**Fact Sheet: Projects of National Significance**

Adapted from Administration on Intellectual and Developmental Disabilities (AIDD) <http://www.acl.gov/NewsRoom/Publications/docs/PNSfactsheet.pdf>

Projects of National Significance (PNS) focus on the most pressing issues affecting people with developmental disabilities and their families, creating and enhancing opportunities for these individuals to contribute to, and participate in, all facets of community life. Through PNS, the

Administration on Intellectual and Developmental Disabilities (AIDD) supports the development of national and state policy and awards grants and contracts that enhance the independence, productivity, inclusion, and integration of people with developmental disabilities.

Current PNS priorities include improving state employment policies and employment outcomes of individuals with developmental disabilities, collecting data on family support and service outcomes, and providing technical assistance and training for AIDD network entities. One project is currently collecting and analyzing data on individual and service outcomes and family services and supports.

***Short-Term Projects, Long-Term Differences***

Projects are typically short term (1–5 years) and address critical issues. PNS funds have supported families, increased community living options, assisted with family leadership development, and increased opportunities for involving self-advocates in systems change initiatives.

***Supporting Emerging Needs***

PNS projects enable more rapid response to emerging issues by targeting unserved or underserved areas, with the intent of eventually implementing programs on a broader, national level. Program activities include helping individuals develop self-advocacy and leadership skills, creating opportunities for economic development in communities, and developing initiatives to improve individuals’ employment outcomes. For example, the Autism NOW project collects and disseminates the most current information and resources on autism through its website to empower individuals and their families.

***Ongoing Longitudinal Data Collection***

PNS funds support national long-term data collection projects that help policymakers, service providers, and individuals with developmental disabilities and their families make the most informed policy and individual care decisions. These studies allow for an overarching, higher-level evaluation of the conditions of individuals with developmental disabilities in the United States.

**Fact Sheet: State Councils on Developmental Disabilities**

Adapted from Administration on Intellectual and Developmental Disabilities <http://www.acl.gov/NewsRoom/Publications/docs/Councils_factsheet.pdf>

State Councils on Developmental Disabilities (Councils) are federally funded, self-governing organizations charged with identifying the most pressing needs of people with developmental disabilities in their state or territory. Councils are committed to advancing public policy and systems change that help these individuals gain more control over their lives.

The 56 Councils across the United States and its territories work to address identified needs by conducting advocacy, systems change, and capacity building efforts that promote self-determination, integration, and inclusion. Key activities include conducting outreach, providing training and technical assistance, removing barriers, developing coalitions, encouraging citizen participation, and keeping policymakers informed about disability issues.

***Diverse Council Membership***

Council members are appointed by a state’s governor; by law, more than 60 percent of a Council’s membership must consist of individuals with developmental disabilities or their family members.

Advocates and state agency representatives also serve as members. This diversity enables Councils to better analyze and improve systems and services within a state and ensure that the voices of people with developmental disabilities and their families are heard.

***Empowerment through Self-Advocacy***

Councils focus on empowering individuals through activities that teach self-advocacy skills and support self-determination. By empowering individuals and their families to both advocate for themselves and seek long-term solutions through systems change, Councils are creating an environment of self-sufficiency, self-determination, inclusion, and acceptance. Councils also play a critical role in quality assurance and as innovators in the development of person-centered systems.

***State-Level Planning and Goal Implementation***

To serve their communities, Councils design 5-year state plans that address new ways of improving service delivery. To implement the state plans, Councils work with different groups in many ways, including educating communities to welcome people with developmental disabilities, funding projects to show new ways that people with disabilities can work, play, and learn, and seeking information from the public and from state and national sources.

**Fact Sheet: Protection and Advocacy Systems**

Adapted from Administration on Intellectual and Developmental Disabilities

<http://www.acl.gov/NewsRoom/Publications/docs/PandAs_factsheet.pdf>

Protection and Advocacy Systems (P&As) work at the state level to protect individuals with developmental disabilities by empowering them and advocating on their behalf. There are 57 P&As in the United States and its territories, and all are independent of service-providing agencies within their states.

Along with the other Administration on Intellectual and Developmental Disabilities grantees, P&As are dedicated to the ongoing fight for the personal and civil rights of individuals with developmental disabilities. P&As provide legal support to traditionally unserved or underserved populations to help them navigate the legal system to achieve resolution and encourage systems change. P&As ensure that individuals with disabilities are able to exercise their rights to make choices, contribute to society and live independently.

***Beyond Litigation***

While their focus is most often legal, P&As also engage in a full range of other efforts to promote the rights of individuals with developmental disabilities.

P&As often provide information and referrals, as well as training and technical assistance to service providers, state legislators and other policymakers. They also conduct self-advocacy trainings and raise public awareness of legal and social issues affecting individuals with developmental disabilities and their families.

***Working Toward Inclusive Education and Independent Living***

P&As provide substantial advocacy and legal services on educational issues, and work to ensure that students receive an appropriate education in an inclusive setting.

P&As have also made great strides in increasing the opportunities for individuals with developmental disabilities to make decisions for themselves about where and with whom they live.

