PROGRAM REGULATION

TO:
Directors, Designated State Agencies
Executive Directors, State Developmental Disabilities Councils
Chairpersons, State Developmental Disabilities Councils
Directors, State Protection and Advocacy Systems
Directors, University Affiliated Programs

SUBJECT:
Final Rule for the Developmental Disabilities Program

LEGAL AND RELATED REFERENCES:
Public Law 101-496, Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1990 (42 U.S.C. 6000 et seq.);
Public Law 103-230, Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1994 (42 U.S.C. 6000 et seq.); and
Public Law 104-183, Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1996 (42 U.S.C. 6000 et seq.).

DISCUSSION:
The Department published a Notice of Proposed Rulemaking in the FEDERAL REGISTER on May 18, 1995 (60 FR 26774-26793). All written comments were analyzed and form the basis for the editorial and technical changes which the Department has made in the attached final rule which was published in the FEDERAL REGISTER on September 30, 1996 (61 FR 51142-51166).
The final rule implements the Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1990 (Pub. L. 101-496) and the 1994 Amendments (Pub. L. 103-230). These regulations will also administer the provisions of the 1996 Amendments (Pub. L. 104-183), which simply reauthorized the program's authority through Fiscal Year 1999. The rule includes guidance on the following areas: redesignation of the Protection and Advocacy system and the appeal process; the Protection and Advocacy annual statement of objectives and priorities; State Developmental Disabilities Council responsibilities and those of the Designated State Agency; and program standards for the University Affiliated Programs.

EFFECTIVE DATE: October 30, 1996

INQUIRIES TO: Administration on Developmental Disabilities
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Regional Administrators, ACF, Regions I-X

COPY TO: Regional Administrators, ACF, Regions I-X
Director, Regional Operations Staff, ACF
Executive Director, National Association on Developmental Disabilities Councils
Vice-President for Government Relations, Consortium of Developmental Disabilities Councils
Executive Director, National Association of Protection and Advocacy Systems, Inc.
Executive Director, American Association of University Affiliated Programs

ATTACHMENT: Final Rules
Monday
September 30, 1996

Part II

Department of
Health and Human
Services

Administration for Children and Families

45 CFR Parts 1385, 1386, 1387, and 1388
Developmental Disabilities Program; Final
Rule
DEPARTMENT OF HEALTH AND 
HUMAN SERVICES

Administration for Children and 
Families

45 CFR Parts 1385, 1386, 1387, and 
1388

RIN: 0970-AB11

Developmental Disabilities Program

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

ACTION: Final rule.

SUMMARY: The Department is issuing 
this final rule for the Developmental 
Disabilities Program which implements 
the Developmental Disabilities 
Assistance and Bill of Rights Act 
Amendments of 1990 and the 1994 
Amendments. The rule includes: 
Requirements clarifying redesignation 
of the Protection and Advocacy system 
and the appeal process; requirements 
on the Protection and Advocacy annual 
statement of objectives; State 
Developmental Disabilities Council 
responsibilities and those of the 
Designated State Agency; and new 
program standards for the University 
Affiliated Programs.

EFFECTIVE DATE: The effective date of 
these regulations is October 30, 1996.

However, affected parties do not have to 
comply with the information 
requirements in §§1386.23(a), 
1386.30(c), 1386.32(a), and 1386.32(b) 
until the Administration for Children 
and Families publishes in the Federal 
Register the control numbers assigned 
by the Office of Management and 
Budget (OMB) to these information 
collection requirements. (Please note 
that these sections had been previously 
approved by OMB but the control 
numbers for them have expired.)
Publication of the control numbers 
notifies the public that OMB has 
approved these information collection 
requirements under the Paperwork 

FOR FURTHER INFORMATION CONTACT: 
Elsbeth Wyatt, Administration on 
Developmental Disabilities; Telephone: 
(202) 690-5841 (Voice), (202) 690-6415 
(TDD). These are not toll-free numbers. 
This document will be made available 
in accessible formats upon request.

SUPPLEMENTARY INFORMATION:

I. Program History

In 1963, the Mental Retardation 
Facilities and Construction Act (Pub.L. 
83-164) was enacted to plan activities 
and construct facilities to provide 
services to persons with mental 
retardation. This legislation was 
subsequently amended by the 
Developmental Disabilities Services and 
Facilities Construction Amendments of 
1970 (Pub.L. 91-517) which constituted 
the first Congressional effort to address 
the needs of a group of persons with 
disabilities designated as developmental 
disabilities. The 1970 Amendments 
defined developmental disabilities to 
include individuals with mental 
retardation, cerebral palsy, epilepsy and 
other neurological conditions closely 
related to mental retardation which 
originated prior to age 18 and 
constituted a substantial disability. It 
also created State Planning Councils to 
avocate for, plan, monitor and evaluate 
services for persons with developmental 
disabilities; and authorized grants for 
constructing, administering and 
operating University Affiliated 
Facilities. The legislation authorizing 
the Developmental Disabilities program 
has been revised periodically. The major 
changes of note included the following: 
(1) The 1975 Amendments (Pub.L. 
94-103) deleted the construction 
authority, authorized studies to 
determine the feasibility of having 
University Affiliated Facilities establish 
Satellite Centers, established the 
Protection and Advocacy System and 
added a section on “Rights of the 
Developmentally Disabled;”
(2) The 1978 Amendments (Pub.L. 
95-602) included a functional 
definition of developmental disabilities;
(3) The Developmental Disabilities 
Amendments of 1984 (Pub.L. 98-527) 
added a new emphasis regarding the 
purpose of the program, to assist States 
that persons with developmental disabilities receive the 
care, treatment and other services 
necessary to enable them to achieve 
their maximum potential through 
increased independence, productivity and 
inclusion into the community; and
(4) The 1987 Amendments (Pub.L. 
100-146) established an annual report 
to Congress on the Developmental 
Disabilities program. The 
Administration on Developmental 
Disabilities (ADD) compiles this report 
using information received from the 
State Planning Councils, the 
Protection and Advocacy Systems, the University 
Affiliated Programs and grantees of the 
Projects of National Significance. Also 
included in the 1987 Amendments was 
a special 1990 Report to Congress on the 
scope and effectiveness of services 
provided to persons with developmental 
disabilities by State agencies and an 
analysis of consumer satisfaction. The 
State Planning Councils prepared the 
State Reports to ADD and this 
information was used as a basis for the 
Report to Congress.

The Developmental Disabilities 
Assistance and Bill of Rights Act 
Amendments of 1990, Pub.L. 101-496, 
(the Act), extended authorization of 
appropriations for programs under the 
Act through Fiscal Year 1993 and made 
revisions that:
(1) Add to the purpose of the Act the 
commitment toward enabling all people 
with developmental disabilities, 
including those with severe disabilities, 
to achieve interdependence and 
inclusion into society;
(2) Strengthen the independence of 
State Protection and Advocacy systems;
(3) Establish core awards for 
University Affiliated Programs training 
projects; and
(4) Broaden the purpose of Projects of 
National Significance to include 
supportive living and quality of life 
opportunities.

The Developmental Disabilities 
Assistance and Bill of Rights Act 
Amendments of 1994, Pub. L. 103-230, 
(the Act), extended authorization of 
appropriations for programs under the 
Act through Fiscal Year 1996 and made 
revisions that:
(1) Include findings that emphasize 
respect for individual dignity, personal 
preferences, and cultural differences in 
the provision of services, supports and 
other assistance, and recognize that 
individuals with developmental 
disabilities and their families are the 
primary decision-makers regarding 
services, supports, and other assistance 
they receive;
(2) Ensure that individuals from 
diverse racial and ethnic backgrounds 
are fully included at all levels and in all 
activities authorized under this Act. 
This includes language regarding 
unserved and underserved populations 
and “culturally competent” services, 
supports and other assistance;
(3) Require State Developmental 
Disabilities Council activities to 
promote systemic change, capacity 
building and advocacy;
(4) Clarify the responsibilities of the 
State Developmental Disabilities 
Council and the Designated State 
Agency;
(5) Require the Protection and 
Advocacy System (P&A) to hire and 
maintain sufficient numbers and types 
of qualified staff to carry out the P&A’s 
function;
(6) Protect the confidentiality of client 
records;
(7) Require development of new 
program standards for University 
Affiliated Programs; and
(8) Direct the Secretary to support grants to conduct an investigation on the expansion of part B programs (State Developmental Disabilities Councils) to individuals with severe disabilities other than developmental disabilities. Public Law 104-183 extends for three years the authorization of appropriations for programs under the Act through Fiscal Years 1997, 1998, and 1999.

II. Developmental Disabilities Program

A. Federal Assistance to State Developmental Disabilities Councils

Formula grants are made to each State to support State Developmental Disabilities Councils. The responsibilities of these Councils are to promote, through systemic change, capacity building and advocacy activities; the development of a consumer and family-centered, comprehensive system; and, a coordinated array of services, supports and other assistance. These activities are designed to achieve independence, productivity, integration and inclusion into the community for individuals with developmental disabilities.

B. Protection and Advocacy of the Rights of Individuals With Developmental Disabilities

Formula grants are made to States for the establishment of a system to protect and advocate for the rights of individuals with developmental disabilities. This system must have the authority to pursue legal, administrative and other appropriate remedies to ensure the protection of the rights of individuals with developmental disabilities who are receiving, or who are eligible to receive, treatment or habilitation services.

C. University Affiliated Programs

Grants are made to universities, or to public or nonprofit entities associated with a college or university, to establish University Affiliated Programs (UAPs). Activities of University Affiliated Programs are to be conducted in a culturally competent manner and include: interdisciplinary pre-service preparation of students and fellows; community service activities which include community training and technical assistance; and the dissemination of subsequent information and research findings.

D. Projects of National Significance

This program provides funding through grants and contracts to public or nonprofit private entities for projects which support national initiatives. Such initiatives include the collection of necessary data; provision of technical assistance to State Developmental Disabilities Councils, protection and advocacy for individuals in university affiliated programs; and support to other nationally significant activities, such as employment and housing.

III. Notice of Proposed Rulemaking

The Department published a Notice of Proposed Rulemaking (NPRM) in the Federal Register on May 18, 1995, (60 FR 26774-26793). Interested persons were given sixty days in which to send written comments regarding the proposed rules. During the sixty (60) day comment period 35 letters were received. The comments were sent from: 20 Protection and Advocacy Systems and the National Association of Protection and Advocacy Systems (NAPAS); 11 Developmental Disabilities State Councils and the National Association of Developmental Disabilities Councils (NADDC); and one University Affiliated Program and the American Association of University Affiliated Programs (AAUAP).

All written comments were analyzed and form the basis for changes which the Department has made in these final rules.

Part 1385 contains provisions which apply to all of the Developmental Disabilities Programs. Part 1386 regulates the two formula grant programs: Federal Assistance to State Developmental Disabilities Councils (Part B of the Act) and the Protection and Advocacy System (Part C of the Act). Part 1387 applies to Projects of National Significance (Part E of the Act); and Part 1388 applies to University Affiliated Programs (Part D of the Act).

Summary of Comments and the Department Response

The discussion which follows includes a summary of all comments, our responses to those comments, and a description of the changes that have been made in the final rule as a result of the comments. It should be noted for purposes of these regulations that when the concept of “days” is indicated we are considering these as “calendar days” unless otherwise specified as “work days.” It should be noted further that we use the initials “P&A” and “P&As” frequently in this preamble for the ease of the reader and the initials stand for protection and advocacy. The context in which these initials are used lets the reader know whether it is the system or the agency under discussion. However, for the most part the “P&A” initials refer to the system.

A number of sections of the NPRM were not changed in the final rule and therefore are not referenced in this preamble. Minor technical changes were made in some areas for clarification purposes but are not significant enough to highlight. In addition, we have worked with the National Center for Mental Health Services, Substance Abuse and Mental Health Services (SAMHSA), to ensure that as permitted by the Developmental Disabilities Assistance and Bill of Rights Act, our requirements are identical or consistent with the SAMHSA requirements that implement the provisions of the Protection and Advocacy for Individuals with Mental Illness (PAIMI) Act.

