



Biennial Report to Congress, the President, and the National Council on Disability

Fiscal Years 2011 and 2012

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Executive Summary

Throughout its history, the Administration on Intellectual and Developmental Disabilities (AIDD) has sought to enable individuals with developmental disabilities across the United States and its territories to live their best, most fulfilling lives. To help meet these needs, in 2012, the U.S. Department of Health and Human Services created a new organization, the Administration for Community Living (ACL), to help all Americans—including people with disabilities and older adults—to be better able to live at home with the supports they need, participating in communities that value their contributions. Comprised of AIDD, the Office on Disability and the Administration on Aging (AoA), ACL is charged with working with states, tribes, community providers, universities, nonprofit organizations, businesses, people with disabilities and families to help people with disabilities and older adults live in their homes and fully participate in their communities.

Within this framework, among other responsibilities, AIDD oversees four grant programs authorized by the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act). The purpose of the DD Act is to assure that individuals with developmental disabilities and their families participate in the design of, and have access to, needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life, through culturally competent programs authorized under the Act.

The DD Act also requires the Secretary to submit a biennial report on the goals and outcomes for these programs. This report identifies the goals and outcomes of AIDD's programs during fiscal years 2011 and 2012.

AIDD's four grantee programs established by the DD Act are responsible for advancing the mandate to provide individuals with developmental disabilities with the information, skills, opportunities and support to make informed choices and decisions about their lives; live in homes and communities where they can exercise their full rights and responsibilities as citizens; pursue meaningful and productive lives; and contribute to their families, communities, states, and the nation.

These four grant programs are:

- **State Councils on Developmental Disabilities (DDCs)**, which work at the state level to advance the interests of individuals with developmental disabilities and promote policies and practices that fully meet the needs of all Americans. DDCs are composed of individuals with developmental disabilities, family members, advocates and state agency representatives, and often focus on empowering individuals with developmental disabilities through activities that teach self-advocacy skills and support self-determination.
- **Protection and Advocacy Systems (P&As)**, which work to protect individuals with developmental disabilities from abuse and neglect by empowering them and advocating

on their behalf. P&As are dedicated to the ongoing fight for the personal and civil rights of individuals with developmental disabilities. They provide legal support and other advocacy services (including mediation, counseling, conflict resolution, and litigation) to traditionally unserved or underserved populations to help them navigate the legal system to achieve resolution and foster systems change.

- **University Centers for Excellence in Developmental Disabilities Education, Research and Service (UCEDDs)**, which are affiliated with universities and represent an expansive national resource for addressing issues, building a professional workforce, finding solutions and advancing research related to the needs of individuals with developmental disabilities and their families. The UCEDD program is framed by four core functions: interdisciplinary pre-service preparation and continuing education of students and fellows; research; information dissemination; and community services, which include model services, training, technical assistance, and demonstrations.
- **Projects of National Significance (PNS)**, which are often short-term endeavors focusing on issues that are of national importance to the developmental disabilities community, funding projects that ensure that services meet the needs of people with developmental disabilities. PNS funds have supported families, increased community living options, developed quality assurance standards, assisted with family leadership development, and increased opportunities for self-advocate involvement in system change initiatives. PNS funds have also supported long-term data collection projects that help policymakers, service providers, individuals with developmental disabilities and their families make the most informed policy and individual care decisions.

The first three of these grantee programs exist in each state and territory and comprise what is referred to as the Developmental Disabilities network in their respective state or territory. The fourth grantee program, Projects of National Significance, focuses on nationally recognized and emerging needs. They support the development of national and state policy that enhance the independence, productivity, inclusion and integration into the community for people with developmental disabilities.

Through the grant programs, technical assistance and interagency collaboration, AIDD worked during FY 2011 and FY 2012, as it has in the past, to embody the core values of the DD Act — self-determination, independence, productivity and inclusion and integration in all facets of community:

- **Self-determination** is represented by successful self-advocacy trainings and conferences, and the activities of the National Youth Leadership Network and the National Training Initiative for Self-Determination to encourage individuals with developmental disabilities and their families to advocate for equal rights and inclusion. For example, in 2011 and 12 a consortium of UCEDD grantees continued work under the National Gateway to Self-Determination project, which included a website that provides self-advocates, professionals, policy-makers and the general public access to current best practices in enhancing self-determination for people with intellectual and developmental disabilities.

- **Independence** is represented by strides made in the areas of community living and housing through victories in the court system and the successful implementation of universal design concepts. It is also advanced in the area of health care as a result of a settlement agreement that upholds the *Olmstead v. L.C.*¹ decision in Georgia hospital settings, which allows individuals with developmental disabilities to receive public health care services in the most integrated settings appropriate to their needs. In addition, independence is represented in education by programs that increase opportunities for educational advancement in university settings. For example, the Learning Academy at the University of South Florida (USF) is a two-year, four-semester transitional experience designed to help students with Autism Spectrum Disorder achieve a life of opportunity, independence and success.
- **Productivity** is exemplified by programs that encourage gainful, meaningful employment and development of job skills. In the past two fiscal years, DDCs whose work included an emphasis on employment reported that they have assisted more than 7,200 Americans with disabilities to either maintain or obtain jobs of their choice. Productivity was also supported through strides made in securing access to technology that enables individuals to participate equally in activities. AIDD continued to invest in the national study *Access to Integrated Employment* conducted by the Institute for Community Inclusion (ICI) at the University of Massachusetts Boston. The 2012 report provided statistics over a 20-year period from several national datasets that address the status of employment and economic self-sufficiency for individuals with DD. Overall, the findings indicate that individuals with developmental disabilities have higher levels of unemployment, underemployment, low wages, and poverty compared to those without disabilities.
- **Integration and inclusion** are represented by quality assurance and community activities that promote supports and services that make it possible for individuals with developmental disabilities to participate in society. These values are also represented in the National Residential Information System Project and State of the States in Developmental Disabilities, two projects that analyze current conditions for Americans living with developmental disabilities. In addition, Family Support 360 projects provide opportunities to create one-stop centers to assist unserved and underserved families of individuals with developmental disabilities, improve community capacity to support these families, and encourage systemic change. In FY 2011 and FY 2012, Family Support 360 projects served 1,773 families.²

AIDD is also involved in technical assistance that supports its mission and mandate. These technical assistance activities help grantees address problems that cross state lines or respond to the needs of clients, and make efficient use of funding. Technical assistance activities include

¹*Olmstead v. L.C.* is a Supreme Court ruling made in 1999 that requires states to eliminate unnecessary segregation of individuals with disabilities in the delivery of public services, and to ensure that individuals with disabilities receive public services in the most integrated setting appropriate to their needs. <http://www.ada.gov/olmstead/index.htm>

² Compiled from year-end reports from all FS360 grantees.

trainings, information dissemination, website maintenance and other support. In FY 2011 and FY 2012, AIDD provided training and technical assistance to its grantee programs through grants and contracts with a number of organizations:

