) To conduct National Training Initiatives on Critical and Emerging Needs as described in § 1388.4.

**§ 1388.3 Core functions.**

The Centers described in § 1388.2 must engage in the core functions referred to in this section, 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, policy-makers, students, and other members of the community; and

(2) That may provide services, supports, and assistance for the persons listed in paragraph (b)(1) of this section 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 of the Act is a national and international resource that includes specific substantive areas of expertise that may be accessed and applied in diverse settings and circumstances.

**§ 1388.4 National training initiatives on critical and emerging needs.**

(a) Supplemental grant funds for National Training Initiatives (NTIs) on critical and emerging needs may 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.

**§ 1388.5 Applications.**

(a) To be eligible to receive a grant under § 1388.2 for a Center, an entity shall submit to the Secretary, or his or her designee, an application at such time, in such manner, and containing such information, as the Secretary, or his or her designee, may require for approval.

(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 of this chapter for each of the core functions.

(2) Measures of progress.

(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;

(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 of the Act, that:

(i) Are developed in collaboration with the Consumer Advisory Committee established pursuant to paragraph (c)(5) of this section;

(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 Protection and Advocacy 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 § 1388.2(a)(1) and (2).

(4) Protect, consistent with the policy specified in section 101(c) of the DD Act of 2000 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 of the Act).

(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) 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

(i) Allocate adequate staff time to carry out activities related to each of the core functions described in § 1388.3.

(ii) [Reserved]

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

(1) 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.

(2) [Reserved]

(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 subtitle D of the Act may not be more than 75 percent of the necessary cost of such project, as determined by the Secretary, or his or her designee.

(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, or his or her designee, 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, or his or her designee.

#### § 1388.6 Governance and administration.

(a) The UCEDD must be associated with, or an integral part of, a university and promote the independence, productivity, integration, and inclusion of individuals with developmental disabilities and their families.

(b) The UCEDD must have a written agreement or charter with the university, or affiliated university that specifies the UCEDD designation as an official university component, the relationships between the UCEDD and other university components, the university commitment to the UCEDD, and the UCEDD commitment to the university.

(c) Within the university, the UCEDD must maintain the autonomy and organizational structure required to carry out the UCEDD mission and provide for the mandated activities.

(d) The UCEDD Director must report directly to, or be, a University Administrator who will represent the interests of the UCEDD within the University.

(e) The University must demonstrate its support for the UCEDD through the commitment of financial and other resources.

(f) UCEDD senior professional staff, including the UCEDD Director, Associate Director, Training Director, and Research Coordinator, must hold faculty appointments in appropriate academic departments of the host or an affiliated university, consistent with university policy. UCEDD senior professional staff must contribute to the university by participation on university committees, collaboration with other university departments, and other university community activities.

(g) UCEDD faculty and staff must represent the broad range of disciplines and backgrounds necessary to implement the full inclusion of individuals with developmental disabilities in all aspects of society, consonant with the spirit of the Americans with Disabilities Act (ADA).

(h) The management practices of the UCEDD, as well as the organizational structure, must promote the role of the UCEDD as a bridge between the University and the community. The UCEDD must actively participate in community networks and include a range of collaborating partners.

(i) The UCEDD's Consumer Advisory Committee must meet regularly. The membership of the Consumer Advisory Committee must reflect the racial and ethnic diversity of the State or community in which the UCEDD is located. The deliberations of the Consumer Advisory Committee must be reflected in UCEDD policies and programs.

(j) The UCEDD must maintain collaborative relationships with the SCDD and P&A. In addition, the UCEDD must be a permanent member of the SCDD and regularly participate in Council meetings and activities, as prescribed by the Act.

(k) The UCEDD must maintain collaborative relationships and be an active participant with the UCEDD network and individual organizations.

(l) The UCEDD must demonstrate the ability to leverage additional resources.

(m) The university must demonstrate that the UCEDD have adequate space to carry out the mandated activities.

(n) The UCEDD physical facility and all program initiatives conducted by the UCEDD must be accessible to individuals with disabilities as provided for by section 504 of the Rehabilitation Act and Titles II and III of the Americans with Disabilities Act.

(o) The UCEDD must integrate the mandated core functions into its activities and

programs and must have a written plan for each core function area.

(p) The UCEDD must have in place a long range planning capability to enable it to respond to emergent and future developments in the field.

(q) The UCEDD must utilize state-of-the-art methods, including the active participation of individuals, families and others of UCEDD programs and services to evaluate programs. The UCEDD must refine and strengthen its programs based on evaluation findings.

(r) The UCEDD Director must demonstrate commitment to the field of developmental disabilities, leadership, and vision in carrying out the mission of the UCEDD.

(s) The UCEDD must meet the "Employment of Individuals with Disabilities" requirements as described in section 107 of the Act.

#### § 1388.7 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 with the requirements of the law and applicable regulation, in accordance with current practice.

(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 and approved by AIDD upon review.

(3) By July 30 of each year, a UCEDD shall submit an Annual Report, using the system established or funded by AIDD. In order to be accepted by AIDD, 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, or his or her designee, to comply with section 105(1), (2), and (3) of the Act (42 U.S.C. 15005) and any other information requested by AIDD. The Report shall include information on progress made in



achieving the UCEDD's 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) The extent to which the goals were not achieved;

(iv) A detailed description of why goals were not met; and

(v) 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.

(b) [Reserved]

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