Part 1385—Requirements Applicable to the Developmental Disabilities Program

Section 1385.1 General

Comments: Some commenters asked that this section be revised to reflect the fact that the regulations, in addition to governing protection and advocacy (P&A) activities, impose obligations on service providers, e.g., access to premises, individuals with developmental disabilities and their records. It was recommended that requirements in this part be applicable not only to the Developmental Disabilities Program components but also to “facilities, and other entities, that provide treatment or habilitative services to persons with developmental disabilities.”

Response: We did not make this change because the purpose of part 1385 is to cover administrative requirements for ADD grantees (Protection and Advocacy Systems, Developmental Disabilities State Councils, University Affiliated Programs and Projects of National Significance).

Section 1385.3 Definitions

Comments: Some commenters fully supported the addition of a definition of the term “Protection and Advocacy System”. It was recommended that a sentence be added to the proposed definition to state what the specific P&A authority was in regards to the P&A System under the Developmental Disabilities Act.

Response: We concur with this recommendation. However, in preparing the final regulation we became concerned that defining the “Protection and Advocacy System” in this way would lead to some confusion. The Act makes a distinction between the P&A Agency, and the “Protection and Advocacy System.” In order to preserve this distinction, we have reformulated the provision as the definition “Protection and Advocacy Agency” and have included the suggestion...
concerning the System’s authority. In addition, we have included a definition for “developmental disabilities”. The reason for adding the definition is addressed in the discussion for § 1386.19.

Section 1385.9 Grants administration

Comments: Some commenters fully supported the revision to paragraph (e)(1) of § 1385.9, recommending that the phrase the Secretary “does not require” P&As to make disclosures should read “shall not require.” Also, they recommended that we apply this prohibition to state and other federal agencies.

Response: We concur with the word change suggestion for paragraph (e)(1). In addition, after carefully reviewing this paragraph again, we have reordered it and included citations for greater clarity. Applying these provisions to other state and Federal agencies in all instances is beyond the authority of the Developmental Disabilities Act and these regulations. However, ADD will work with other Federal agencies and state governments on the issue of access to P&A system client records.

Comments: Some commenters firmly supported either omitting or revising the proposed language of paragraph (e)(2) of § 1386.5. They indicated that as written the regulation provides that the P&A shall have the burden of proving compliance with the Act or regulations where HHS has found, during an audit or other investigation, any evidence of noncompliance. The proposal’s imposition on the P&A of the burden of proof regarding the agency’s compliance was viewed as being at odds with federal due process protection. Another commenter indicated that if (e)(2) remains, then the rule contains assurances that those individuals who, in their official capacity, have access to personally identifiable client information, be required to keep such information confidential. Further, commenters suggested a requirement that such personally identifiable information be destroyed once the audit, monitoring review, evaluation or other investigation process is completed.

Response: We revised the proposed language. The regulations reiterate that the purpose of obtaining personally identifiable client information is solely to determine that P&As are spending their grant funds awarded through Part 142 of the Developmental Disabilities Act on serving exclusively individuals with developmental disabilities. We have included language indicating that officials who have access to such information must keep it confidential to the maximum extent permitted by law and regulations. We did not change the requirement on burden of proof because we do not agree with the comment that making the P&A system bear the ultimate burden of proof regarding their compliance raises due process issues. It is customary that grantees bear exactly that burden, because usually only they are in possession of the information necessary to establish compliance.

Part 1386—Formula Grant Programs

Subpart B—State System for Protection and Advocacy of the Rights of Individuals with Developmental Disabilities

A majority of the comments received by the Administration on Developmental Disabilities were on this subpart. The following is a summary of key comments on this subpart and our response:

Although most commenters were supportive of the regulations, many had specific suggestions, regarding the authority of the P&A systems to conduct investigations and to gain access to records, facilities and individuals receiving treatment or habilitation services. ADD has developed a new section, § 1386.22 Access to Records, Facilities and Individuals with Developmental Disabilities to address many of these concerns. The NPRM had this section as Public notice of Federal onsite review which we have now incorporated in § 1386.21, Requirements of the Protection and Advocacy System. Commenters also requested that the regulations be revised to incorporate similar provisions as those found in the Protection and Advocacy for Individuals with Mental Illness (PAIMI) Act regulations.

Comments indicated that the Developmental Disabilities regulations should be as closely coordinated with the Protection and Advocacy for Individual with Mental Illness (PAIMI) Act regulations as possible. ADD concurs with this recommendation and has incorporated provisions as appropriate.

Many commenters believed it would be useful to repeat the law in the regulations in order to present a complete picture of all the requirements rather than just cite the relevant sections of the Act. ADD recognizes that such information would be operationally helpful but is not appropriate to include in regulations.

Comments were also received to include additional case law opinions in the regulations to assist P&As. Such information would be appropriate for the preamble, however, such language is not included into the Code of Federal Regulations.

Also, it was suggested that the regulations (or appendix to the regulations) should list all authorized P&As by name, address, telephone number and spell out their authority. Comments indicated that facilities serving individuals with developmental disabilities attempt to obstruct P&A advocacy efforts by asserting that particular agencies lack authority. The regulations already cover the issue of P&A authority and such a listing is not appropriate in regulations. P&As have a Notice of Grant Award which could be used for this purpose and a listing of all authorized P&As is available from ADD.

Section 1386.19 Definitions

Comments: We received several comments to include a definition of “complaint” as the receipt of a complaint is one of the bases for obtaining access to the records of an individual with developmental disabilities (see sections 142(a)(2)(l) (ii) and (iii)). Recommended language was also included.

Response: We have included a definition of “complaint”. This definition includes media accounts and newspaper articles because, while such reports are not specifically directed at the P&A system, they are published with the expectation that public officials responsible for conditions will act to stop abuse.

Comments: We received comments to include a definition of “developmental disabilities” as there is inconsistency from state to state in determining whether individuals are eligible for the P&A program. It was recommended that the regulations include an interpretation on the application of the functional definition of the Act (section 102(6)) to assist P&As in making eligibility
determinations, especially for school-age children (e.g., attention deficit problems, learning disabilities and emotional disturbance).

Response: We have included a definition of "developmental disabilities" to reiterate that the P&As receiving funds under the Developmental Disabilities Act must use the functional definition in section 102(e) to determine who they will serve. This determination shall be done on a case-by-case basis. For example, the diagnosis of learning disability or attention deficit disorder, like any other diagnosis, would not in itself be considered a developmental disability unless it meets the functional definition of the legislation. Any State eligibility definition of developmental disability or policy statement which is more restrictive than that of the Act does not apply as the Act takes precedence. The definition of "developmental disabilities" has been placed in §1385.3 because we believe it is more appropriate in a section with definitions for words found in all parts of this rule.

Comments: On the proposed definition of "probable cause", commenters indicated general support but requested that additional language be included to reiterate that the P&A has exclusive authority to make probable cause determinations, and that a judicial or other third party determination is prohibited. Also, commenters requested language regarding the issue of disclosure on the basis of the P&As probable cause finding.

Response: We have revised the final rule for greater clarification. However, we could not make the specific type of edits recommended above as the context of the Act does not support such interpretations.

Comments: We received several comments to include a definition for "legal guardian, conservator and legal representative" and recommended language was included.

Response: We have included a definition of "legal guardian, conservator and legal representative". The definition follows the wording of a statement in the Congressional Report on the P&A legislation. ACF adopted it because of the protection and advocacy requirements in the Act parallel Congressional intent.

Comments: Commenters asked that we include definitions for "abuse" and "neglect".

Response: We concur with this recommendation and have included these definitions.

Comments: Several commenters recommended changing the proposed definition of "full investigations" and recommended language for this.

Response: We have revised the definition in accordance with the recommended language.

Comments: Several commenters recommended that the definition of "good cause" and that such evidence used to make a redesignation decision should be presented to the P&A at the time of issuance of both the initial notice of intent to redesignate and the final redesignation decision.

Response: Because there is no formulation which encompasses all of the possible variations of circumstances serious enough to justify redesignations, we decided not to attempt to define "good cause" in this regulation. We have modified the guidance we included in the NPRM to explain that "good cause" may include, but is not limited to, eliminating longstanding or pervasive inefficiency or a substantial breach of section 142 of the Act, or violations of other State and Federal requirements, such as 45 CFR part 74.

Comment: Comments were offered on the preamble discussion regarding the need for the redesignation. However, the determination of such a meeting being held must be made at the State level. In §1386.20(d)(2)(v) language has been included that the P&A must provide a clear and detailed explanation of the good cause for the proposed redesignation, including failure to take remedial steps suggested in consultation(s) with the State, if applicable.

Response: Such information is considered valuable for the public input process so the community is aware of who is being considered as the new P&A agency and can provide comments early on regarding this organization. Therefore, no such change has been made in the final rule.

Comments: A commenter recommended that the public notice on a P&A redesignation must include a statement of assurance that the proposed new designated State P&A 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 or impairment of the legal or constitutional rights of clients affected by such redesignation.

Response: We concur and such language has been included in §1386.20(d)(2)(c).

Comment: A commenter indicated that the proposed regulation failed to provide the current P&A system adequate time to develop and submit an appeal of redesignation.

Response: We concur and have changed the timeframe from 10 to 20 days in §1386.20(e)(1).

Comments: A commenter wanted the final phrase of paragraph (e)(3), "and may provide any additional relevant
information," removed from the regulation.

Response: We do not concur with this recommendation because we believe it is important to allow submission of information of relevance to the situation.

Section 1386.21 Requirements and Authority of the Protection and Advocacy System

Comments: It was recommended that the title of § 1386.21 be modified to include the word "authority" in support of the goals of the new regulations to provide guidance to assist P&As to advocate for, and protect, when required, individuals with developmental disabilities.

Response: We concur and have revised the title.

Comments: Many commenters recommended that regulatory language be included in the final rule concerning allotments being used to supplement and not to supplant the level of nonfederal funds available in the State to investigate and remedy incidents of abuse or neglect or other rights violations affecting individuals with developmental disabilities; or which are available to otherwise protect and advocate the rights of such individuals.

Response: We concur with this recommendation and have included regulatory language in paragraph (b) of this section of the final rule. Paragraphs (b)(1), (2), and (3) of the NPRM are now covered in § 1386.22.

Comments: Commenters recommended that regulatory language be included in the final rule stipulating that allotments not be used to support lobbying activities to influence proposed or pending Federal legislation or appropriations. Suggested language also included in which P&As can perform certain activities which do not constitute lobbying.

Response: We plan to study this issue in more detail in cooperation with all interested parties (Federal and Non-Federal) to find the best approach for addressing concerns about lobbying activities. We will issue further guidance following these discussions. Paragraph (c)(1), (3) and (4) of the NPRM are now covered in § 1386.22.

Comments: Commenters recommended that regulatory language be included in the final rule concerning the determination of trained staff must be made by individual P&As. Language has been included in § 1386.21(b) to indicate the P&A 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. Since the investigation of allegations of abuse, neglect or rights violations is a priority of the system, the system must have staff appropriately trained or access to expert consultants to conduct full investigations of abuse, neglect or rights violations upon the system’s determination of probable cause or if the incidents are reported to the system.

Comments: Comments were received on paragraph (d) of this section, acknowledging the validity that a P&A system should not implement a policy or practice restricting the remedies which may be sought on the behalf of individuals with developmental disabilities. However, opinions were expressed that P&As should be allowed to choose what level of remedy to pursue on an individual case-by-case basis. Such determinations would be made for such reasons as: (1) Resources; (2) the factual circumstances of a particular case; and (3) priorities established through the annual P&A Statement of Objectives and Priorities.

Response: We recognize the concerns expressed and therefore have revised the regulation at paragraph (c) by using regulatory language to add a final sentence to the regulation which indicates that the requirement does not prevent the P&A from developing case or client acceptance criteria as part of the annual priorities identified by the P&A system as described in § 1386.23(c) of the final rule. The regulation also indicates that clients must be informed at the outset of such criteria.