- The Information and Technical Assistance Center for Councils on Developmental Disabilities (iTACC), operated under a grant to the National Association of Councils on Developmental Disabilities, provides technical assistance to DDCs. Through iTACC, NACDD assisted the Council members, staff and executive directors with access to information, technical assistance and training resources quickly. In FY 2011, 189 requests were received and completed by iTACC staff and in FY 2012, 266 requests were received and completed.
- The Training and Advocacy Support Center (TASC), operated under contract by the National Disability Rights Network, (NDRN) provides technical assistance to P&As. For example, TASC staff members provide consultation via e-mail and phone on disabilities law, organizational management, and board management. Additionally, staff responded to more than 1500 programmatic issues per year, especially with regard to abuse, neglect, seclusion, restraint, community integration and ADA compliance. Staff also responded to nearly 400 P&A management related issues per year.
- The UCEDD Resource Center, operated under contract by the Association of University Centers on Disabilities (AUCD), provides technical assistance to UCEDDs. Through this project, AUCD provided a number of national training events on topics such as youth transition, post-secondary education opportunities for individuals with intellectual and developmental disabilities, community integration, alternate assessments, and AIDD reporting requirements. In 2012, AUCD launched first ever Leadership Institute to better support the development of leaders for the UCEDD network. In partnership with The National Leadership Consortium on Developmental Disabilities at the University of Delaware, AUCD offered a week long intensive executive development program to 24 new UCEDD directors, Assistant Directors, Program Directors and others in UCEDDs who, in the opinion of the UCEDD's leadership, demonstrate both potential and willingness to assume senior leadership roles in the UCEDD network.
- BETAH Associates provides technical assistance to PNS family support grantees. This contract promotes knowledge sharing, builds skills, and facilitates problem-solving among grantees. As part of these efforts, in 2012, BETAH held the Family Support 360 Technical Assistance Institute, an event that received positive ratings from grantees regarding its effectiveness.
- The Institute for Community Inclusion (ICI) provides technical assistance to eight Partnerships in Employment Systems Change projects (PIE) focused on assisting states with systems efforts and identifying, developing, and promoting policies and practices to improve transition, post-secondary and competitive employment outcomes for individuals with intellectual and developmental disabilities. Technical assistance activities included site visits to assist states with incorporating elements of the high

performing states framework into their systems change efforts as well as to ensure project activities focused on systems change efforts. Additional technical assistance efforts included monthly coaching calls with PIE project managers, facilitation of peer-to-peer information exchange, bi-monthly E-news distributed to grantees and stakeholders, assistance with legislation and regulations on employment, transition and postsecondary options. ICI also facilitated web-based network meeting on topics that included Leadership in Transition and Employment, Employment First, Systems Change and Sustainability, Medicaid Funding for Employment Services

AIDD undertook a number of partnerships and collaborative efforts, including work with the U.S. Department of Education, U.S. Department of Housing and Urban Development, Interagency Autism Coordinating Committee, and with the Office of Child Care, Office of Head Start, and the Office of Child Abuse and Neglect in the Administration for Children and Families. While much work has been done to improve the lives of individuals with developmental disabilities, AIDD is looking toward the future. AIDD conducted a series of listening sessions, conferences and other events to inform the development of the AIDD strategic framework. AIDD's mission and the DD Act's mandates remain the primary focus driving AIDD's and its grantees' work across the United States and its territories, with the paramount goal of enabling successful lives for individuals with developmental disabilities.

This report also includes information from the Center for Mental Health Services (CMHS) of the Substance Abuse and Mental Health Services Administration (SAMHSA) on the Protection and Advocacy for Individuals with Mental Illness grant program. Section 114(a)(1) of the Protection and Advocacy for Individuals with Mental Illness Act of 1986 requires that the AIDD Report include a statement describing the activities, accomplishments, and expenditures of State Protection and Advocacy Systems which serve individuals with mental illness. This statement is prepared by CMHS, SAMHSA and is being forwarded for inclusion in this Report as an Appendix.

Introduction: AIDD and the DD Act

The Administration on Intellectual and Developmental Disabilities (AIDD) is dedicated to ensuring that individuals with developmental disabilities and their families are able to fully participate in and contribute to all aspects of community life in the United States and its territories.

AIDD's work supports approaches that shape attitudes, raise expectations, change outdated or broken systems and empower individuals with disabilities to pursue the lives they imagine for themselves. To that end, AIDD provides financial and leadership support to organizations in every state and territory in the United States. These bodies assist individuals with developmental disabilities of all ages and their families obtain the support they need to achieve all aspects of a life envisioned and defined by the DD Act.

DD Act: Ensuring Access and Support

The Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act) ensures that individuals with developmental disabilities and their families have access to community-based services and supports to promote opportunities for independence, productivity and inclusion through culturally competent programs established and authorized by the law.

The DD Act establishes four grant programs that are overseen by AIDD: State Councils on Developmental Disabilities (DDCs); State Protection and Advocacy Systems (P&As); University Centers for Excellence in Developmental Disabilities Education, Research and Service (UCEDDs); and Projects of National Significance (PNS).

These grantees ensure that individuals with developmental disabilities have access to opportunities and the necessary supports to be included in community life, have interdependent relationships, live in homes and neighborhoods of their choosing, and make contributions to their families, communities, states and the nation. Individuals with developmental disabilities and their family members influence the grantees and their actions in a variety of ways - through public forums, membership on boards, committees and councils, partnership on projects, etc. This engagement with individuals with developmental disabilities and family members helps grantees determine what areas to invest in and how to use their AIDD funding. Each grantee has its own process for choosing these areas. Some grantees use public forums to assess the needs of individuals with developmental disabilities. Many of these forums are conducted as a collaborative effort across the DD network. P&As are able to use information from their client-initiated work, which means that someone approaches them with a problem or issue that needs solving on a case-by-case basis. They analyze this information to identify trends and areas needing to be prioritized.

Through research, education, advocacy and the implementation of diverse projects, AIDD and its grantees help individuals with developmental disabilities receive quality care and education, protect their health, excel in careers of their choice, travel freely, live independently, participate in activities that they find fulfilling, and make informed choices about the kinds of services and supports they receive.

Meeting National Policy Goals

AIDD's work significantly relates to the current policy efforts in place to enhance the lives of the estimated five million Americans with developmental disabilities.³ AIDD has been working on strengthening health care and supports, increasing employment opportunities, expanding educational opportunities, protecting civil rights, promoting access to community living, and supporting the development and use of accessible technologies.

Visions for the Future

All Americans, including persons with disabilities and older adults, should be able to live at home with the supports they need. To help support this vision and meet these needs, in 2012 the U.S. Department of Health and Human Services created the Administration for Community Living (ACL). ACL brings together the Administration on Intellectual and Developmental Disabilities, the HHS Office on Disability, and the Administration on Aging to serve as the Federal agency responsible for increasing access to community supports, while focusing attention and resources on the unique needs of people with disabilities and older Americans.

ACL is charged with working with states, tribes, community providers, universities, nonprofit organizations, businesses and families to maximize the independence, well-being, and health of older adults, people with disabilities, and their families and caregivers. ACL's Mission is to maximize the independence, well-being, and health of older adults, people with disabilities, and their families and caregivers. And ACL's Vision is that all people, regardless of age and disability, live with dignity, make their own choices, and participate fully in society.

