LEGISLATION:

The final rule implemented the Act's amendments of 1990 and 1994.

The Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1990, Pub.L. 101-496, (the Act), made such revisions as:

1. included 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. strengthened the independence of State Protection and Advocacy systems;

3. established core awards for University Affiliated Programs training projects; and

4. broadened 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), made such revisions as:

1. included 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. ensured 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) required State Developmental Disabilities Council activities to promote systemic change, capacity-building and advocacy;

(A) clarified the responsibilities of the State Developmental Disabilities Council and the Designated State Agency;

required 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) protected the confidentiality of client records;

(7) required development of new program standards for University Affiliated Programs; and

(8) directed 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. There were no amendments.

KEY REGULATORY PROVISIONS

SUBCHAPTER I--THE ADMINISTRATION ON DEVELOPMENTAL DISABILITIES, DEVELOPMENTAL DISABILITIES PROGRAM

PART 1385--REQUIREMENTS APPLICABLE TO THE DEVELOPMENTAL DISABILITIES PROGRAM

Section 1385.3 updated DEFINITIONS...

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 1388 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--

(A) is attributable to a mental or physical impairment or combination of mental and physical impairments;

(B) is manifested before the individual attains age 22;

(C) is likely to continue indefinitely;

(D) 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

(E) 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
Section 1385.6 is updated re 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, demotion or transfer, and layoff or termination. This obligation is in addition to the requirements of 45 CFR Part 84, Subpart B, prohibiting discrimination in employment practices on the basis of disability in programs receiving assistance from the Department. Recipients of funds under the Act also may be bound by the provisions of the Americans with Disabilities Act [Pub. L. 101-336, 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.

Section 1385.9 Grants administration requirements was updated re P&A and access to client records.

(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(j) 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

Subpart A--Basic Requirements

Section 1386.2 was amended to include additional guidance re obligation of funds...

:b) (i) 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.

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.

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

A new section 1386.19 was added to include definitions tied to the P&As:

Abuse means any act or failure to act which was performed, or which was failed to be performed, knowingly, recklessly, or intentionally, and which caused, or may have caused, injury or death to an individual with developmental disabilities, and includes 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.
centers, hospitals, nursing homes, homeless shelters, jails and prisons.

Full Investigation means access; to facilities, clients and records authorized under these regulations, that is necessary for a protection and advocacy (P&A) system to make a determination about whether alleged or suspected instances of abuse and neglect are taking place or have taken place. Full investigations may be conducted independently or in cooperation with other agencies authorized to conduct similar investigations.

Legal Guardian, conservator and legal representative 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 on 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.

Section 1386.20, Designated State Protection and Advocacy agency updated the redesignation process.
(d)(1) Prior to any redesignation of the agency which administers and operates the State Protection and Advocacy (P&A) System, the designating official must give written notice of the intention to make the redesignation to the agency currently administering and operating the State Protection and Advocacy System by registered or certified mail. The notice must indicate that the proposed redesignation is being made for good cause. The designating official must also publish a public notice of the proposed action. The agency and the public shall have a reasonable period of time, but not less than 45 days to respond to the notice.

(2) The public notice must include:

(i) The Federal requirements for the Protection and Advocacy system for individuals with developmental disabilities (section 142 of the Act); and, where applicable, the requirements of other Federal advocacy programs administered by the State Protection and Advocacy System.

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

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

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

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

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

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

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

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

(x) A statement of assurance that the proposed new designated State 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.

The public notice as required by paragraph (d)(1) of this section, must be in a format accessible to individuals with developmental disabilities or their representatives, e.g., tape, diskette. The designating official must provide for publication of the notice of the proposed redesignation using the State register, 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.

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)(i) 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.

1) 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. To do so, 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 responses to those comments.

4) In the event that the designating official withdraws the redesignation while under appeal pursuant to paragraph (e)(1) of this section, the designating official must notify the Assistant Secretary, and the current agency, and must give public notice of his or her decision through the same means utilized under paragraph (d)(3) of this section.
(5) As part of their submission under paragraph (e)(1) or (e)(3) of this section, either party may request, and the Assistant Secretary may grant, an opportunity for an informal meeting with the Assistant Secretary at which representatives of both parties will present their views on the issues in the appeal. The meeting will be held within 20 working days of the submission of written comments by the designating official under paragraph (e)(2) of this section. The Assistant Secretary will promptly notify the parties of the date and place of the meeting.