Comments: The comments received on paragraph (e) of this section, concerning State’s interfering with the administration of the Protection and Advocacy System, e.g., hiring freezes, reductions in force, prohibitions on staff travel, or other policies which impact staff or funds functions with Federal funds and would prevent the system from carrying out its mandates under the Act. It was recommended that the regulations should clarify that it is the P&A that has the sole authority to make the determination whether a proposed state policy or practice would improperly interfere with its operation. Language should indicate that pending resolution of the matter by appropriate Federal officials, the P&A need not comply with such a policy or practice. Also, regulations should be established which outline an expedient resolution process for such disputes, placing the burden on the State to establish that the policy in issue does not conflict with the Act’s mandates.

Response: We recognize that P&As administered by state agencies have had difficulties in spending their Federal money to carry out the requirements of the P&A system due to state budget policies restricting the use of funds. On the other hand, to include a provision designating the P&A the sole authority to make the determinations as to whether a proposed State policy or practice would improperly interfere with its operation, would conflict with the intent of Congress and evidence in the Act that States play a role in monitoring P&As. (See section 142(a)(4) and (c)(3)). We have modified this provision (now found at paragraph (d)) to more clearly cover the State’s situation. Regulations on compliance procedures are covered in part 1386—subpart D—Practice and Procedure for Hearings Pertaining to State’s Conformity and Compliance with Developmental Disabilities Plans, Reports, and Federal Requirements.

The language of the NPRM for paragraph (g) of this § 1386.21, is now found at paragraph (f) unchanged.

Comments: Commenters recommended that regulatory language be included concerning the issue of “standing” which would allow the system to bring lawsuits in its own right to redress incidents of abuse or neglect, discrimination and other rights violations impacting on individuals with developmental disabilities; such individuals need not be joined as a party to such actions.

Response: We understand the concern with regard to P&A standing and have addressed this concern in a new § 1386.25 Allowable Litigation Costs.

Comment: A comment was received to incorporate provisions for an Advisory Council.

Response: Language has been included in paragraph (g) of this section regarding P&As that are a public system without a multisc- member governing or advisory board. These P&As must establish an advisory council in order to provide a voice for individuals with developmental disabilities. The Advisory Council shall advise the P&A on program policies and priorities and a majority of the membership (including the chair) shall be comprised of individuals with developmental disabilities who are eligible for services, or have received or are receiving services or parents, family members, (including those representing individuals with developmental disabilities who live in institutions and
home and community based settings, guardians, advocates, or authorized representatives of such individuals.

As noted earlier, the regulation in the NPRM, § 1386.22 Public notice of Federal onsite review has now been incorporated as paragraph (h) of this section. § 1386.21.

Paragraph (b)(3) of the NPRM of § 1386.21 is now paragraph (i). The regulation requires the P&A to obtain written consent of the client requesting assistance or from his or her guardian before releasing information to individuals not authorized to receive it.

Section 1386.22 Access to Records, Facilities and Individuals with Developmental Disabilities

Comments: Commenters recommended including a new section on Access to Records, Facilities and Residents, incorporating PAlMI regulations as appropriate, and including relevant ADD program regulations from § 1386.21 of the NPRM.

Response: We concur with this recommendation and have established § 1386.22 entitled Access to Records, Facilities and Individuals with Developmental Disabilities. Language has been included based on the PAlMI regulations. We have included as many points as possible.

In adapting the language of the PAlMI final rule in this section, we had to make some modifications. We had to separate the provisions dealing with access to records, access to individuals and the authority to investigate abuse and neglect. This was necessary because the scope of authority of P&A Systems under the DD Act is different in each of these areas; and, in the case of access to facilities, is different than the PAlMI Act under the PAlMI statute, 42 U.S.C. 10805(a)(3), the P&As “must have access to facilities in the State providing care or treatment * * *” (Emphasis added.) There is no equivalent provision of the DD Act. That statute provides authority under section 142(a)(2)(H) to “have access at reasonable times and locations to any resident who is an individual with a developmental disability in a facility that is providing services, support and other assistance to such a resident.” (Emphasis added.) However, under the DD Act, P&As have authority, under section 142(a)(2)(B), “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 * * *.” We have reasonably interpreted this provision as authorizing access to facilities when necessary to complete an investigation of alleged or suspected abuse or neglect.

With respect to § 1386.22(a)(1) and (2), we are interpreting reference to client to include all those individuals with developmental disabilities who request assistance from the system or who have died or whose whereabouts are unknown.

In § 1386.21, paragraph (c)(1) of the NPRM, regulations were proposed regarding access to records of deceased individuals and the authority to conduct abuse and neglect Investigations. These regulations have been deleted as this topic is now covered in § 1386.22 Access to Records, Facilities and Individuals with Developmental Disabilities, paragraph (a)(2).

Comments: A few comments were received regarding § 1386.21, paragraph (c)(3) requesting that further guidance be provided in relation to P&As having access at reasonable times and locations to individuals with developmental disabilities who reside in public and private facilities, especially when P&As are investigating incidents of abuse and neglect.

Response: This regulation is now covered in § 1386.22, paragraphs (f), (g) and (h). P&As shall have reasonable unaccompanied access to service recipients at all times necessary to conduct a full investigation of an incident of abuse, neglect, or violation of rights.

Comments: Several commenters indicated support for the proposed regulatory language in § 1386.21, paragraph (c)(4), (see § 1386.22(e) of the final rule) on keeping confidential the names and identity of individuals who report incidents of abuse and neglect. A commenter suggested additional requirements regarding confidentiality.

Response: We have included the additional language regarding confidentiality as the language suggested went beyond the authority of the Developmental Disabilities Act and these regulations. However, we have included language comparable to PAlMI provisions at § 1386.22(f) on Delay or Denial of Access. If a system is denied access to facilities and its programs, individuals with developmental disabilities, or records covered by the Act or these regulations, it shall be provided promptly with a written statement of reasons, including, in the case of a denial for alleged lack of authorization, the name and address of the legal guardian, conservator, or other legal representative of an individual with developmental disabilities.

Section 1386.23 Periodic Reports: Protection and Advocacy System

Comments: Commenters requested that P&As be allowed to submit the Statement of Objectives and Priorities (SOP) Report (paragraph (c)) and the Program Performance Report (paragraph (a)) at the same timeframe, by January 1 of each year.

Response: We concur with this recommendation and the final rule has been revised accordingly.

Comment: A comment was received on paragraph (c)(5) of the NPRM now (c)(2) regarding the requirement for the P&As to report on how the system operates and coordinates with other Federal Protection and Advocacy programs. It was recommended that such a requirement may not be appropriate for an individual P&A system based on the State's priorities.

Response: We concur with this recommendation and have deleted the lengthy list of programs indicating that where applicable, the SOP provide such information on other Federal advocacy programs. We have also deleted the references to the Council and UAPs as such information on advocacy activities will be obtained through the requirements of paragraph (d) (3), (4), and (5).

Comment: A comment was received on the structure of paragraph (c) in relation to the SOP and the level and type of administrative information required for the public input process. A recommendation was also made that regulatory language be included to reiterate that one of the critical functions of the SOP and the public comment process was to establish case load priorities unique to each State and as such the P&As have the authority to turn down a request for assistance when it is outside the scope of the SOP.

Response: We concur with these recommendations and have restructured the final rule accordingly. We have included regulatory language that when a P&A turns down a request for
assistance because it is outside the scope of the SOP, they must inform individuals that this is the basis for turning them down.

Comments: We received a few comments that the language of the phrase "publication of general distribution" in paragraph (d)(2) on the public review process for the Statement of Objectives and Priorities (SOP) was too prescriptive.

Response: We have deleted the word "publication" and have revised the language to indicate that the P&As provide for a broad distribution of the proposed SOP.

Section 1386.24 Non-Allowable Costs for the Protection and Advocacy System

Comment: A comment was received on § 1386.24 paragraph (a)(1) regarding allowable costs for the P&As on issues which relate to a disability but also may be faced by the general population.

Response: We have included language to cite examples of such activities which would not be considered allowable costs for the P&As, such as the preparation of wills, divorce decrees and real estate proceedings. Language has been included on allowable costs in cases which relate to an individual with a disability but may also be faced by the general population. In such cases P&As may provide disability related technical assistance information and referral to appropriate programs and services.

We made additional edits for clarification purposes concerning attorney fees that must be considered as income, by adding to the last sentence of paragraph (b) "earned by contractors".

Section 1386.25 Allowable Litigation Costs. (New)

Comments: A number of the commenters urged that the regulations clarify whether or not a P&A has standing to take legal action in its own name.

Response: The legislative history of the 1994 Developmental Disability Act Amendments (S. Rep. 120, 103rd Cong., 1st Sess. 39-40 (1993)) supports the conclusion that, without showing injury to itself, a P&A does have standing to bring suit on behalf of persons with disabilities. Although Congress has not amended the Developmental Disability Act to insert a right of standing, the Committee commented that "the current statute is clear that P&A agencies have standing to pursue legal remedies to ensure the protection of and advocacy for the rights of individuals with developmental disabilities within the State." Additionally, we note that the following courts have affirmed the P&A's independent standing: Goldstein v. Coughlin, 83 F.R.D. 613 (W.D.N.Y. 1979); and Herschberger v. Missouri Protection and Advocacy Services, Inc., No 48169 (MO Ct. of Appeals, August 2, 1994).

We wish to make it clear through these regulations that allotments may be used to pay the otherwise allowable costs incurred by a Protection and Advocacy System in bringing lawsuits in its own right to redress incidents of abuse or neglect, discrimination and other rights violations impacting on individuals with developmental disabilities.

Subpart C- State Plan for Assisting in the Development of a Comprehensive System of Services and Supports for Individuals With Developmental Disabilities

Comments: Several commenters stated that the wording of the title of subpart C should be consistent with the language of the statute.

Response: We concur and have revised the title of subpart C to read, "Subpart C—Federal Assistance to State Developmental Disabilities Councils."

Section 1386.30 State Plan Requirements

Comments: We received several comments regarding paragraph (a) of § 1386.30, State Plan requirements. Overall, commenters approved of the proposed language which emphasized that the State Plan is the responsibility of the Council. However, commenters indicated that the regulations should reflect that DD Councils approve the State Plan for submission to ADD.

Response: The final rule indicates that the annual development of the State Plan and applicable annual amendments are responsibilities of the State Developmental Disabilities Council. The Council will provide opportunities for public input during the planning and development of the State plan, and will consult with the Designated State Agency to determine that the plan is not in conflict with applicable State laws and to obtain appropriate State Plan assurances. Requirements regarding State Plan submission and approval are covered in § 1386.31, State Plan submittal and approval.

Comments: A commenter indicated that the last sentence of the proposed rule at § 1386.30(c) should be moved to § 1386.31(b)(1) where regulations pertaining to the Designated State Agency are covered in relation to the State Plan. This sentence addressed the area of the Designated State Agency providing support services as requested by and negotiated with the Council.

Response: We have developed regulatory language to address this issue in paragraph (a), § 1386.34, Designated State Agency. The Designated State Agency shall provide the assistance required under section 124(d)(3) of the Act in developing the State Plan.

Comments: We received several comments on paragraph (c)(1) of § 1386.30. Commenters approved of the proposed regulations on identification of program unit(s), as written. However, a commenter indicated that requiring the identity of the program unit(s) within the Designated State Agency or office within the State went beyond the Act and was burdensome on the State.

We also received recommended language to address the fact that in some States, State agencies other than the Designated State Agency provide services. Also, Councils are now allowed to use other organizations, including private ones, to provide fiscal and other support services.

Response: Because administration ties to more than one State agency are possible, we have not changed the proposed regulatory language to identify the program unit(s) within the Designated State Agency responsible for providing assurances and fiscal and other support services. We have included language pursuant to section 124(d)(4)(C) of the Act to address the fact that Councils may use or contract with State agencies other than the Designated State agency in securing support services. This language was inserted in § 1386.30 for this section on the Designated State Agency is more appropriate for this requirement. We did not include language covering the use of private agencies as we could not find any such reference in the statute or conference report language.

Response: Several comments were received on paragraph (c)(3).

A commenter supported the proposed regulation which focused on the Council reporting through the State Plan on the collaborative efforts of the Council, the Protection and Advocacy Systems and the University Affiliated Programs to bring about systems change to benefit individuals with developmental disabilities, and, where appropriate, individuals with other disabilities.