AIDD's priorities within ACL's strategic framework include:

- Ensuring the continued protection of the rights of individuals with developmental disabilities and preventing their abuse, neglect and exploitation;
- Empowering individuals with developmental disabilities and their families to access home and community-based services and supports that ensure opportunity for full and meaningful community participation;
- Promoting "employment first" as a key strategy for individuals with developmental disabilities to be contributing and productive members of society participating in the competitive, integrated workforce;
- Supporting the advocacy efforts of individuals with developmental disabilities in order to ensure participation in system and service delivery design; and
- Maintaining effective and responsive management of the DD Act programs.

More information about ACL's strategic plan for 2013-2018 and AIDD's strategic framework for 2012 – 2017 can be found at http://www.acl.gov/About_ACL/StrategicPlan/Index.aspx.

³National Aggregated Data from 2011 Council State Plans.

Biennial Report (FY 2011 and FY 2012)

The Biennial Report to Congress, the President and the National Council on Disability is a requirement of the DD Act. This report presents an overview of achievements by AIDD's grantees during FY 2011 and FY 2012 as reported by the grantees in their annual reports to AIDD. These achievements were reached using funding from AIDD, state and local communities and other sources, and reflect the core values of the Administration: self-determination, independence, productivity, integration and inclusion in all facets of community.

This report offers examples of successful implementation of each of the core values as they have been achieved by AIDD grantees, as well as through training and technical assistance programs and interagency collaboration.

Chapter 1: The Developmental Disabilities Network

Developmental disabilities grant programs authorized by the DD Act include three state- and territory-based programs that collaborate with each other as well as with other entities in their respective states and territory: DDCs, P&As and the national network of UCEDDs. In each state⁴, these programs form a developmental disabilities network (DD network) that is uniquely positioned to meet the diverse needs of individuals with developmental disabilities in that state. A fourth program, Projects of National Significance (PNS), is directed toward current and emerging needs of individuals with developmental disabilities. These nationwide projects work across the DD networks.

While each grantee within the DD networks serves specific and unique purposes, these entities were established with overlapping goals that facilitate collaboration and interconnectivity among the different units. Because of its structure, each grantee within a state's DD network is able to work cross-functionally to effectively and efficiently fulfill the mandates of the DD Act and its core values: self-determination, independence, productivity, integration and inclusion in all facets of the community.

State Councils on Developmental Disabilities (DDCs)

There are 56 DDCs in the United States, its territories, and the District of Columbia. DDCs are independent, self-governing organizations that work at the state level to advance the interests of individuals with developmental disabilities and promote policies and practices that fully meet the needs of all Americans.

DDCs are committed to the advancement of public policy that helps individuals with developmental disabilities gain more control over their lives. They are composed of individuals with developmental disabilities, family members, advocates and state agency representatives appointed by Governors. In part because of their diverse membership, DDCs analyze and improve systems, services and trends within a state, and ensure that the voices of people with developmental disabilities and their families are heard.

Empowerment through self-advocacy. DDCs often focus on empowering individuals with developmental disabilities through activities that teach self-advocacy skills. These activities include:

- Providing workshops that teach individuals with developmental disabilities how to advocate for their rights and holding leadership academies that teach them how to mentor other individuals;
- Supporting the growth of local self-advocacy organizations;
- Providing programs that teach young people advocacy and activism strategies to help them influence policies that affect their choices (e.g., education and employment).

⁴ In this context, "state" refers to the 50 States, the United States territories, and the District of Columbia.

By empowering individuals and their families to advocate not only for themselves, but also to seek long-term solutions through systems change, DDCs are creating an environment of self-sufficiency, self-determination, inclusion, and acceptance, both today and for future generations. (For details on self-advocacy efforts funded by DDCs, see *Chapter 3, Self-Determination.*)

State-level planning and goal implementation. To serve their communities, DDCs design five-year state plans that address new ways of improving service delivery so that individuals with developmental disabilities have the opportunity to exercise their rights and reach their personal goals. To carry out the state plans and their respective missions, DDCs work with different groups in many ways to achieve the goals of the DD Act, including:

- Involving and supporting people with developmental disabilities and family members in leadership roles (by law, more than 60 percent of a DDC's membership must consist of individuals with developmental disabilities or their family members);
- Educating communities to welcome individuals with developmental disabilities.
- Informing policymakers about disability issues;
- Funding projects to show new ways for people with disabilities to work, play and learn; and
- Seeking information from the public and from state and national sources.

For example, the Massachusetts DDC partnered with the Arc of Massachusetts, an advocacy organization for people with intellectual and developmental disabilities, to form a coalition of statewide cross-disability organizations called the Massachusetts Alliance for 21st Century Disability Policy partnership (MA21). This coalition worked to educate individuals, families and policymakers on the principles of MA21.

Protection & Advocacy Systems (P&As)

Each P&A works to empower, protect and advocate on behalf of individuals with developmental disabilities and their families. There are 57 P&As in the United States, its territories, and the District of Columbia. There is a P&A for the Native American community. Each P&A is independent of service-providing agencies.

Protecting individuals with developmental disabilities from abuse and neglect is at the core of the P&A mission. Along with the other AIDD 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 individuals with developmental disabilities, as well as other populations of persons with disabilities, to help them navigate the legal system to achieve resolution. P&As ensure that individuals with disabilities have the ability to exercise their rights to make choices, contribute to society and live independently.

Diverse focus. 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. P&As also focus on educational issues, working to ensure that students receive an appropriate education in an integrated and inclusive setting. Historically, the majority of the workload and cases handled by P&As has dealt with securing an education in an inclusive setting for children with developmental disabilities.

Olmstead and other cases. P&As have been involved in a significant number of landmark cases and work closely with other partners, especially DDCs and UCEDDs. 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 ensure that they receive services in the most integrated setting.

University Centers for Excellence in Developmental Disabilities Education, Research and Service (UCEDDs)

The 67 UCEDD grants are spread among 68 centers across the United States and its territories. UCEDDs differ from the other grantees established by the DD Act in that they are affiliated with universities. This affiliation positions UCEDDs to serve as liaisons between academia and the community.

This nationwide network of independent but interconnected centers represents an expansive national resource for addressing issues, finding solutions, improving the quality of the workforce, 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 of students and fellows.
- Research.
- Information dissemination.
- Community services, which include model services, training, technical assistance and demonstration services.

Examples of the UCEDDs' work include the efforts of the Washington UCEDD, which collaborates with numerous agencies to provide direct services such as job development, job placement, job training, and continued employment support (see *Chapter 5, Productivity*). In Tennessee, the Vanderbilt Kennedy Center UCEDD developed and implemented a postsecondary education program for students with intellectual disabilities at Vanderbilt University. This two-year nonresidential certification program is the first and only program of its kind in the state (see *Chapter 6, Integration and Inclusion*).

AIDD awards UCEDDs a discretionary grant to 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 them to pursue other sources of support to carry out various activities. UCEDDs leverage funding from a variety of sources, including

federal, state and local agencies; private foundations and donations; and charging fees for services.

Projects of National Significance (PNS)

Projects of National Significance (PNS) focus on nationally recognized and emerging needs, supporting the development of national and state policy that enhances the independence, productivity, inclusion and integration into the community for people with developmental disabilities.