(6) Within 30 days of the informal meeting under paragraph (e)(5) of this section, or, if there is no informal meeting under paragraph (e)(5) of this section, within 30 days of the submission under paragraph (e)(3) of this section, the Assistant Secretary will issue to the parties a final written decision on whether the redesignation was for good cause as defined in (d)(1) 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.

(f)(1) Within 30 days after the redesignation becomes effective under paragraph (d)(4) of this section, the designating official must submit an assurance to the Assistant Secretary that the newly designated 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.

Section 1386.21, Requirements and authority of the Protection and Advocacy System was extensively updated.
(b) Allotments must be used to supplement and not to supplant the level of non-federal funds available in the State for activities under the Act, which shall include activities on behalf of individuals with developmental disabilities to remedy abuse, neglect and violations of rights as well as information and referral activities.

(c) A Protection and Advocacy System shall not implement a policy or practice restricting the 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 priorities identified by the P&A system as described in §1386.23(c) of this part. Clients must be informed at the time they apply for services of such criteria.

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

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

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

(g) Each P&A system that is a public system without a multimember governing or advisory board must establish an advisory council in order to provide a voice for individuals with developmental disabilities. The Advisory Council shall advise the P&A on program
policies and priorities and shall be comprised of a majority of individuals with developmental disabilities who are eligible for services, or have received or are receiving services or parents or family members, (including those representing individuals with developmental disabilities who live in institutions and home and community based settings), guardians, advocates, or authorized representatives of such individuals.

(h) Prior to any Federal review of the State program, a 30 day notice and an opportunity for public comment must be provided. Reasonable effort shall be made by the appropriate Regional Office to seek comments through notification to major disability advocacy groups, the State Bar, other disability law resources, the State Developmental Disabilities Council and the University Affiliated Program, for example, through newsletters and publications of those organizations. The findings of public comments may be consolidated if sufficiently similar issues are raised and they shall be included in the report of the onsite visit.

(i) Before the P&A system releases information to individuals not otherwise authorized to receive it, the P&A must obtain written consent from the client requesting assistance, if competent, or his or her guardian.

Section 1386.22 was ADDED to emphasize the requirements regarding 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 any 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 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; and

(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 of incidents; 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) (whether written or in another medium, draft or final, including hand written 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.
A system shall be permitted to inspect and copy information and records, subject to a reasonable charge to offset duplicating costs.

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 records, 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, court order or the rules of attorney-client privilege;

2. Have written policies governing access to, storage of, duplication of, and release of information from the client's record; and

3. Be authorized to keep confidential the names and identity of individuals who report incidents of abuse and neglect and individuals who furnish information that forms the basis for a determination that probable cause exists.

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 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; and 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.

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 and training 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.

(i) If a system is denied access to facilities and its programs, individuals with developmental disabilities, or records covered by the Act 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 was updated to include the Annual Statement of Objectives and Priorities:

(c) By January 1 of each year, the Protection and Advocacy System shall submit an Annual Statement of Objectives and Priorities, (SOP) for the coming fiscal year as required under Section 1421(a) (2) (C) of the Act.

(1) The SOP is a description and explanation of the priorities and selection criteria for the system's individual advocacy caseload; systemic advocacy work and training activities, and the outcomes which it strives to accomplish.

(2) Where applicable, the SOP must include a description of how the Protection and Advocacy System operates and how it coordinates the Protection and Advocacy program for individuals with developmental disabilities with other Protection and Advocacy (P&A) programs administered by the State Protection and Advocacy System. This description must address the System's intake process, internal and external
referrals of eligible clients, duplication and overlap of services and eligibility, streamlining of advocacy services, collaboration and sharing of information on service needs and development of Statements of Objectives and Priorities for the various advocacy programs.

(3) Priorities as established through the SOP serve as the basis for PSAs to determine which cases are selected in a given fiscal year. P&As have the authority to turn down a request for assistance when it is outside the scope of the SOP but they must inform individuals that this is the basis for turning them down.