Other commenters did not agree with the proposed regulation. Primarily, the concern was that there was no legislative basis for this State Plan reporting requirement to be prepared by the Councils. While it was viewed as a worthwhile goal to encourage collaboration and cooperation between
Councils, the State Plan. One Councils, the State Plan. One Councils, the State Plan. The Councils, Protection and Advocacy Systems and the University Affiliated Programs, commenters did not believe that this should be added as a requirement for the State Plan. One suggestion was to make this discretionary by adding the phrase “where applicable” to the regulation. Also, a few commenters indicated the phrase “Developmental Disabilities Network” should not be used as there was no statutory definition.

Response: Recognizing the concerns raised by the comments received we revised the final rule to include the phrase “where applicable” and have deleted the phrase “Developmental Disabilities Network”. Commenters indicated that there was no legislative basis for this State Plan reporting requirement to be prepared by the Councils. Please note section 122(c)(5)(N) of the Act provides “...the plan shall contain such additional information and assurances as the Secretary may, in her discretion, determine necessary to carry out the provisions and purposes of this part.” We want to reiterate that though Protection and Advocacy Systems and University Affiliated Programs have individual roles and responsibilities that are separate and distinct from each other and the Developmental Disabilities Council, the Act requires their membership on the Council. Commenters recognized the importance of collaborative efforts through the State Plan highlights the systems change role of the Council. It should also be noted that these final rules contain requirements for both the Protection and Advocacy Systems and the University Affiliated Programs to document collaborative efforts with the Developmental Disabilities Council (see §1386.23 Periodic Reports, Statement of Objectives and Priorities. (c) and (d) (5), (4), and (5); §1388.1 Definitions, collaboration and §1388.4 Program criteria-governance and administration, paragraph (k)).

Comments: Comments on the proposed language regarding short-term demonstrations, paragraph (e). §1366.30 State Plan requirements, concerned the specific time-frame limitation of three years. Commenters recognized that Councils should not be in the service delivery business, however, Councils indicated that they needed more flexibility to fund systems change projects such as advocacy training for longer periods of time. Adding the phrase “direct care projects” and “direct services” were recommended to address these points.

Also, language was recommended to include information on estimated project duration and a description of how the services will be continued without Developmental Disabilities program funds in the State Plan. Response: In the final rule, we used language from ADD-IM-95-2, issued February 20, 1995, Use of Part B Funds in Funding Time-Limited Demonstrations and Other Projects in which we addressed the issue of Council funds supporting on-going direct services. We appreciate the commenters reaffirmation that Councils should not be in the service delivery business. We also recognize the concerns raised through the comments so we have included the reference to “direct services” and have deleted the time-frame of three-years to allow for greater Council flexibility (see paragraph (e)(1)). The final rule also reflects the comments on the State Plan information regarding such demonstration projects (see paragraph (e)(2)).

Comments: Several comments were received on paragraph (f)(4) of §1366.30 State Plan requirements, which addressed budgeting, staff hiring and supervision and staff assignment. Commenters indicated that there continues to be State interference regarding the work of the Councils. The commenters overall concern with the proposed language was that in our attempts to clarify “consistent with State law” we went beyond the intent of the statutory change and instead provided Councils with more flexibility than most States provide in their budgeting and personnel activities.

Response: We have not revised the proposed language of the NPRM in the final rule. Such language reiterates that the State Developmental Disabilities Councils shall follow the requirements of section 122(c) (6), (9), and (10) regarding budgeting, staffing, hiring and supervision and staff assignment. In relation to the concerns about State interference, we have included regulations to cover this issue, in paragraph (a) of §1366.34, Designated State Agency.

Section 1366.31 State Plan Submittal and Approval

Comments: We received comments on paragraphs (a) and (b) of the proposed regulations for §1366.31 State Plan submittal and approval. Overall, the comments indicated that two rounds of public hearings were overly complex and burdensome and created too long a timeframe for the State Plan preparation. An issue was raised as to why public notices would be from the Governor or the Governor’s designee as the development/preparation of the State Plan is the responsibility of the Council. Also, comments expressed concern as to why the Governor was still referenced as approving the State Plan.

Response: We concur with the comments that the process should be simplified and that the Council should perform all requirements tied to the preparation and submission of the State Plan. Paragraph (a) of the final rule has been revised to indicate that the Council shall issue a public notice about the availability of the proposed State Plan or State Plan amendment(s) for comment and that there is only one 45 day review period. The notice shall be published in accessible formats. The Council then indicates that a summary of the Council’s response to the 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. We recognize that the 1994 amendments greatly increase the independence of Councils but it seems questionable whether the amendments were meant to deprive the Governor of his or her authority to give the plan final approval. Upon further review, we decided to delete paragraph (b) of the NPRM and to keep the language of the paragraph in the current regulation on this matter, which is now paragraph (a) in the current regulations but will be renumbered paragraph (b) when this final rule is codified.

Section 1366.32 Periodic Reports: Federal Assistance to State Developmental Disabilities Councils

Comments: We received comments on paragraph (b) of this section opposing the Program Performance Report being in a mandated format.

Response: We concur with the comments on the Council Program Performance Report and have revised paragraph (b) of the final rule to indicate that pursuant to section 107(a) of the Act (42 U.S.C.6006a), the State Developmental Disabilities Council shall submit an Annual Program Performance Report in a format that facilitates Council reporting of results of activities required under sections 122 and 124 of the Act. The report shall be submitted to the appropriate Regional Office, by January 1 of each year. At this time ADD is working with Councils on the development of reporting guidelines that will result in program performance measures as required by the Government Performance Results Act (GPRA) and such guidelines will also be used as part of an ADD Management...
Information System where reporting could be done electronically.

Section 1386.33 Protection of Employee’s Interests

Comments: We received several comments on this section. One commenter asked that we include the term “assurance” to highlight that this is an assurance tied to the State Plan. Two other commenters wanted the current regulation to stand. One commenter wanted significant policy changes made to the current regulation.

Response: We included the term “assurance” in this section as requested. However, we have not changed the rest of the proposed section as it is current policy based on section 122(c)(9)(K) of the Act (42 U.S.C. 6022).

Section 1386.34 Designated State Agency

Comment: A comment was received regarding the responsibilities of the Designated State Agency and the State Plan as in § 1386.30.

Response: Paragraph (a) of this section reiterates that the Designated State Agency shall provide the assistance required under section 124(d)(3)(C) of the Act in developing the State Plan. Paragraphs (b), (c), and (d) reflect the appeals process. Only editorial changes were made in the final rule. It should be noted that ADD, for purposes of convenience in drafting this section, has referred to the appeal by “a majority” of the non-State agency members of the Council as an appeal by the “Council”.

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

Comment: Comments were received with suggested language to revise paragraph (d)(2) and (3) of this section regarding variable match on an activity by activity basis.

Response: We have modified the language of the NPRM as follows: In paragraph (d)(1) we have revised the phrase “priority area” to “projects or activities”, in relation to expenditures which require non-Federal participation. Paragraph (d)(2) indicates that expenditures for “priority areas” now reads “projects or activities or products targeted to urban or rural” poverty areas but not carried out directly by the Council and Council staff, as described in section 125A(a)(2) of the Act, shall have non-Federal participation of at least 10% in the aggregate. The suggested language to include the phrase “The Council may elect to have a lower, or no match, for such priority area activities” was not included, see paragraph (d)(4). Paragraph (d)(3) has been edited to provide that all other activities not directly carried out by the Council and Council staff shall have non-Federal participation of 25% in the aggregate. In accordance with comments, a new paragraph (d)(4) has been added to indicate that the Council may vary the non-Federal participation required on a project by project or activity by activity basis (both poverty and non-poverty activities), including allowing no non-Federal participation from particular projects or activities as the Council deems appropriate so long as the requirement for aggregate non-Federal participation is met.

Section 1386.37 Public Notice of Federal Onsite Review

Comments: We received a few comments indicating that this requirement is not statutorily based for State Developmental Disabilities Councils and that these reviews would place an inappropriate burden on grantees for an activity that is the Administration on Developmental Disabilities responsibility.

Response: We concur with the comments. This requirement has been dropped.

Additional Comment: We received a comment to include language in regulation to clarify that Councils may provide information to policymakers pursuant to section 124(e)(4)(I) of the Act and that such activities do not constitute lobbying.

Response: We plan to study this issue in more detail in cooperation with all interested parties (Federal and Non-Federal) to find the best approach for addressing concerns about lobbying activities. We will issue further guidance following these discussions.

Part 1387—Projects of National Significance

Section 1387.1 General Requirements

Comments: A few comments were received on paragraph (d) of this section. One commenter supported the language but indicated that some national projects such as national surveys of program costs may not be appropriate for local replication. The other commenter indicated that all Projects of National Significance should be exemplary and innovative, including all technical and data collection projects.

Response: We concur with the comment regarding local replication, which is why the NPRM language included a reference to projects which “otherwise meet the goals of part E of the Act”. Therefore no language change is necessary with respect to local replication. We also concur with the comment regarding all projects being exemplary and innovative and we have revised the final rule accordingly.

Part 1388—University Affiliated Programs

Section 1388.1 Definitions

Comment: A commenter wanted the first example included in the definition of “capacity building” to be revised to delete the reference to the dental school and add language on the recruitment of individuals with developmental disabilities and their families, local community leaders, additional faculty and students to participate in the UAP.

Response: We concur with this recommendation and have revised the definition of capacity building accordingly.

Comment: A few commenters wanted to add the term “cultural diversity” to the definition section. The language would read, “Cultural diversity means that UAPs are characterized by their commitment to involve individuals with disabilities, family members and trainees from diverse cultural backgrounds in all levels of their activities. This commitment to cultural diversity means that each UAP must assure that individuals from racial and ethnic minority backgrounds are fully included; that efforts are made to recruit individuals from minority backgrounds into the field of developmental disabilities; that specific efforts must be made to ensure that individuals from minority backgrounds have effective and meaningful opportunities for full participation in the developmental disabilities service system; and that recruitment efforts at the levels of preservice training, community training, practice, administration and policymaking must focus on bringing larger numbers of racial and ethnic minorities into the field in order to provide appropriate skills, knowledge, role models, and sufficient personnel to address the growing needs of an increasingly diverse population.”

Response: We concur with the addition of this term and the language as written. Therefore, “cultural diversity” has been included in the final rule.

Comment: A comment was received on the definition of “culturally competent manner” with the request to drop the word “manner”.

Response: We concur with this edit and have revised the final rule accordingly.
Comment: A comment was received on the definition of “lifespan approach” with the request to revise the language that UAP activities address the needs of individuals with disabilities who are “all” ages rather than “various” ages.
Response: We concur with this wording and the final rule has been revised.

Comment: A commenter wanted to include the term “research and evaluation” to the definition section. The language would read, “Research and evaluation means the UAP refines its activities on the basis of evaluation results. As members of the university community, involvement in program-relevant research and development of new knowledge are important components of UAPs.”
Response: We concur with the addition of this term and the language as written. Therefore, “research and evaluation” has been included into the final rules.

Section 1388.2 Program Criteria—Purpose

The program criteria of the final rule are considered as the standards for the UAPs and include performance standards (see section 153(b) of the Act). Comment: A few commenters requested that the regulations include language that the program criteria are one part of the Quality Enhancement System (QES) and provide a structure for self-assessment and peer review of each UAP.
Response: We concur with these recommendations and have changed the final rule to reflect these points. The QES was developed by ADD in response to amendments to the Act. These amendments include a series of quality assurance provisions for the UAP network. The QES is a holistic approach to the development and maintenance of programs and services to enable persons with developmental disabilities and their families to achieve maximum potential. All UAPs use the QES.

Section 1388.3 Program Criteria—Mission

Comments: A few commenters wanted the language of the NPRM regarding the Introduction to mission, § 1388.3(a) revised to: (1) Add language that the UAP is guided by the values of independence, productivity, integration and inclusion of individuals with developmental disabilities and their families and (2) include “research and evaluation” in the listing of activities to be performed by UAPs. Also, the commenters recommended that the language concerning the “mission statement” be removed.
Response: We concur with the recommended text and have incorporated such language in the final regulation.