In FY 2011, AIDD awarded 43 PNS grants, 10 of which were new that year. PNS funds create grants, contracts and cooperative agreements to public and private nonprofit organizations to create opportunities for individuals with developmental disabilities to directly and fully contribute to and participate in all facets of community life.

PNS funding supports the development of national and state policies that reinforce and promote the self-determination, independence, productivity, and integration and inclusion of individuals with developmental disabilities in all facets of community life. These projects are supported by families, guardians, advocates and communities, and include family support activities, data collection, technical assistance to UCEDDs and DDCs, and other projects that hold promise to expand or improve opportunities for individuals with disabilities.

Short-term projects, long-term differences. Projects are typically short-term (one to five years) and focus on the most pressing issues affecting people with developmental disabilities and their families. Over the years, PNS funds have supported families and caregivers, increased community living options, developed quality assurance standards, assisted with family leadership development, and increased opportunities for self-advocate involvement in system change initiatives.

Longitudinal data studies. PNS funds have also supported long-term data collection projects that help policymakers, service providers, individuals with developmental disabilities and their families make the most informed policy and individual care decisions. These studies look beyond data collected by each individual grantee within their specific state and allow for an overarching, higher-level evaluation of the conditions of individuals with developmental disabilities within the United States.

Demonstrating and supporting emerging needs and best practices. The projects are intended to enable more rapid responses to emerging issues by targeting an unserved or underserved area, with the intent of eventually implementing programs on a broader, national level. Examples of PNS projects include:

- Data collection and analysis to track longitudinal trends significant to individuals with intellectual and developmental disabilities and their families, such as the residential and employment service in each state. For example, the National Residential Information System Project continues more than 20 years of analysis of annual state-by-state and national statistics and analysis on residential services for people with developmental disabilities (see *Chapter 2, Supporting the Core Values of the DD Act*).

- Programs to assist youth with developmental disabilities in the transition from school to the workforce and postsecondary education opportunities. (See *Chapter 3, Self-Determination*).
- Programs to develop self-advocacy and leadership skills among people with developmental disabilities. (See *Chapter 3, Self-Determination*).
- Projects that create employment opportunities for individuals with disabilities. (See *Chapter 5, Productivity*).
- Family support activities, including those for military families, which rely on collaborative efforts and community-based solutions to reach unserved and underserved families. (See *Chapter 6, Integration and Inclusion*).
- Programs designed to enhance the participation of minorities in initiatives in developmental disabilities. (See *Chapter 6, Integration and Inclusion*).

Chapter 2: Supporting the Core Values of the DD Act

“The purpose of this title is to assure that individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life, through culturally competent programs authorized under this title, including specifically State Councils on Developmental Disabilities in each State to engage in advocacy, capacity building, and systemic change activities ... protection and advocacy systems in each State to protect the legal and human rights of individuals with developmental disabilities ... [and] University Centers for Excellence in Developmental Disabilities Education, Research, and Services ... funding for national initiatives to collect necessary data on issues that are directly or indirectly relevant to the lives of individuals with developmental disabilities; technical assistance to entities who engage in or intend to engage in activities consistent with the purpose described in this subsection or the policy described in sub-section (c); and other nationally significant activities....”

— *Developmental Disabilities Assistance and Bill of Rights Act of 2000*

The DD Act requires that AIDD and its grantees work to ensure that individuals with developmental disabilities and their families receive assistance that promotes the core values of self-determination, independence, productivity, and integration and inclusion into all aspects of community life. These four values represent a broad definition of what it means to be an American, participating fully in life in the United States, and relate directly to the four goals of the Americans with Disabilities Act: equality of opportunity, full participation, independent living, and economic self-sufficiency for all people with disabilities.

In FY 2011 and FY 2012, AIDD sought, as it had earlier, to embody these values with great success, enabling individuals with developmental disabilities and their families across the United States to achieve a better quality of life. The examples that follow in this report offer a glimpse at the extensive work being done across the country by AIDD grantees.

Meeting the Goals of the DD Act

Longitudinal data are the basis for AIDD’s strategic mission and provide quantitative support for AIDD’s continued efforts to better the lives of individuals with developmental disabilities. The data are collected on a national level and have been funded by Projects of National Significance more than 20 years. The data are used to identify areas of specific need, and are helping lawmakers and other stakeholders make the most educated policy and care decisions for individuals with developmental disabilities in the United States.

The comprehensive, population-level data collected from grantee annual reports embody the four core areas of the DD Act, and are used to analyze the movement of individuals with developmental disabilities from segregated environments to integrated and inclusive ones, as

well as the state of employment opportunities, and the quality and availability of community services.

These longitudinal data studies are the National Residential Information System Project (RISP), State of the States in Developmental Disabilities, and Access to Integrated Employment: National Data Collection on Day and Employment Services for Citizens with Developmental Disabilities.

National Residential Information System Project (RISP)

RISP continues more than 20 years of analysis of annual state-by-state and national statistics and analysis on residential services for people with developmental disabilities, including state and non-state institutional settings and community and home-based residential services. With the guidance of an advisory group made up of people with intellectual and developmental disabilities and their family members, the research is conducted through the Research and Training Center on Residential Services and Community Living Institute on Community Integration, the UCEDD at the University of Minnesota.

A PNS-funded project, RISP examines the associations between personal characteristics, living arrangements, financing and support models, state systems and other factors on the achievement of inclusion, self-determination, satisfaction and other outcomes. It also conducts research on state policy and program outcomes relating to key topics in residential and other community services, and maintains clearinghouses of information and resources on consumer-controlled housing, the direct support workforce, and community living outcomes. The project also collects data from states on the number of children and youth with intellectual and developmental disabilities living and receiving supports outside the home of biological or adoptive family members.

These data sets provide information that is not available in other national surveys for analyses of demographic, service and policy topics specific to people with intellectual and developmental disabilities.

In FY 2011, 71.5 percent of individuals with intellectual and developmental disabilities receiving publicly funded supports lived with family members, and 16 percent lived alone or with a roommate. These findings beg the question: *How are people with disabilities and families being supported in their homes to ensure that the family unit stays intact and what happens to people with disabilities as their family caregivers start to age?*

Furthermore, an estimated 49 percent lived in congregate settings with three or fewer residents, 26.6 percent lived in congregate settings with four to six residents, 12.6 percent lived in congregate settings with 7 – 15 residents, and 12 percent lived in large public or private facilities, nursing homes, or public psychiatric facilities, an increase from 9 percent in 2011. Of individuals with intellectual and developmental disabilities who did not live with family members in 2011, 49 percent lived in settings with one to three people (including homes of their own, host homes, and small group settings), and 32 percent lived in settings with 6 or fewer residents. RISP data regarding state services varies widely. In FY 2011, 18 states served 90 percent or more of all

citizens with developmental disabilities who lived in congregate settings with six or fewer residents, while four states served more than 90 percent of such people in settings for one to three people. On the other hand, three states served less than 50 percent of such people in settings for fewer than six people.

RISP disseminates information based on its findings through a variety of formats, including annual reports; the *IMPACT*, *Policy Research Brief*, and *Community Services Reporters* newsletters; the *QualityMall.org* website; and the “Trends and Milestones” feature in the journal *Intellectual and Developmental Disabilities* (formerly *Mental Retardation*).