**Olmstead *and Other Cases***

P&As have been involved in a significant number of landmark cases and work closely with other entities, especially State Councils on Developmental Disabilities and University Centers for Excellence in Developmental Disabilities. P&As work to implement the U.S. Supreme Court’s 1999 decision in *Olmstead* v. *L.C.*, which requires states to eliminate unnecessary segregation of people with disabilities, and to ensure that they receive services in the most integrated setting possible.

**Fact Sheet: University Centers for Excellence in Developmental Disabilities Education, Research & Service**

Adapted from Administration on Intellectual and Developmental Disabilities <http://www.acl.gov/NewsRoom/Publications/docs/UCEDDs_factsheet.pdf>

The University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDDs) are unique among Administration on Intellectual and Developmental Disabilities (AIDD) program grantees in that they are affiliated with universities. This connection enables the 68 UCEDDs located throughout the United States and its territories to serve as liaisons between academia and the community. UCEDDs receive a discretionary grant that is awarded to interdisciplinary education, research, and public service units of universities, or public or nonprofit entities associated with universities. AIDD funding is used to support the organizational foundation of UCEDDs, which allows the grantees to pursue other sources of support to conduct various activities. UCEDDs leverage funding from a variety of sources, including federal, state, and local agencies; private foundations; donations; and fee-for-service earnings.

***Addressing Issues, Finding Solutions, Advancing Research***

UCEDDs are a nationwide network of independent but interlinked centers, representing an expansive national resource for addressing issues, finding solutions, and advancing research related to the needs of individuals with developmental disabilities and their families.

Four core functions frame the UCEDD program:

* Interdisciplinary pre-service preparation and continuing education
* Research, including basic or applied research, evaluation, and public policy analysis
* Information dissemination
* Community services, including direct services, training, technical assistance, and model demonstrations

Representing a broad range of disabilities, UCEDDs support activities that address various issues, from prevention to early intervention to supported employment. Additional grants may be awarded to UCEDDs to conduct national training and other initiatives. Current training initiatives are funded to support post-secondary education opportunities for people with developmental disabilities and to enhance self-determination skills, and two grants focus on partnerships with minority serving institutions.

**Section 109 from The Developmental Disabilities Assistance and Bill of Rights Act of 2000**

From the Administration on Intellectual and Developmental Disabilities <http://www.acl.gov/Programs/AIDD/DDA_BOR_ACT_2000/p2_tI_subtitleA.aspx>

**SEC. 109. RIGHTS OF INDIVIDUALS WITH DEVELOPMENT DISABILITIES. [42 USC 15009]**

1. IN GENERAL.—Congress makes the following findings respecting the rights of individuals with developmental disabilities:
   1. Individuals with developmental disabilities have a right to appropriate treatment, services, and habilitation for such disabilities, consistent with section 101(c).
   2. The treatment, services, and habitation for an individual with developmental disabilities should be designed to maximize the potential of the individual and should be provided in the setting that is least restrictive of the individual’s personal liberty.
   3. The Federal Government and the States both have an obligation to ensure that public funds are provided only to institutional programs, residential programs, and other community programs, including educational programs in which individuals with developmental disabilities participate, that—
      1. provide treatment, services, and habilitation that are appropriate to the needs of such individuals; and
      2. meet minimum standards relating to—
         1. provision of care that is free of abuse, neglect, sexual and financial exploitation, and violations of legal and human rights and that subjects individuals with developmental disabilities to no greater risk of harm than others in the general population;
         2. provision to such individuals of appropriate and sufficient medical and dental services;
         3. prohibition of the use of physical restraint and seclusion for such an individual unless absolutely necessary to ensure the immediate physical safety of the individual or others, and prohibition of the use of such restraint and seclusion as a punishment or as a substitute for a habilitation program;
         4. prohibition of the excessive use of chemical restraints on such individuals and the use of such restraints as punishment or as a substitute for a habilitation program or in quantities that interfere with services, treatment, or habilitation for such individuals; and
         5. provision for close relatives or guardians of such individuals to visit the individuals without prior notice.
   4. All programs for individuals with developmental disabilities should meet standards—
      1. that are designed to assure the most favorable possible outcome for those served; and
      2. 1. in the case of residential programs serving individuals in need of comprehensive health-related, habilitative, assistive technology or rehabilitative services, that are at least equivalent to those standards applicable to intermediate care facilities for the mentally retarded, promulgated in regulations of the Secretary on June 3, 1988, as appropriate, taking into account the size of the institutions and the service delivery arrangements of the facilities of the programs;
         2. in the case of other residential programs for individuals with developmental disabilities, that assure that—
            1. care is appropriate to the needs of the individuals being served by such programs;
            2. the individuals admitted to facilities of such programs are individuals whose needs can be met through services provided by such facilities; and
            3. the facilities of such programs provide for the humane care of the residents of the facilities, are sanitary, and protect their rights; and
         3. in the case of nonresidential programs, that assure that the care provided by such programs is appropriate to the individuals served by the programs.
2. CLARIFICATION. —The rights of individuals with developmental disabilities described in findings made in this section shall be considered to be in addition to any constitutional or other rights otherwise afforded to all individuals.