Comment: A comment was received on paragraph (b) of this section requesting the word “promotes” be included before the phrase “goals of the university” and that a listing of such goals be included, “training, the development of new knowledge, and service.”
Response: We concur with this language and have changed the final rule accordingly.

Comment: In paragraph (e) of this section we received a comment requesting that we use the term “mission” rather than the phrase goals, objectives, and activities and delete the word “services” and replace it with the word “attitudes”.
Response: We concur with these recommendations and have incorporated this change in the final rule.

Comment: In paragraph (g) of this section we received a comment to include the phrase “be consistent with the mission statement” in relation to the UAP’s goals, objectives, and activities.
Response: We agree with the recommended language and the final rule has been revised.

Section 1388.4 Program Criteria—Governance and Administration

Comment: A commenter wanted the language of the NPRM revised regarding the introduction to governance and administration, § 1388.4(a). The revision centered around the inclusion of the phrase independence, productivity, integration and inclusion of individuals with developmental disabilities and their families.
Response: We concur with the recommended text and have incorporated such language in the final regulation.

Comment: A commenter wanted the proposed language in paragraph (f) expanded to include language indicating UAP senior professional staff contribute to the university by participation on university committees, collaboration with other university departments, and other university community activities.
Response: We concur with the added language and have revised the final regulation accordingly.

Comment: A comment was received on paragraph (q) regarding the use of the phrase “strategic planning”. This phrase is viewed as a trademark so the phrase “long range planning” was suggested as a more useful term.
Response: We agree with the recommended language and the final rule has been changed.

Comment: A comment was received regarding paragraph (r) requesting that “UAP” be inserted for clarification on which programs and services are being evaluated.
Response: We concur with this edit and have modified the final rule.

Comment: We received a recommendation for two additional program criteria for this section regarding (1) UAP activities, programs, and products being accessible to individuals with developmental disabilities, families and the community and (2) commitment of the UAP Director to the field of developmental disabilities.
Response: Regarding the comment on additional program criteria on accessibility, this is adequately covered in § 1388.9 of the current regulation, Grants Administration Requirements, which cross references to 45 CFR part 84, Nondiscrimination on the Basis of Handicap in Program and Activities Receiving or Benefiting from Federal Financial Assistance. With respect to the comment on adding program criteria for the commitment of the UAP program Director, we have added paragraph (s) which states that the UAP Director must demonstrate commitment to the field of developmental disabilities and leadership and vision in carrying out the mission of the UAP. There have been instances where the current UAP Director has been replaced by the University with someone who has experience in the health/medical field but none in the social services field. It is important that the director know all aspects of the field of developmental disabilities because UAPs must develop and execute inter-disciplinary training for people going into the field of developmentally disabilities which includes, social workers, teachers, paraprofessionals, etc., not just medical personnel.

Section 1388.5 Program Criteria—Preparation of Personnel

Comment: In relation to paragraph (a), program criteria on UAP inter-disciplinary training programs, a commenter wanted the phrase “at the preservice level” deleted and the phrase “reflect state-of-the-art practices” be used in its place. Also, it was recommended that the phrase “to promote the independence, productivity, integration and inclusion of individuals with developmental disabilities and their families” be referenced.
Response: We concur with these recommendations and have made these changes to the final regulations.

Comment: A commenter recommended revised language for paragraph (b). The commenter requested that paragraph (b) read as follows with the added language in quotes: (b) Interdisciplinary training programs must be based on identified personnel preparation needs "and have identified outcomes that are consistent with the mission and goals of the UAP."

Response: We concur with the recommended language and have modified the final regulation accordingly.

Comment: A comment was received regarding paragraph (c) with the suggestion that the term "academic" be included in relation to trainees receiving credit for participation in UAP training programs.

Response: We concur with this change and have added this word to the final language.

Comments: A few commenters requested that paragraph (e) be revised to include language that the UAP must encourage trainees to work in "situations where they promote the independence, productivity, integration and inclusion of people with developmental disabilities and their families."

Response: We agree with this recommendation and have revised the regulation accordingly.

Comment: A commenter wanted a new program criteria regarding training and research and dissemination efforts added to this section.

Response: We have reviewed the suggested language and concur with most of the ideas presented but have edited the language. We did not include the phrase "trainees may become active participants in the creation of new knowledge throughout their careers" as this language does not relate to the compliance of the UAP end training requirements under the Act. We have included this criteria as paragraph (f) of § 1388.5 in the final rule. It reads: (f) The UAP core curriculum must prepare trainees to be active participants in research and dissemination efforts. In addition, the curriculum must prepare trainees to be consumers of research as it informs practice and policy.

Section 1388.6 Program Criteria—Services and Supports

Comment: We received several comments on paragraph (a) of this section, Introduction to services and supports. It was recommended that we include language that the UAP engage in a variety of system interventions and may also engage in a variety of individual interventions "to promote independence, productivity, integration and inclusion of individuals with developmental disabilities and their families."

Response: We concur with this recommendation and have changed the regulation accordingly.

Comment: We received a comment on paragraph (b) of this section requesting significant changes to the NPRM language.

Response: We concur with the recommended language for § 1388.6(b) and have incorporated the language into the final rule. The revised language indicates that UAP community training and technical assistance activities must: (1) Use capacity building strategies to strengthen the capability of communities, systems and service providers; (2) plan collaboratively; (3) target to a wide range of audiences, including individuals with disabilities, family members, service and support personnel, and community members; (4) plan and be structured in a manner that facilitates the participation of targeted audiences; and (5) address the unique needs of individuals with developmental disabilities and their families from diverse cultural and ethnic groups.

Comment: A commenter requested the addition of a sentence to the language proposed in paragraph (c)(1) of this section indicating that "the UAP must maintain cooperative relationships with other community service providers, including specialized state and local providers, including specialized state and local provider agencies."

Response: We concur with the recommended language and have incorporated it into the final rule.

Section 1388.7 Program Criteria—Dissemination

Comment: In paragraph (a) of this section, a commenter recommended that the phrase "best practices" be added to the criteria regarding dissemination of information. Also, two comments were received requesting the addition of the following language. "Dissemination activities promote the independence, productivity, integration and inclusion of individuals with developmental disabilities and their families."

Response: We concur with these recommendations and have revised the final rule accordingly.

Comment: A commenter asked that we include in paragraph (b) reference to the fact that the UAP must be identified "by individuals with developmental disabilities and their families, community members, state agencies and other provider and advocacy organizations" as a resource for information, produce a variety of products to promote public awareness and visibility of the UAP, and facilitate replication of best practices.

Response: We agree with the suggested addition and have included it in the final rule with some modification for clarification purposes.

Comment: A commenter requested another program criteria for this section.

Response: We concur and have placed the following language in paragraph (i) of this section: (i) The UAP must contribute to the development of knowledge base through publications and presentations, including those based on research and evaluation conducted at the UAP.

Section 1388.9 Peer Review

Comment: A commenter requested that we include language in paragraph (a) of this section which indicates that the peer review process is "to provide the UAP with technical assistance and other recommendations to improve program quality and enhance response to program mandates."

Response: We do not concur with this language to be included in the final regulation. The provision of technical assistance is an administrative function of the Administration on Developmental Disabilities and is provided on an as needed basis. The Program Criteria are requirements for the University. Affiliated Program, not the administering agency.

Impact Analysis

Executive Order 12866

Executive Order 12866 requires that regulations be reviewed to ensure that they are consistent with the priorities and principles set forth in the Executive Order. The Department has determined that this rule is consistent with these priorities and principles. An assessment of the costs and benefits of available regulatory alternatives (including not regulating) demonstrated that the approach taken in the regulation is the most cost-effective and least burdensome while still achieving the regulatory objectives.

The final rule amends current regulation to implement changes made by the Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1990 (Pub. L. 101-496 and by the 1994 Amendments (Pub. L. 103-230). The regulations provide guidance on redesignation of the Protection and Advocacy agency and the appeal process; include regulations on the Protection and Advocacy annual statement of objectives; address State
Developmental Disabilities Council responsibilities and those of the
Designated State Agency; set new program standards for the University
Affiliated Program; and make other clarifying, technical, and conforming
changes.

We estimate that these regulations will not result in additional costs to the
Federal government, the States, universities and any other organizations
to which they may apply.

Regulatory Flexibility Act of 1980

Consistent with the Regulatory Flexibility Act (5 U.S.C. Ch.6), we try to
anticipate and reduce the impact of rules and paperwork requirements on
small businesses. For each rule with a "significant economic impact on a
substantial number of small entities", we prepare an analysis describing the
rule's impact on small entities. The primary impact of these regulations is
on the States, which are not "small entities" within the meaning of the Act.
However, they will affect small private institutions providing services to
individuals with developmental disabilities. This impact will be
minimal in that the institutions will simply be subject to review at no cost
when a complaint is made against them.

For the reasons noted in the preamble, 45 CFR chapter xm, Part 1385 is amended as follows:

(a) Section 1385.3 is amended by removing the section (c) and adding the

(b) Section 1385.4 is amended by adding the section (f) and removing the

(c) Section 1385.5 is amended by removing the section (g) and adding the

An analysis and a statement of objectives for the
Disability Flexibility Act of 1980 are included as part of the
Regulatory Flexibility Act. This analysis and statement of objectives is
available for review at the Office of Management and Budget
(OMB). OMB has reviewed these regulations and has determined that they
will not have a significant impact on a substantial number of small entities.
ACF means the Administration for Children and Families within the Department of Health and Human Services.

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

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

Developmental disability shall have the same meaning in 45 CFR parts 1385, 1386, 1387, and 1366 as it does in the Developmental Disabilities Act, section 102(8), which reads “the term ‘developmental disability’ means a severe, chronic disability of an individual 5 years of age or older that—

(1) Is attributable to a mental or physical impairment or combination of mental and physical impairments;

(2) Is manifested before the individual attains age 22;

(3) Is likely to continue indefinitely;

(4) Results in substantial functional limitations in three or more of the following areas of major life activity—

(i) Self-care;

(ii) Receptive and expressive language;

(iii) Learning;

(iv) Mobility;

(v) Self-direction;

(vi) Capacity for independent living; and

(vii) Economic self-sufficiency.

(5) Reflects the individual’s need for a combination and sequence of special, interdisciplinary, or generic services, supports, or other assistance that is of lifelong or extended duration and is individually planned and coordinated, except that such term, when applied to infants and young children means individual from birth to age 5, inclusive, who have substantial developmental delay or specific congenital or acquired conditions with a high probability of resulting in developmental disabilities if services are not provided.” Such determination shall be made on a case-by-case basis and any State eligibility definition of developmental disability or policy statement which is more restrictive than that of the Act does not apply as the Act takes precedence.

Protection and Advocacy Agency means the organization or agency designated in a State to administer and operate a protection and advocacy (P&A) system for individuals with developmental disabilities under part C of the Developmental Disabilities Assistance and Bill of Rights Act, as amended (A P&A System under part C is authorized to investigate incidents of abuse and neglect regarding persons with developmental disabilities; pursue administrative, legal and appropriate remedies or approaches to ensure protection of, and advocacy for, the rights of such individuals; and provide information on and referral to programs and services addressing the needs of such individuals (section 142(a)(2)(A)); and advocacy programs under the Protection and Advocacy for Mentally Ill Individuals Act of 1986 (PAIMI Act), as amended, (42 U.S.C. 10801 et seq.) the Protection and Advocacy of Individual Rights Program (PAIR), (29 U.S.C. 794(e); and the Technology-Related Assistance for Individuals With Disabilities Act of 1988, as amended (29 U.S.C. 2212(e)). The Protection and Advocacy agency also may be designated by the Governor of a State to conduct the Client Assistance Program (CAP) authorized by section 112 of the Rehabilitation Act of 1973, as amended, (29 U.S.C. 732). Finally, the Protection and Advocacy agency may provide advocacy services under other Federal programs.

4. Section 1385.4 is revised to read as follows:

§ 1385.4 Rights of individuals with developmental disabilities.

(a) Section 110 of the Act, Rights of individuals with Developmental Disabilities Act, is applicable to the programs authorized under the Act, except for the Protection and Advocacy System.