The activities carried out through this project provide timely and accurate information about residential services and newly implemented policies in the United States so that policymakers, service providers, individuals with developmental disabilities and their families can make informed decisions regarding housing and community living.

State of the States in Developmental Disabilities

State of the States in Developmental Disabilities is administered by the University of Colorado, funded in part by AIDD. Established in 1982 to investigate the determinants of public spending for intellectual/developmental disabilities services in the United States, the project maintains a longitudinal record of revenue, spending and programmatic trends in the 50 states, the District of Columbia, and the United States as a whole for fiscal years 1977–2012.

The project is a benchmarking study of the states’ performances as they work to implement the Supreme Court’s *Olmstead v. L.C.* decision promoting community living, while seeking to recover from the recent, severe budgetary challenges of the recession and its aftermath. By 2011, 77 percent of all spending for all intellectual and developmental disabilities (I/DD) services came from Medicaid. Spending for community services was provided by the Home and Community Based Services (HCBS) Waiver in addition to other state and local government funding. In the same year, 85 percent of all I/DD spending was dedicated to community services. Five states and the District of Columbia committed 100 percent of I/DD funds on community services and 24 states spent at least 90 percent of their I/DD budget on community services.⁵ This is a vastly different trend than 10 years ago when I/DD funding was dedicated to institutional versus community services.⁶

With the guidance of an advisory group of people with intellectual and developmental disabilities and their family members, the project provides substantive quantitative data on community services and supports, public and private institutions, fiscal efforts in states, and demand for services and supports. The project provides a ‘create a chart’ option on its website where the public can also customize a report to suit their needs.

This project provides a significant amount of information to AIDD, other federal agencies, state policymakers and other stakeholders. It enables a thorough understanding of supports and service

⁵ State of the States. <https://www.cu.edu/ColemanInstitute/stateofthestates/index.html>

⁶ State of the States, 9th Edition

systems in the United States, and offers both quantitative and qualitative information about the living and working status of individuals with disabilities.

Access to Integrated Employment: National Data Collection on Day and Employment Services for Citizens with Developmental Disabilities

The Access to Integrated Employment: National Data Collection on Day and Employment Services for Citizens with Developmental Disabilities studies have been in place since 1988, extending research describing day⁷ and employment services for individuals with developmental disabilities and contributing to an understanding of the factors that influence employment at the individual, service provider and state levels.

Conducted by the Institute for Community Inclusion at the University of Massachusetts Boston, the project assesses the effectiveness of state intellectual disability and developmental disabilities agencies and vocational rehabilitation agencies in promoting full inclusion of individuals with developmental disabilities through employment and other community activities, and the employment and economic status of individuals with developmental disabilities on a state and national basis. The project also identifies “promising practices” that were used by employment specialists to find employment-related services for people with intellectual and developmental disabilities.

With the guidance of an advisory group consisting of individuals with intellectual and developmental disabilities and their family members, the project describes and promotes promising state and local policy and practices that enhance access to integrated employment at both the systems and individual customer levels. It demonstrates the use of Geographic Information System (GIS) Technology to illustrate patterns of investment in service system outcomes, and provides online access to a catalog of best practices in state and local policy and practice that promotes access to integrated employment, including outcome data collection tools, funding structures, and employment policies and initiatives.

It also implements <http://www.statedata.info>, an interactive website that provides fully accessible on-demand charts and tables illustrating service system investment in day and employment services and employment outcomes.

⁷ For this data collection project, “day services” refers to facility-based and community-based non-work services for individuals with intellectual and developmental disabilities. Community-based non-work includes services focused on supporting people with disabilities to access community activities in settings where most people do not have disabilities. Facility-based non-work includes all services that are located in a setting where the majority of participants have a disability. Neither service involves paid employment of the participant.

Chapter 3: Self-Determination

Self-determination refers to a characteristic of a person that leads them to make choices and decisions based on their own preferences and interests, to monitor and regulate their own actions, and to be goal-oriented and self-directed.

Self-determination is at the core of the DD Act. As outlined in Section 102, self-determination activities are defined as:

“... activities that result in individuals with developmental disabilities, with appropriate assistance, having—

- (A) the ability and opportunity to communicate and make personal decisions;
- (B) the ability and opportunity to communicate choices and exercise control over the type and intensity of services, supports, and other assistance the individuals receive;
- (C) the authority to control resources to obtain needed services, supports, and other assistance;
- (D) opportunities to participate in, and contribute to, their communities; and
- (E) support, including financial support, to advocate for themselves and others, to develop leadership skills, through training in self-advocacy, to participate in coalitions, to educate policymakers, and to play a role in the development of public policies that affect individuals with developmental disabilities.”⁸

For individuals with developmental disabilities, self-determination is an important factor in their ability to pursue their own definition of happiness and to make choices that will enable them to achieve their goals and aspirations, and protect their rights as individuals within American society. Individuals with developmental disabilities who have the degree of control they desire over their lives consistent with their capacities, strengths and needs are more likely to express satisfaction in other areas of their lives, like employment.

By providing supports and services to individuals with developmental disabilities to help them determine their own futures, AIDD not only is investing in the futures of individuals immediately served, but also in the futures of Americans with disabilities in generations to come.

Self-Advocacy

Individuals with developmental disabilities and their families are their own best champions. They are self-advocates and advocates for their family members, speaking up about their needs and rights, and rightly asserting themselves as vital contributors to the national conversation about the services and systems that support them. Across the United States, self-advocates and advocates are raising their voices for themselves, their peers and their family members, and often times do so in partnership with the DD networks in their states. However, more needs to be done

⁸ Public Law 106-402, Section 102(27)

to ensure that people with disabilities and their families are empowered to speak up and have the necessary confidence, skill-set, and policy knowledge to do so.

In 2011, 49 DDCs directly or indirectly provided \$3.67 million in funding across the states to self-advocacy organizations that were led by individuals with developmental disabilities.

The following are a few examples of self-advocacy activities that were undertaken throughout the nationwide DD network during FY 2011 and FY 2012:

Indiana DDC

Council efforts in youth self-advocacy continued with a technology project called My VOICE, which focused on multimedia presentations for student-led Individualized Education Plan (IEP) meetings. Three high schools within a school district were involved and 89 students used their My VOICE presentation to develop their IEPs. In addition, pre-service teachers at a local University participated in the project. As a result, many of those students graduated and became employed in other districts, using the My VOICE approach to help others in their communities. The Consumer Involvement Fund enabled 289 self-advocate and their families attend conferences and trainings that provided valuable information and opportunities related to developmental disabilities.

Michigan DDC

The Council funded a statewide self-advocacy network of 38 consumer-driven local advocacy coalitions called Regional Interagency Consumer Committees and a statewide project entitled *Connections for Community Leadership (CCL)* which provided training on disability identity, leadership development, and various handbooks and curricula. Additionally, they hosted the second “*Her Power Her Pride Her Voice*” event for young high school girls with various disabilities. Participants challenged the stereotypes of mainstream media through hands-on activities, discussions, reflections, and art creation.