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

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

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

(3) Provide to the State Developmental Disabilities Council and the University Affiliated Program a copy of the proposed Statement of Objectives and Priorities for comments concurrently with the public notice;

(4) Incorporate or address any comments received through the public input and any input received from the State Developmental Disabilities Council and the University Affiliated Program in the final Statement submitted to the Department; and

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

Section 1386.24, Non-allowable costs were updated:

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

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

A new section 1386.25 is added to provide guidance on allowable costs in relation to the issue of "standing":

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

Subpart C--Federal Assistance to State Developmental Disabilities Councils

Key areas regarding Section 1386.30 State Plan requirements included regulations regarding collaboration activities, the funding of projects and administrative provisions on budgeting, staff hiring, supervision and staff assignment:

(c)(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.

The State Plan may provide for funding projects to demonstrate new approaches to direct services which enhance the independence, productivity, and integration and inclusion into 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.

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:

(4) The State Developmental Disabilities Council shall follow the requirements of §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 §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.

Section 1386.31 State Plan submittal and approval, regulations included guidance on a public review and comment process on the State Plan:

(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 in 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.

A NEW Section 1386.34 was included to address the requirements of the Designated State Agency, especially on the redesignation of the DSA and the right to appeal by non-State agency members of the State DD Council to the Assistant Secretary.

(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.

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.

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 actions or inactions of the designated State agency.

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.

(e) 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.

Section 1386.35 Allowable and non-allowable costs for Federal Assistance to State Developmental Disabilities Councils included new regulations to clarify implementation of the non-Federal share requirements:

(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 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.

(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.

Several technical and editorial updates were made to Subpart D--Practice and Procedure for Hearings Pertaining to States' Conformity and Compliance with Developmental Disabilities State Plans, Reports and Federal Requirements. Key changes included:

In Section 1386.80 selected definitions:

- **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."

Section 1386.92, Place. Language regarding accessibility was included:

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.

Part 1387--PROJECTS OF NATIONAL SIGNIFICANCE
Technical changes were made to Section 1387.1, General requirements, along with language to define the type of project ADD considers most appropriate for funding with this limited amount of discretionary money:

(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.

Part 1388 WAS COMPLETELY REVISED TO UPDATE THE STANDARDS ISSUED THROUGH THE FEDERAL REGISTER ON NOVEMBER 20, 1987:

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 systemically 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 one 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), (f), (g), and (h) 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 unserved 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), (i), and (l) 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, the university commitment to the UAP, and 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. 6008] 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. The UAP must refine and strengthen its programs based on evaluation findings.

(s) 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.

8.6 Program criteria - services and supports.

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.

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 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 who reside within the geographic locale.

Direct Services. These requirements apply only where direct services are offered.

(1) A UAP must integrate direct services and projects into community settings. These services may be provided in a service delivery site or training setting within the community including the university. Direct service projects may involve interdisciplinary student trainees, professionals from various disciplines, service providers, families and/or administrators. Direct services must be extended, as appropriate, to include adult and elderly individuals with developmental disabilities. The UAP must maintain cooperative relationships with other community service providers, including specialized state and local provider agencies.
Services and projects provided in community-integrated settings are to:

(i) Be scheduled at times and in places that are consistent with routine activities within the local community; and

(ii) Interact with and involve community members, agencies, and organizations.

The bases for the services or project development must be:

(i) A local or universal need that reflects critical problems in the field of developmental disabilities; or

(ii) An emerging, critical problem that reflects current trends or anticipated developments in the field of developmental disabilities.

State-of-the-art and innovative practices include:

(i) Services and project concepts and practices that facilitate and demonstrate independence for the individual, community integration, productivity, and human rights;

(ii) Practices that are economical, accepted by various disciplines, and highly beneficial to individuals with developmental disabilities, and that are integrated within services and projects;

(iii) Innovative cost-effective concepts and practices that are evaluated according to accepted practices of scientific evaluation;

(iv) Research methods that are used to test hypotheses, validate procedures, and field test projects; and

(v) Direct service and project practices and models that are evaluated, packaged for replication and disseminated through the information dissemination component.

§1388.7 Program criteria - dissemination.

(a) Introduction to dissemination:
The UAP disseminates information and research findings, including the empirical validation of activities related to training, best practices, services and
supports, and contributes to the development of new knowledge. Dissemination activities promote the independence, productivity, integration and inclusion of individuals with developmental disabilities and their families.

(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.

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

(f) The values of the UAP must be reflected in the language and images used in UAP products.

(g) 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.