(b) In order to comply with section 122(c)(5)(G) of the Act (42 U.S.C. 6022(c)(5)(G)), regarding the rights of individuals with developmental disabilities, the State must meet the requirements of 45 CFR 1386.30(1)(2).

(c) Applications from university affiliated programs or for projects of national significance grants must also contain an assurance that the human rights of individuals assisted by these programs will be protected consistent with section 110 (see section 153(c)(3) and section 162(c)(3) of the Act).

§ 1385.5 [Removed and reserved]

5. Section 1385.5, Recovery of Federal funds used for construction of facilities is removed and reserved.

6. Section 1385.6 is revised to read as follows:

§ 1385.6 Employment of individuals with disabilities.

Each grantee which receives Federal funding under the Act must meet the requirements of section 109 of the Act (42 U.S.C. 6008) regarding affirmative action. The grantee must take affirmative action to employ and advance in employment and otherwise treat qualified individuals with disabilities without discrimination based upon their physical or mental disability in all employment practices such as the following: Advertising, recruitment, employment, rates of pay or other forms of compensation, selection for training, including apprenticeship, upgrading, promotion 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.

Recipient of funds under the Act also may be bound by the provisions of the Americans with Disabilities Act (Pub. L. 101–366, 42 U.S.C. 12101 et seq.) with respect to employment of individuals with disabilities. Failure to comply with section 109 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 D of 45 CFR part 1386.

§ 1385.7 [Reserved]

7. Section 1385.7 Waivers, is removed and reserved.

8. Section 1385.8 is amended by revising the introductory text to read as follows:

§ 1385.8 Formula for determining allocations.

The Commissioner will allocate funds appropriated under the Act for the State Developmental Disabilities Councils and the Protection and Advocacy Systems on the following basis:

9. Section 1385.9 is amended by revising the first sentence of paragraph (a); revising paragraphs (b), (c), and (d) and adding a new paragraph (e) to read as follows:

§ 1385.9 Grants administration requirements.

(a) The following parts of title 45 CFR apply to grants funded under parts 1386 and 1388 of this chapter and to grants for Projects of National Significance under section 162 of the Act (42 U.S.C. 6002).
(b) The Departmental Appeals Board also has jurisdiction over appeals by grantees which have received grants under the University Affiliated program or for Projects of National Significance. The scope of the Board's jurisdiction concerning these appeals is described in 45 CFR part 16.

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

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

(e) (1) The Department or other authorized Federal officials may access client and case eligibility records or other records of the Protection and Advocacy system for audit purposes and for purposes of monitoring system compliance pursuant to section 104(b) of the Act. However, such information will be limited pursuant to section 142(f) 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 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 system may elect to obtain a release from all individuals requesting or receiving services at the time of intake or application. The release shall state only information directly related to client and case eligibility will be subject to disclosure to officials of the Department.

PART 1386—FORMULA GRANT PROGRAMS

10. The authority citation for Part 1386 continues to read as follows:

Authority: 42 U.S.C. 6000 et seq.

Subpart A—Basic Requirements

11. Section 1386.1 is revised to read as follows:

§ 1386.1 General.

All rules under this subpart are applicable to both the State Developmental Disabilities Councils and the Protection and Advocacy Agencies.

12. Section 1386.2 is amended by revising paragraphs (b)(1), (c), to read as follows:

§ 1386.2 Obligation of funds.

(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 Developmental Disabilities Council enters into an Interagency Agreement with an agency of State government for acquisition of personal property or for the performance of work.

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

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

§ 1386.4 [Reserved]

13. § 1386.4. Eligibility for services is revised to read as follows:

Subpart B—State System for Protection and Advocacy of the Rights of Individuals with Developmental Disabilities

15. A new section 1386.19 is added to include definitions to read as follows:

§ 1386.19 Definitions.

As used in §§ 1386.20, 1386.21, 1386.22 and 1386.25 of this part the following definitions apply:

Abuse means any act or failure to act which was performed, or which was failed to be performed, knowingly, recklessly, or with intentional, and which caused, or may have caused, injury or death to an individual with developmental disabilities, and includes 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.

Complaint includes, but is not limited to any report or communication, whether formal or informal, written or oral, received by the system including media accounts, newspaper articles, telephone calls (including anonymous calls), from any source alleging abuse or neglect of an individual with a developmental disability.

Designating Official means the Governor or other State official, who is empowered by the Governor or State legislature to designate the State official or public or private agency to be accountable for the proper use of funds by and conduct of the State Protection and Advocacy agency.

Facility includes any setting that provides care, treatment, services and habilitation, even if only "as needed" or under a contractual arrangement. Facilities include, but are not limited to the following:

Community living arrangements (e.g., group homes, board and care homes, individual residences and apartments), day programs, juvenile detention
§ 1386.20 Designated State Protection and Advocacy agency.

(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 agency.

(b) The designating official must give written notice to the agency currently administering and operating the State Protection and Advocacy 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 all mean an individual appointed and regularly reviewed by a State court or agency empowered under State law to appoint and review such officers and having authority to make all decisions on behalf of individuals with developmental disabilities. It does not include persons acting only as a representative payee, person acting only to handle financial payments, attorneys or other persons acting or behalf of an individual with developmental disabilities only in individual legal matters, or officials responsible for the provision of treatment or habilitation services to an individual with developmental disabilities or their designees.

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

Probable cause means a reasonable ground for belief that an individual with developmental disabilities has been, or may be, subject to abuse or neglect. 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.

16. Section 1386.20 is amended by revising the heading; revising paragraphs (a), (d), and (e); and adding a new paragraph (f) to read as follows:

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 startup operations; and

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

(3) The public notice as required by paragraph (d)(1) of this section, must be in a format accessible to individuals with developmental disabilities and their representatives, e.g., tape, diskette. The designating official must provide for publication of the notice of the proposed redesignation using the State register, State-wide newspapers, public service announcements on radio and television, or any other legally equivalent process. Copies of the notice must be made generally available to individuals with developmental disabilities and mental illness who live in residential facilities through posting or some other means.

(4) After the expiration of the public comment period required in paragraph (d)(1) of this section, the designating official must conduct a public hearing on the redesignation proposal. After consideration of all public and agency comments, the designating official must give notice of the final decision to the currently designated agency and the public through the same means used under paragraph (d)(3) of this section. This notice must include a clear and detailed explanation of the good cause finding. If the notice to the currently designated agency states that the redesignation will take place, it also must inform the agency of its right to appeal this decision to the Assistant Secretary, Administration for Children and Families 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 Protection and Advocacy agency or, if the agency appeals, until the Assistant Secretary has considered the appeal.

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

(2) In the event that the agency subject to redesignation does exercise its right to appeal under paragraph (e)(1) of this section, the designating official must give public notice of the Assistant Secretary's final decision regarding the appeal through the same means utilized under paragraph (d)(3) of this section within 10 working days of receipt of the Assistant Secretary's final decision under paragraph (e)(6) of this section.

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

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

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

(6) Within 30 days of the informal meeting under paragraph (e)(5) of this section, or, if there is no informal meeting under paragraph (e)(5) of this section, within 30 days of the submission under paragraph (e)(3) of this section, the Assistant Secretary will issue to the parties a final written decision on whether the redesignation was for good cause as defined in paragraph (d)(6) of this section. The Assistant Secretary will consult with Federal advocacy programs that will be directly affected by the proposed redesignation in making a final decision on the appeal.

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

(2) In the event that the Protection and Advocacy agency subject to redesignation does not exercise its rights to appeal within the period provided under paragraph (e)(1) of this section, the designating official must provide to the Assistant Secretary documentation that the agency was redesignated for good cause. Such documentation must clearly demonstrate that the Protection and Advocacy agency subject to redesignation was not redesignated for any actions or activities which were carried out under section 142 of the Act, these regulations or any other Federal advocacy program's legislation or regulations.

17. Section 1386.21 is revised to read as follows:

§ 1386.21 Requirements and authority of the Protection and Advocacy System.

(a) In order for a State to receive Federal financial participation for Protection and Advocacy activities under this subpart, as well as the State Developmental Disabilities Council activities (subpart C of this part), the Protection and Advocacy System must meet the requirements of section 142 of the Act (42 U.S.C. 6042) 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 and in information and referral activities.

(c) A Protection and Advocacy System shall implement a policy or practice restricting any remedies which may be sought on the behalf of individuals with developmental disabilities or compromising the authority of the Protection and Advocacy System (P&A) to pursue such remedies through litigation, legal action or other forms of advocacy. However, the above requirement does not prevent the P&A from developing case or client acceptance criteria as part of the annual performance standards that would ensure that the P&A system can be supplant pursuant to section 142 of the Act (42 U.S.C. 6042) and that system must be operational.

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

(2) In the event that the Protection and Advocacy agency subject to redesignation does not exercise its rights to appeal within the period provided under paragraph (e)(1) of this section, the designating official must provide to the Assistant Secretary documentation that the agency was redesignated for good cause. Such documentation must clearly demonstrate that the Protection and Advocacy agency subject to redesignation was not redesignated for any actions or activities which were carried out under section 142 of the Act, these regulations or any other Federal advocacy program's legislation or regulations.

17. Section 1386.21 is revised to read as follows:

§ 1386.21 Requirements and authority of the Protection and Advocacy System.

(a) In order for a State to receive Federal financial participation for Protection and Advocacy activities under this subpart, as well as the State Developmental Disabilities Council activities (subpart C of this part), the Protection and Advocacy System must meet the requirements of section 142 of the Act (42 U.S.C. 6042) 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 and in information and referral activities.

(c) A Protection and Advocacy System shall implement a policy or practice restricting any remedies which may be sought on the behalf of individuals with developmental disabilities or compromising the authority of the Protection and Advocacy System (P&A) to pursue such remedies through litigation, legal action or other forms of advocacy. However, the above requirement does not prevent the P&A from developing case or client acceptance criteria as part of the annual performance standards that would ensure that the P&A system can be supplant pursuant to section 142 of the Act (42 U.S.C. 6042) and that system must be operational.

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

(2) In the event that the Protection and Advocacy agency subject to redesignation does not exercise its rights to appeal within the period provided under paragraph (e)(1) of this section, the designating official must provide to the Assistant Secretary documentation that the agency was redesignated for good cause. Such documentation must clearly demonstrate that the Protection and Advocacy agency subject to redesignation was not redesignated for any actions or activities which were carried out under section 142 of the Act, these regulations or any other Federal advocacy program's legislation or regulations.

17. Section 1386.21 is revised to read as follows:

§ 1386.21 Requirements and authority of the Protection and Advocacy System.

(a) In order for a State to receive Federal financial participation for Protection and Advocacy activities under this subpart, as well as the State Developmental Disabilities Council activities (subpart C of this part), the Protection and Advocacy System must meet the requirements of section 142 of the Act (42 U.S.C. 6042) 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 and in information and referral activities.

(c) A Protection and Advocacy System shall implement a policy or practice restricting any remedies which may be sought on the behalf of individuals with developmental disabilities or compromising the authority of the Protection and Advocacy System (P&A) to pursue such remedies through litigation, legal action or other forms of advocacy. However, the above requirement does not prevent the P&A from developing case or client acceptance criteria as part of the annual performance standards that would ensure that the P&A system can be supplant pursuant to section 142 of the Act (42 U.S.C. 6042) and that system must be operational.
§1386.22 Access to records, facilities and individuals with developmental disabilities.

(a) Access to records—A protection and advocacy (P&A) system shall have access to the records of the following individuals with developmental disabilities:

(1) An individual who is a client of the system, including any person who has requested assistance from the system, if authorized by that individual or their legal guardian, conservator or other legal representative.

(2) An individual, including an individual who has died or whose whereabouts is unknown, to whom all of the following conditions apply:

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

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

(iii) With respect to whom a complaint has been received by the system or the 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 or neglect.

(3) An individual who has a legal guardian, conservator, or other legal representative, with respect to whom a complaint has been received by the system or with respect to whom the system has determined that there is probable cause to believe that the health or safety of the individual is in serious and immediate jeopardy, whenever all of the following conditions exist:

(i) The system has made a good faith effort to contact the representative upon receipt of the representative's name and address;

(ii) The system has offered assistance to the representative to resolve the situation;

(iii) The representative has failed or refused to act on behalf of the individual.