North Dakota P&A

The ND P&A was involved in number of collaborative activities related to self-advocacy and health care. For example, the North Dakota Disability Advocacy Consortium (NDDAC), a private, not-for-profit organization made up of approximately 16 members with a common interests regarding the rights of, and services for, people with disabilities, worked to provide information and education regarding health care to individuals with disabilities, their families, services providers, and others who are interested. Members include: ND Center for Persons with Disabilities, ND Association of Community Providers, P&A, The Arc of ND, The Arc Upper Valley, AARP ND, Experience Works, Family Voices North Dakota, Mental Health America of ND, ND Association of the Blind, ND APSE, the Federation of Families for Children’s Mental Health, The Arc of Bismarck, American People Self Advocacy Association, Western Sunrise, Multiple Sclerosis Society.

Additionally, the ND Disabilities Health Project is a collaborative project whose mission is to promote the health and wellness of ND citizens with disabilities, while working to prevent or

lessen the effects of secondary conditions associated with disabilities. The objectives of this collaborative project between the ND Center for Persons with Disabilities at Minot State University, the Center for Rural Health at the University of North Dakota, P&A, and the ND State Department of Health-Division of Chronic Disease included working to establish a state office in the disability division to collect statewide data, analysis and reporting on the health and wellness conditions of ND citizens with disabilities and to promote healthy lifestyles, and to improve access to healthcare and wellness programs for people with disabilities will be focused on through these efforts.

Hawaii UCEDD

Living to Our Full Potential, a multi-dimensional project, is targeted to young people with mental health challenges, their families and the community at large. The purpose of the project was to: build the capacity of youth to determine and forge their destinies; provide a platform these individuals to have their voices heard; and to create venues and strategies whereby collaborators, working groups, and teams can continue to be inspired, informed and educated about best practices, current research and initiatives, while developing professional skills. Initiatives included:

- Developing community engagement programs which promote mental health awareness, prevention and build capacity for self-advocacy through the implementation of a skills-based program for families and youth to support healthy diets and exercise.
- Developing youth self-advocacy through storytelling, which can positively support overall mental health, increase individual and collective self-esteem and reduce stigma in the community. Stories continue to have communal efficacy and have the power to unify cultures, influence behaviors and support inclusive environments, diversity and self-determination. The workshops provided attention to the personal voice, exercises, mastery of voice, face and body and the creation of person narratives, culminating in a performance and digital storytelling project which can be used for media promotions.
- Providing an employment training ground for mental health consumers to support a four month job internship program in events management. The unit provided leadership and training for mental health consumers in the field of events management, a certificate of graduation, and a small stipend for each job trainee graduate. The activity timeline involved recruiting and outreach, curriculum development and on-site supervision of a mental health event. For the Pacific Rim 2011 conference, the job trainees organized a five hour forum for and by people with mental health challenges utilizing a social justice framework.

Minnesota UCEDD

Self-Advocacy Online provided an educational and networking website in development for teens and adults with intellectual and related cognitive disabilities, targeted at those who participate in organized "self-advocacy" groups and activities in the United States. For the vast majority of self-advocates, the internet has largely been an untapped resource for learning and collaborating.

Self-Advocacy Online served as a tool for translating important issues for persons with intellectual and related cognitive disabilities to understandable and entertaining interactive lessons and information, while connecting individuals and groups to a larger group of learners. Too often, self-advocacy groups work in isolation. Although most groups benefit from support from a parent organization, with support staff and office resources (e.g., meeting space, computers), they often are not connected to other groups and know little about current issues in self-advocacy outside of their geographic area. Accordingly, Self-Advocacy Online provided a hub for individuals and groups to collaborate and share ideas, while providing necessary computer literacy skills in the process. The Self-Advocacy Online web site at can be accessed at: <http://www.selfadvocacyonline.org>

Self-Advocacy Summits

In 2011-2012, AIDD funded self-advocacy summits and leadership gatherings of self-advocates and partners to gather information around self-advocacy activities and policies in each of the 56 U.S. states and territories and seek ideas on what AIDD should do to better support self-advocacy and encourage it through the DD network partners . Before each summit, state teams worked together to develop a PowerPoint overview of accomplishments, strengths, and challenges in self-advocacy. During each summit, state teams continued to work together to develop a plan for possible next steps that could be taken in their own state to strengthen self-advocacy. Teams developed recommendations for national activities and policies that could help strengthen self-advocacy at the national level, and had informal discussions about the roles, functions, and needed supports for growing the self-advocacy movement. Overall, the purpose of the summits was to strengthen and enhance self-advocacy efforts in the states and nationally. During 2011, summits were held in Kansas City, MO; Providence, RI; Columbus, OH; Los Angeles, CA; and Atlanta, GA. In 2012, they were held in Baltimore, MD; Honolulu, HI; Chicago, IL; and Seattle, WA. AIDD is using this information to enhance our self-advocacy efforts in FY 2013 and beyond.

Chapter 4: Independence

At its core, independence for individuals with developmental disabilities is about the ability to determine one's own future and access the appropriate supports necessary to make those plans a reality. Because this may not be possible for all individuals, independence becomes about living interdependent lives with the supports one needs and finding the most self-sufficient ways to participate in daily life in the United States.

AIDD's grantees support and foster independence for individuals with developmental disabilities through efforts to improve community living and housing, education and financial independence initiatives, and emergency preparedness planning.

Native American P&A

The Native American Disability Law Center (NADLC) received a grant to address the housing needs of persons with developmental disabilities living on the Navajo and Hopi reservations. NADLC is based in New Mexico, but has an effective and ongoing relationship with both tribes as well as the Navajo Housing Authority (NHA). The grant served two purposes: 1) to improve the NHA's policies, procedures and application process to make their housing programs and services easier to access by persons with a developmental disability; and 2) to educate persons with developmental disabilities and their families about northern Arizona's affordable and accessible housing options, and the services and supports available to help people live independently in their own communities. At the end of the contract period, two focus groups were held with Navajo members to discuss barriers to affordable housing on the reservation and ways the NHA policies and procedures could be improved upon. Work continues with the NHA to review current policies in place and ways to improve upon them. Legal assistance was provided by a team from the NADLC who are experts in this field, as well as able to effectively partner and communicate with the NHA. Two thousand housing guide manuals were created for distribution to a larger network of partners in northern Arizona as a resource guide to find affordable housing, and were distributed to service providers, NHA offices and other community partners on the Navajo and Hopi reservations.

District of Columbia P&A

University Legal Services for the District of Columbia (ULS) participated in a workgroup organized by SchoolTalk to discuss and create a plan for improving alternative dispute resolution options in special education disputes in the District. Participants learned about national best practices in alternative dispute resolution and broke into small groups to discuss how DC would improve its alternative dispute resolution options.

ULS gave many presentations on the rights of students with disabilities. For example, ULS presented to 27 Americorp teachers and classroom aides about the special education process and identifying students with special needs and presented to individuals with disabilities and their family members at DC Advocacy Partners about the rights of students and families in special education.

ULS submitted comments to the Office of the State Superintendent of Education (OSSE) regarding the proposed rules for the early intervention system for infants and toddlers with disabilities, encouraging OSSE to expand eligibility to more infants and toddlers, and allow individualized family service plans (IFSPs) to continue until a child starts kindergarten, as opposed to when they a child turns three years old.

New York DDC

During FY 2011, the New York DDPC worked to improve educational opportunities for individuals with developmental disabilities through:

- An outreach campaign was undertaken to reach Spanish-speaking families and childcare providers with the assistance of CDC. In 2011, “Learn the Signs” materials were distributed to approximately 11,400 staff and over 2,500 families.
- DDPC worked with the NYS Afterschool Network (NYSAN) to develop and implement a statewide webinar on inclusion. The webinar was designed to provide information to afterschool administrators, providers, and frontline staff about making existing afterschool programs more inclusive to youth with disabilities. Informational material from the webinar was distributed to over 1200 afterschool, recreation, and fitness providers nationally via the National Center on Physical Activity and Disability and the NYSAN communications network.
- The Special Ed Taskforce (SET) Meetings & Inclusion Conference, comprised of more than 250 SET members and the participation of more than 500 individuals, promoted advocacy, mentoring, training & collaboration in upstate NY. Training topics in 2011 included: Changes to Special Education Regulations, Mandate Relief, Assistive Technology in Reading & Math, Bulling and Harassment, McKinney-Vento, and Strengthen the Role of the Parent Member.
- DDPC worked with Think College NY to build capacity in post-secondary institutions to effectively include and serve students with developmental disabilities using a community of practice/learning approach.

Florida DDC and P&A

Through workshops and the development and dissemination of 1500 DVDs on special education law & advocacy, the Council collaborated with Disability Rights Florida to provide information to families, school personnel and self-advocates with the purpose of assisting them in advocating for improved educational benefits for children with disabilities in schools throughout Florida. Through the Universal Education Project, the Council trained 29 district staff in three school districts to facilitate programs to be more inclusive. They, in turn, implemented training for 375 people to implement inclusive programs for children in their schools. This activity was undertaken by using the Best Practices in Inclusive Education Assessment (BPIE) tool and developing action plans from the results of the assessment. All three school districts made great strides in changing attitudes & setting up placements for children with significant disabilities for

the next school year. Project Discover worked in the area of transition for students from third grade through post-school outcomes. Project Discover expanded its reach into a neighboring county in order to improve the transition programs for students with significant disabilities in ten schools. This project assisted 12 students to gain paid & unpaid jobs in the community. More than 60 students developed visual resumes & employment portfolios to eventually lead to work experiences.

Virginia UCEDD

The purpose of this initiative was to increase opportunities for older persons and individuals with disabilities to use self-direction in order to provide greater choice and control in identifying, accessing, and managing the long-term services and supports they need to live successfully in their communities. Through enhanced self-direction strategies, the VA Partnership for People with Disabilities worked to increase individuals' abilities to discuss, communicate, and direct their choices and gain access to information about the availability and use of supports and services, including creative and inclusive options for employment, housing, transportation, health care, and other supports that maximize life in the community.

Connecticut DDC

The Council funded an on-demand transportation study in the Danbury Transportation District. The survey, in English and Spanish, was distributed to 300 residents and completed by 224 residents with developmental disabilities in Greater Danbury to determine the demand for a transportation service enabling people to attend meetings and events or work opportunities. The survey focused on mobility needs, type of transportation used, and reasons that certain types of transportation were not used. The survey also addressed likes and dislikes of transportation services, how much a person could or would be able to pay, days and times when transportation is needed, and destinations that are challenging to access through existing transportation services. The survey indicated that the two most significant negative aspects of transportation options were wait times and the need to schedule trips in advance. The study recommended enhancement of existing taxi services. Connecticut has implemented accessible taxis in New Haven.

Kansas UCEDD

The Assistive Technology for Kansans project (ATK), coordinated by the University of Kansas at Parsons, and its non-profit partner, Kansas Assistive Technology Cooperative (KATCO) operated a telework financial loan program for the purchase of assistive technology devices and services necessary for employment by distance. The Kansas Telework Program, directed by persons with disabilities, provided the financial guarantee necessary for personal financing of devices such as computer hardware and software, adapted peripherals, hearing and vision aids, and other devices necessary for work. The establishment of a telework program provided a financial mechanism to develop employment opportunities and to support persons with disabilities in purchasing assistive technology devices and services needed to work from a remote site or at a telework center.

Program activities focused on developing financial loan services and supports that make working by distance an employment option for Kansans who have disabilities. Dissemination and outreach efforts for the telework program included public service announcements, media campaigns, informational booths at state and regional meetings, direct mailings, articles in newsletters, and presentations made to disability and non-disability groups. Information gained from operating the telework pilot programs was made available through these efforts. Employers, potential employers, assistive technology providers, and durable medical equipment vendors were involved in media outreach efforts and included in public awareness efforts.

Data regarding applicant characteristics, device selection, impact of access to technology, and employment outcomes will be collected and shared with the national database. Information and outcomes will be shared with policymakers.

Colorado P&A

The Colorado P&A conducted 12 investigations of the use of restraint in schools and provided half-day training to school staff in a rural school district. For example: A seven-year-old student diagnosed with cytomegalovirus (“CMV”) came home from school one day with red abrasions on his neck, indicating that he had been strangulated. The Legal Center determined that the injury was caused by the mechanical device, a butterfly harness, which was used to help support him in his wheelchair. After The Legal Center conducted its investigation into what caused the injury, The Legal Center recommended that the school district train its staff on follow up procedures that would prevent this sort of injury from happening in the future. Specifically, it was recommended that the procedure include a secondary check on mechanical devices that have the potential to cause injury when in use. In this case, it appeared that the butterfly harness had slipped up to the student's neck while he was riding home on the bus, and because his bib covered the harness all the way up to his neck, neither the bus staff nor the school staff were able to see that the harness was causing the neck injury.

The Legal Center received allegations that a fifth grade student with autism was being repeatedly placed in a “quiet room” in two elementary schools, Jackson and Meridian Elementary. Because it was alleged that the student was often placed in the “quiet rooms” with the door shut for non-emergency reasons, The Legal Center contacted the school district’s attorney to discuss the allegations. The school district’s attorney agreed to conduct restraint training, along with The Legal Center, for the special education staff and school administrators. The training focused mainly on seclusion and what seclusion restraint looks like under the Department of Education’s Rules for the Administration of the Protection of Persons from Restraint Act (“Restraint Rules”). The training, consisting of a PowerPoint presentation, included detailed images of what it looked like when a student was placed in seclusion. This was extremely helpful for staff, since many members were not aware that leaving a student alone in a room and preventing egress from the room would be considered seclusion. In addition, the definition of emergency was explained in detail so that students would no longer be placed in seclusion unless there was an actual emergency, as defined by the Restraint Rules. The training impacted about 40 people, all of whom indicated that they would be better prepared to follow the Restraint Rules in the future.