(b) Individual records to which P&A systems must have access under section 142(A)(2)(I) (whether written or in another medium, draft or final, including handwritten notes, electronic files, photographs or video or audio tape records) shall include, but shall not be limited to:

(1) Records prepared or received in the course of providing intake, assessment, evaluation, education, training and other supportive services, including medical records, financial records, and monitoring and other reports prepared or received by a member of the staff of a facility that is providing care or treatment;

(2) Reports prepared by an agency charged with investigating incidents of abuse or neglect, injury or death occurring at a facility or while the individual with a developmental disability is under the care of a member of the staff of a facility, or by or for such facility, that describe any or all of the following:

(i) Abuse, neglect, injury, death;

(ii) The steps taken to investigate the incidents;

(iii) Reports and records, including personnel records, prepared or maintained by the facility in connection with such reports; or

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

(3) Discharge planning records.

(c) Information in the possession of a facility which must be available to P&A systems in investigating instances of abuse and neglect under section 142(a)(2)(B) of the Act (whether written or in another medium, draft or final, including handwritten notes, electronic files, photographs or video or audio tape records) shall include, but not be limited to:

(1) Information in reports prepared by individuals and entities performing certification or licensure reviews, or by professional accreditation organizations, as well as related assessments prepared for a facility by its staff, contractors or related entities, except that nothing in this section is intended to preempt State law protection records produced by medical care evaluation or peer review committees.

(2) Information in professional, performance, building or other safety standards, demographic and statistical information relating to a facility.

(d) A system shall be permitted to inspect and copy information and records, subject to a reasonable charge to offset duplicating costs.

(e) The client's record is the property of the Protection and Advocacy System which must protect it from loss, damage, tampering, or use by unauthorized individuals. The Protection and Advocacy System must:

(1) Keep confidential all information contained in a client's record, which includes, but is not limited to, information contained in an automated data bank. This regulation does not limit access by parents or legal guardians of minors unless prohibited by State or Federal law.

(f) Access to Facilities and individuals with Developmental Disabilities—A system shall have reasonable unaccompanied access to public and private facilities which provide services, supports, and other assistance for individuals with developmental disabilities in the State when necessary to conduct a full investigation of an incident of abuse or neglect under section 142(a)(2)(B) of the Act. This authority shall include the opportunity to:

(1) Interview any facility service recipient, employee, or other person, 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;

(2) To inspect, view and photograph all areas of the facility's premises that might be reasonably believed by the system to have been connected with the incident under investigation.

(g) Under section 142(a)(2)(H) of the Act, the system and all of its authorized agents shall have unaccompanied access to all residents of a facility at reasonable times, which at a minimum shall include normal working hours and visiting hours, for the purpose of:

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

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

(h) Unaccompanied access to residents of a facility shall include the opportunity to meet and communicate
privately with such individuals regularly, both formally and informally, by telephone, mail and in person.

(c) If a system is denied access to its \textit{objections}, which are faced by the State Developmental Disabilities Council and the University Affiliated Program in the final Statement submitted to the Department; and

(3) Address the Protection and Advocacy System; State Developmental Disabilities Council; the University Affiliated Program will collaborate with each other and with other public and private entities.

§ 1386.25 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 on individuals with developmental disabilities to obtain access to records and when it appears on behalf of named plaintiffs or a class of plaintiff for such purposes.

The heading of subpart C is revised to read as follows:

Subpart C—Federal Assistance to State Developmental Disabilities Councils

23. Section 1386.30 is amended by revising paragraphs (a) and (c)(1); redesignating paragraph (e) as (f); revising the newly redesignated paragraphs (f) republishing newly redesignated paragraph (g), introductory text; (2) and (3); and adding new paragraphs (c)(3) and (e) to read as follows:

§ 1386.30 State Plan requirements.

(a) In order to receive Federal financial assistance under this subpart, each State Developmental Disabilities Council must prepare and submit to the Secretary, and have in effect, a State Plan which meets the requirements of sections 122 and 124 of the Act (42 U.S.C. 6022 and 6024) and these regulations. Development of the State Plan and applicable annual amendments are responsibilities of the State Developmental Disabilities Council. The Council will provide opportunities for public input during the planning and development of the State Plan and will consult with the Designated State Agency to determine that the plan is not in conflict with...
applicable State laws and to obtain appropriate State Plan assurances.

(c) * * * * *
(1) Identify the program unit(s) within the Designated State Agency responsible for helping the Council to obtain assurances and fiscal and other support services.

(3) Where applicable, describe activities in which the State's Developmental Disabilities Council, Protection and Advocacy System agency, and University Affiliated Program(s) collaborate to remove barriers or address critical issues within the State and bring about broad systems changes to benefit individuals with developmental disabilities and, as appropriate, individuals with other disabilities.

(e) (1) The State Plan may provide for funding projects to demonstrate new approaches to direct services which enhance the independence, productivity, and integration and inclusion in the community of individuals with developmental disabilities. Direct service demonstrations must be short-term and include a strategy to locate on-going funding from other sources. For each demonstration funded, the State Plan must include an estimated period of the project's duration and a brief description of how the services will be continued without Federal developmental disabilities program funds. Council funds may not be used to fund on-going services which should be paid for by the State or other sources.

(2) The State plan may provide for funding of other projects or activities, including but not limited to, studies, evaluation, outreach, advocacy, self-advocacy, training, community supports, public education, and prevention. Where extended periods of time are needed to achieve desired results, these projects and activities need not be time-limited.

(f) The State Plan must contain assurances that:

(2) The human rights of individuals with developmental disabilities will be protected consistent with section 110 of the Act (42 U.S.C. 6009).

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

(4) The State Developmental Disabilities Council shall follow the requirements of section 124(c) (8), (9) and (10) of the Act regarding budgeting, staff hiring and supervision and staff assignment. Budget expenditures must be consistent with applicable State laws and policies regarding grants and contracts and proper accounting and bookkeeping practices and procedures.

In relation to staff hiring, the clause "consistent with State law" in section 124(c)(9) means that the hiring of State Developmental Disabilities Council staff must be done in accordance with State personnel policies and procedures except that a State shall not apply hiring freezes, reductions in force, prohibitions on staff travel, or other policies, to the extent that such policies would impact staff or functions funded with Federal funds and would prevent the Council from carrying out its functions under the Act.

24. Section 1386.31 is amended by revising the section heading, redesignating the current paragraphs (a), (b), (c), and (d) as (b), (c), (d), and (e), and adding a new paragraph (a) to read as follows:

§ 1386.31 State Plan submittal and approval.

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

25. Section 1386.32 is revised to read as follows:

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

(a) The Governor or appropriate State financial officer must submit financial status reports on the programs funded under this subpart according to a frequency interval which will be specified by the Administration for Children and Families. In no case will such reports be required more frequently than quarterly.

(b) Pursuant to section 107(a) of the Act (U.S.C. 6006a), the State Developmental Disabilities Council shall submit an Annual Program Performance Report in a form that facilitates Council reporting of results of activities required under sections 122 and 124 of the Act. The report shall be submitted to the appropriate Regional ACF office, by January 1 of each year.

26. Section 1386.33 is amended by revising paragraph (e) as follows:

§ 1386.33 Protection of employee's interests.

(a) Based on section 122(c)(5)(K) of the Act (42 U.S.C. 6022(c)(5)(K)), 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. Specific arrangements for the protection of affected employees must be developed through negotiations between the appropriate State authorities and employees or their representatives. 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. The State must inform employees of the State's decision to provide for community living activities.

27. Section 1386.34 is added to read as follows:

§ 1386.34 Designated State Agency.

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

(1) Provision of financial reporting and other services as provided under section 124(d)(3)(C) 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 Developmental Disabilities Council requests a review by the Governor (or legislature) of the Designated State Agency, the Council must provide documentation of the reason for change and recommend a preferred Designated State Agency.

(c) After the review is completed, a majority of the non-State agency members of the Council may appeal to the Assistant Secretary for a review of the designation of the designated State agency if the Council's independence as an advocate is not assured because of the action or inaction of the designated State agency.

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

(1) Prior to an appeal to the Assistant Secretary, Administration for Children and Families, the State Developmental Disabilities Council, must give a 30 day written notice, by certified mail, to the Governor (or legislature) 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 actions or inactions of the designated State agency.

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

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

(5) During any time of this appeals process the State Developmental Disabilities Council may withdraw such request if resolution has been reached with the Governor (or legislature) on the designation of the Designated State Agency. The Governor (or legislature) must notify the Assistant Secretary in writing of such an occurrence.

(a) The designated State agency may authorize the Council use or contract with State agencies other than the designated State agency to perform functions of the designated State agency.

28. Section 1386.35 is amended by revising the heading and paragraph (b)(1) and adding new paragraphs (d), (e), and (f) to read as follows:

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

|   |   |   |   |   |

(b) * * *

(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 110 of the Act (42 U.S.C. 6009).

* * * * *

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

(1) Expenditures for projects or activities carried out directly by the Council and Council staff, as described in section 125A(a)(2) of the Act, require no non-Federal aggregate participation.

(2) Expenditures for projects with activities or projects targeted to urban or rural poverty areas but not carried out directly by the Council and Council staff, as described in section 125A(a)(2) of the Act, shall have non-Federal participation of at least 10% in the aggregate.

(3) All other activities not directly carried out by the Council and Council staff, shall have non-Federal participation of at least 25% in the aggregate.

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

29. Section 1386.36 is amended by revising the section heading and paragraph (e) to read as follows:

§ 1386.36 Final disapproval of the State plan or plan amendment.

|   |   |   |   |   |

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

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

30. Section 1386.80 is revised to read as follows:

§ 1386.80 Definitions.

For purposes of this subpart:

Assistant Secretary means the Assistant Secretary for Children and Families (ACF).

ADD means Administration on Developmental Disabilities, Administration for Children and Families.

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

Payment or Allotment means an amount provided under Part B or C of the Developmental Disabilities Assistance and Bill of Rights Act. 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.”

31. Section 1386.85 is amended by revising paragraph (a) to read as follows:

§ 1386.85 Filing and service of papers.

(a) All papers in the proceeding 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.

* * * * *

32. Section 1386.90 is revised to read as follows:

§ 1386.90 Notice of hearing or opportunity for hearing.

Proceedings are commenced by mailing a notice of hearing or opportunity for hearing from the Assistant Secretary to the State Developmental Disabilities Council 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 which will be considered. The notice must be published in the Federal Register.

33. Section 1386.92 is revised to read as follows:
§ 1386.92 Place.

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

34. Section 1386.93 is amended by revising paragraphs (c)(2) and (d) to read as follows:

§ 1386.93 Issues at hearing.

(c) * * *

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

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

§ 1386.94 Request to participate in hearing.

(a) The Department, the State, the State Developmental Disabilities Council, 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) * * *

(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 present;

(iv) Whether the petitioner intends to present witnesses.

§ 1386.111 Decisions following hearing.

(c) If the Assistant Secretary concludes:

(1) In the case of a hearing pursuant to sections 122, 127, or 142 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 must also specify whether the State's payment or allotment will not be made available to the State or whether, in the exercise of his or her discretion, the payment or allotment will be limited to the parts of the State plan not affected by such noncompliance. The Assistant Secretary may ask the parties for recommendations or briefs or may hold conferences of the parties on these questions.

(d) The decision of the Assistant Secretary under this section is the final decision of the Secretary and constitutes "final agency action" within the meaning of 5 U.S.C. 704 and the "Secretary's action" within the meaning of Section 129 of the Act (42 U.S.C. 6092). The Assistant Secretary's decision must be promptly served on all parties and amici.

38. Section 1386.112 is amended by revising paragraphs (a) and (b) to read as follows:

§ 1386.112 Effective date of decision by the Assistant Secretary.

(a) If, in the case of a hearing pursuant to section 122 of the Act, the Assistant Secretary concludes that a State plan does not comply with Federal requirements, and the decision provides that the payment or allotment will be authorized but limited to parts of the
State plan not affected by such noncompliance, the decision must specify the effective date for the authorization of the payment or allotment.

(b) In the case of a hearing pursuant to section 1387 or 142 of the Act, if the Assistant Secretary concludes that the State is not complying with the requirements of the State plan or 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's Protection and Advocacy System not affected, must specify the effective date for withholding payments of allotments.

PART 1387—PROJECTS OF NATIONAL SIGNIFICANCE

39. The authority citation for part 1387 continues to read as follows:
Authority: 42 U.S.C. 6000 et seq.

40. Section 1387.1 is amended by revising paragraphs (a), (b), and (d) to read as follows:

§ 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 section 162 of the Act.
(b) Based on section 162(d), proposed priorities for grants and contracts will be published in the Federal Register and a 60 day period for public comments will be allowed.
(d) Projects of National Significance, including technical assistance and data collection grants, must be exemplary and innovative models and have potential for dissemination or knowledge utilization at the local level as well as nationally or otherwise meet the goals of part E of the Act.

41. Part 1388 is revised to read as follows:

PART 1388—THE UNIVERSITY AFFILIATED PROGRAMS

Sec.
1388.1 Definitions.
1388.2 Program criteria—purpose.
1388.3 Program criteria—mission.
1388.4 Program criteria—governance and administration.
1388.5 Program criteria—preparation of personnel.
1388.6 Program criteria—services and supports.
1388.7 Program criteria—dissemination.
1388.8 [Reserved].
1388.9 Peer review.
Authority 42 U.S.C. 6063 et seq.

§ 1388.1 Definitions.
For purposes of this part: Accessible means UAPs are characterized by their program and physical accommodation and their demonstrated commitment to the goals of the Americans with Disabilities Act. Capacity Building means that UAPs utilize a variety of approaches to strengthen their university and their local, State, regional and National communities. These approaches include, but are not limited to such activities as:

1. Enriching program depth and breadth, for example, recruiting individuals with developmental disabilities and their families, local community leaders, additional faculty and students to participate in the UAP;
2. Acquiring additional resources, for example, grants, space, and volunteer manpower; and
3. Carrying out systems changes, for example, promoting inclusive programming for persons with developmental disabilities across all ages.

Collaboration means that the UAP cooperates with a wide range of persons, systems, and agencies, whether they utilize services of the UAP or are involved in UAP planning and programs. These entities include individuals with developmental disabilities and family members, as well as the State Developmental Disabilities Councils, the Protection and Advocacy agencies, other advocacy and disability groups, university components, generic and specialized human service agencies, State agencies and citizen and community groups. An example of this cooperation is the Consumer Advisory Committee, a required element in each UAP.

Cultural Diversity means that UAPs are characterized by their commitment to involve individuals with disabilities, family members and trainees from diverse cultural backgrounds in all levels of their activities. This commitment to cultural diversity means that each UAP must assure that individuals from racial and ethnic minority background are fully included; that efforts are made to recruit individuals from minority backgrounds into the field of developmental disabilities; that specific efforts must be made to ensure that individuals from minority backgrounds have effective and meaningful opportunities for full participation in the developmental disabilities service system; and that recruitment efforts at the levels of preservice training, community training, practice, administration and policymaking must focus on bringing large numbers of racial ethnic minorities into the field in order to provide appropriate skills, knowledge, role models, and sufficient personnel to address the growing needs of an increasingly diverse population.

Culturally competent means provision of services, supports, or other assistance in a manner that is responsive to the beliefs, interpersonal styles, attitudes, language and behaviors of individuals who are receiving services, and that has the greatest likelihood of ensuring their maximum participation in the program.

Diverse Network means that although each UAP has the same mandates under the Act, the expression of these common mandates differs across programs. Each UAP must implement these mandates within the context of their host university, their location within the university, the needs of the local and State community, the cultural composition of their State, their resources and funding sources, and their institutional history. These factors converge to create a network of unique and distinct programs, bound together by common mandates but enriched by diverse composition.

Interdisciplinary Training means the use of individuals from different professional specialties for UAP training and service delivery.

Lifespan Approach means that UAP activities address the needs of individuals with disabilities who are of all ages.

Mandated Core Functions means the UAP must perform:
1. Interdisciplinary preservice preparation;
2. Community service activities (community training and technical assistance); and
3. Activities related to dissemination of information and research findings.

Program Criteria means a statement of the Department's expectation regarding the direction and desired outcome of the University Affiliated Program's operation.

Research and evaluation means that the UAP refines its activities on the basis of evaluation results. As members of the university community, involvement in program-relevant research and development of new knowledge are important components of UAPs. State-of-the-art means that UAP activities are of high quality (using the latest technology), worthy of replication (consistent with available resources), and systematically evaluated.
§ 1388.2 Program criteria—purpose.

The program criteria will be used to assess the quality of the University Affiliated Programs (UAP). The overall purpose of the program criteria is to assure the promotion of independence, productivity, integration and inclusion of individuals with developmental disabilities. Compliance with the program criteria is a prerequisite for a UAP to receive the minimum funding level of a UAP. However, compliance with the program criteria does not, by itself, assure funding. The Program Criteria are part of the Quality Enhancement System (QES), and provide a structure for self-assessment and peer review of each UAP. (The QES is a holistic approach to enable persons with developmental disabilities and their families to achieve maximum potential. All UAPs use the QES.)

§ 1388.3 Program criteria—mission.

(a) Introduction to mission: The UAP is guided by values of independence, productivity, integration and inclusion of individuals with developmental disabilities and their families. The purpose and scope of the activities must be consistent with the Act as amended and include the provision of training, service, research and evaluation, technical assistance and dissemination of information in a culturally competent manner, including the meaningful participation of individuals from diverse racial and ethnic backgrounds. (The concept of “diverse network” as defined in § 1388.1 of this part applies to paragraphs (b), (c), (d), (e), and (f) of this section.)

(b) The UAP must develop a written mission statement that reflects its values and promotes the goals of the university in which it is located, including training, the development of new knowledge and service. The UAP’s goals, objectives and activities must be consistent with the mission statement.

(c) The UAP’s mission and programs must reflect a life span approach, incorporate an interdisciplinary approach and include the active participation of individuals with developmental disabilities and their families.

(d) The UAP programs must address the needs of individuals with developmental disabilities, including individuals with developmental disabilities who are uninsured or underserved, in institutions, and on waiting lists.

(e) The UAP’s mission must reflect a commitment to culturally competent attitudes and practices, which are in response to local culture and needs.

(f) The UAP’s mission must reflect its unique role as a bridge between university programs, individuals with developmental disabilities and their families, service agencies and the larger community.

(g) The UAP’s goals, objectives, and activities must be consistent with the mission statement and use capacity building strategies to address State’s needs.

(h) The UAP’s goals, objectives, and activities must reflect interagency collaborations and strategies to effect systemic change within the university and in State and local communities and service systems.

§ 1388.4 Program criteria—governance and administration.

(a) Introduction to governance and administration: The UAP 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. (The concept of “diverse network” as defined in § 1388.1 of this part applies to paragraphs (b), (c), (d), (e), and (f) of this section.)

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

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

(d) The UAP must report directly to a University administrator who will represent the interests of the UAP within the University.

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

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

(g) UAP 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 UAP must meet the requirements of section 109 of the Act (42 U.S.C. 6006) regarding affirmative action. The UAP 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.

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

(j) The UAP’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 UAP is located. The deliberations of the Consumer Advisory Committee must be reflected in UAP policies and programs.

(k) The UAP must maintain collaborative relationships with the State Developmental Disabilities Council and the Protection and Advocacy agency. In addition, the UAP must be a member of the State Developmental Disabilities Council and participate in Council meetings and activities, as prescribed by the Act.

(l) The UAP must maintain collaborative relationships and be an active participant with the UAP network and individuals, organizations, State agencies and Universities.

(m) The UAP must demonstrate the ability to leverage resources.

(n) The UAP must have adequate space to carry out the mandated activities.

(o) The UAP physical facility and all program initiatives conducted by the UAP 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.

(p) The UAP must integrate the mandated core functions into its activities and programs and must have a written plan for each core function area.

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

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

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

§ 1388.5 Program criteria—preparation of personnel.

(a) Introduction to preparation of personnel: UAP interdisciplinary training programs reflect state-of-the-art practices and prepare personnel concerned with developmental disabilities to promote the independence, productivity, integration and inclusion of individuals with developmental disabilities and their families.

(b) UAP interdisciplinary training programs must be based on identified personnel preparation needs and have identified outcomes that are consistent with the mission and goals of the UAP.

(c) The interdisciplinary training process, as defined by the UAP, must reflect a mix of students from diverse academic disciplines/academic programs and cultures that reflect the diversity of the community. Faculty represent a variety of backgrounds and specialties, including individuals with disabilities and family members, and a variety of learning experiences, as well as reflecting the cultural diversity of the community. Trainees must receive academic credit as appropriate for participation in UAP training programs.

(d) Preservice training must be integrated into all aspects of the UAP, including community training and technical assistance, direct services (if provided), and dissemination.

(e) Trainees must be prepared to serve in a variety of roles, including advocacy and systems change. The UAP must encourage graduates to work in situations where they will promote the independence, productivity, integration and inclusion of individuals with developmental disabilities and their families.

(f) The UAP must influence University curricula to prepare personnel who, in their future career in a broad range of social and community roles, will contribute to the accommodation and inclusion of individuals with developmental disabilities, as mandated in the Americans with Disabilities Act.

(g) The UAP core curriculum must incorporate cultural diversity and demonstrate cultural competence. Trainees must be prepared to address the needs of individuals with developmental disabilities and their families in a culturally competent manner.

(h) The UAP core curriculum must prepare trainees to be active participants in research and dissemination efforts. In addition, the curriculum must prepare trainees to be consumers of research as it informs practice and policy.

§ 1388.6 Program criteria—services and supports.

(a) Introduction to services and supports: The UAP engages in a variety of system interventions and may also engage in a variety of individual interventions to promote independence, productivity, integration and inclusion of individuals with developmental disabilities and their families.

(b) UAP community training and technical assistance activities must:

(1) Use capacity building strategies to strengthen the capability of communities, systems and service providers;

(2) Plan collaboratively, including the participation of individuals with developmental disabilities and their families;

(3) Target a wide range of audiences, including individuals with developmental disabilities, family members, service and support personnel, and community members;

(4) Plan and be structured in a manner that facilitates the participation of targeted audiences; and

(5) Address the unique needs of individuals with developmental disabilities and their families.

(i) UAP dissemination activities must:

(1) Assist in coordination for dissemination of information for individuals with developmental disabilities and their families, community members, State agencies and other provider and advocacy organizations, produce a variety of products to promote public awareness and visibility of the UAP, and facilitate replication of best practices.

(b) The UAP must be a resource for information for individuals with developmental disabilities and their families, community members, State agencies and other provider and advocacy organizations, produce a variety of products to promote public awareness and visibility of the UAP, and facilitate replication of best practices.

(c) Specific target audiences must be identified for dissemination activities and include individuals with developmental disabilities, family members, service providers, administrators, policy makers, university faculty, researchers, and the general public.

(d) UAP dissemination activities must be responsive to community requests for
information and must utilize a variety of networks, including State Developmental Disabilities Councils, Protection and Advocacy agencies, other University Affiliated Programs, and State service systems to disseminate information to target audiences.

(a) The process of developing and evaluating materials must utilize the input of individuals with developmental disabilities and their families.

(b) The process of developing and evaluating materials must utilize the input of individuals with developmental disabilities and their families.

(c) Dissemination products must reflect the cultural diversity of the community.

(h) Materials disseminated by the UAP must be available in formats accessible to individuals with a wide range of disabilities, and appropriate target audiences.

(i) The UAP must contribute to the development of the knowledge base through publications and presentations, including those based on research and evaluation conducted at the UAP.

§ 1388.8 [Reserved]

§ 1388.9 Peer review.

(a) The purpose of the peer review process is to provide the Commissioner, ADD, with technical and qualitative evaluation of UAP applications, including on-site visits or inspections as necessary.

(b) Applications for funding opportunities under part D, Section 152 of the Act, must be evaluated through the peer review process.

(c) Panels must be composed of non-Federal individuals who, by experience and training, are highly qualified to assess the comparative quality of applications for assistance.

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