North Carolina P&A

In October 2011, Disability Rights NC received a complaint about the use of restraint in a local county school system – specifically, that an elementary school student with autism was belted into a chair for the majority of the day. After a brief investigation, the Team Attorney determined that the student was restrained, the use of restraint was not included in the student’s IEP, and its use was not documented appropriately. The Attorney identified nine other students who were similarly restrained. Based on that information, Disability Rights NC filed a complaint with the U.S. Department of Education, Office for Civil Rights in March 2012. In August, OCR issued its findings letter in the case. OCR identified 18 students, including the original complaining students, who were subjected to mechanical restraint. The use of restraint was not included in the students’ IEPs, had not been discussed with their parents, and in many cases had not even been reported to the parents, all in violation of Section 504 of the Rehabilitation Act. The school system entered into a settlement agreement with OCR. The agreement requires the system to provide training for staff, and to convene IEP meetings for all 18 students to determine (a) whether the use of mechanical restraint is necessary for the student and, if so, to put specific information about its use in the student’s IEP, and (b) whether the student is due compensatory education services for the use of mechanical restraint during the last two school years. Disability Rights NC is keeping the investigation open until OCR confirms that it has approved the implementation of the settlement agreement and that their investigation is closed.

Chapter 5: Productivity

The DD Act defines productivity as the engagement in income-producing work that is measured by increased income, improved employment status, or job advancement or engagement in work that contributes to a household or community.

To that end, AIDD's grantees worked in FY 2011 and FY 2012 to increase productivity through programs that encourage gainful, competitive, integrated employment and the development of job skills. Productivity was also supported through strides made in securing access to technology that enables individuals to participate equally in activities.

Assistive technology can improve the functional capabilities of individuals with disabilities. These devices, pieces of equipment and other products enable individuals with disabilities to adapt to environments and circumstances, making them productive members of society. Seventeen UCEDDs and two P&As are the state-wide assistive technology providers.

The use of assistive technology creates a necessary bridge for individuals with disabilities to participate in an activity that they would have been excluded from previously. Through the self-advocacy of those individuals and many others around the country, school systems, employers, landlords and other public bodies are being held accountable to provide reasonable accommodations for individuals with disabilities.

Employment is a critical component of community living for most adults, including people with intellectual and developmental disabilities. Work is not only the means to economic self-sufficiency, it is also an important way for individuals to contribute to their communities, build a network of social relationships and create opportunities for lifelong learning.

However, obtaining competitive employment in an integrated setting can be difficult. DD networks across the United States have been working to ensure that all individuals with developmental disabilities have access to the employment opportunities that they desire and that allow them to be contributing members of their communities.

Education is one of the key determinants in employment success for students with intellectual and developmental disabilities. Even with a diploma, however, youth with intellectual disabilities demonstrate the lowest rate of paid employment among students with disabilities (29.8 percent), one to four years after exiting high school. Despite these statistics, individuals with intellectual disabilities can, and do, succeed in employment.

Arizona DDC

The Sonoran UCEDD at the University of Arizona was funded a one year contract to expand Project SEARCH to Maricopa County. Identifying a host business has been time consuming and is often a 12-18 month process according to Project SEARCH data gleaned from other programs across the country. This is due to identifying host employers, coordinating educational support and negotiating agreements that lead to outcomes of competitive employment. First year funding for this project has concentrated upon identifying and securing a business site, establishing and

holding ongoing meetings with an advisory board, developing necessary informal and formal contractual agreements, and obtaining necessary support and training from Project SEARCH national consultants. As an adjunct to developing competitive employment opportunities, the Council has also paid the membership fee for the state DD agency to participate in the State Employment Leadership Network (SELN). This initiative will allow the state DD agency to benefit from the services offered and coordinated by SELN and other state DD agencies in updating identified employment needs, developing a strategic plan for increasing statewide competitive employment for persons with DD and partnering with the Council and other key organizations in rolling out a structured plan. The state DD agency is in the initial stages of assessment and will be developing the strategic plan over the next year.

Tennessee DDC Network

One example of a successful collaboration is the Tennessee Collaborative on Meaningful Work. Collaborators include the UT Boling Center UCEDD; the Vanderbilt Kennedy Center UCEDD; Tennessee's Council on Developmental Disabilities; Disability Law & Advocacy Center of Tennessee (DLAC); The Arc Tennessee; and the Tennessee Departments of Labor and Workforce Development, Education, Children's Services, Human Services/Division of Rehabilitation Services, and Intellectual and Developmental Disabilities. The goals of this collaboration are to stimulate and advance systems/policy change statewide; raise the aspirations and capacities of people with intellectual disabilities/developmental disabilities (ID/DD), their families, service systems, employers and communities regarding competitive work as the first choice; and increase access to meaningful work while individuals with ID/DD are still in high school and to multiple pathways to future careers after school. This is a statewide effort which includes rural communities and students of all racial/ethnic backgrounds. The DD Community also assisted the Department of Labor and Workforce Development in implementing strategies to increase employment opportunities for persons with disabilities utilizing funding from a \$2.9 million dollar federal grant.

Disability Law & Advocacy Center of Tennessee (DLAC) has spearheaded the formation of the Tennessee Transition Coalition. This coalition meets to determine implementation strategies to address transition issues across Tennessee. DLAC also collaborated with the Division of Special Education Services to promote appropriate procedures for transition from school.

Tennessee P&A

The Disability Law & Advocacy Center of Tennessee's (DLAC) worked to ensure that individuals served by the Tennessee Department of Intellectual and Developmental Disabilities (DIDD) have the opportunity for integrated and competitive employment. As a first step, DLAC worked with DIDD on a data collection process regarding clients who are employed outside of sheltered workshops in order to determine whether those individuals are in integrated and competitive employment or segregated employment. In addition, DLAC advocated for competitive and integrated employment as the first choice employment objective for DIDD clients.

Massachusetts UCEDD

This project provided training for staff in public vocational rehabilitation, community rehabilitation programs and related organizations to increase knowledge and skills acquisition in job development/marketing professionals for the purpose of improving employment outcomes for persons with disabilities. Major activities included:

- establishing an in-service and pre-service training curriculum in job development/marketing;
- offering a series of flexible and diverse training programs for students, including didactic training, distance learning, mentorship experiences and field based work in the area of job development/ marketing for persons with disabilities;
- developing a message board for job placement professionals and community agencies employing such professionals addressing the core staff competencies; and
- evaluating the impact of the training by assessing the graduates and their supervisors on changes in skill levels, overall satisfaction with the program, and outcomes achieved.

Colorado UCEDD

This two-year project worked to develop and evaluate the use of distance technology to deliver intervention to families of children with Autism Spectrum Disorders and anxiety who are geographically removed from specialty centers. Videoconferencing sessions, online learning modules, and phone calls were used to provide long distance trainings.

Chapter 6: Integration and Inclusion

In the DD Act, Congress finds that “disability is a natural part of the human experience that does not diminish the right of individuals with developmental disabilities to live independently, to exert control and choice over their own lives, and to fully participate in and contribute to their communities through full integration and inclusion in the economic, political, social, cultural, and educational mainstream of United States society ...”⁹

For individuals with developmental disabilities, integration into all aspects of society is often achieved through access to community supports, services and technology that are coordinated to benefit each person’s unique strengths, resources, priorities, concerns and capabilities.

Throughout the 2011 and 2012 fiscal years, AIDD and its grantees have worked to ensure that individuals with developmental and intellectual disabilities are receiving the appropriate support and services.

Quality Assurance and Community Supports

Community supports are among the essential elements that enable individuals with developmental disabilities to become fully integrated and included in their communities. These supports can be threatened by tightening budgets and economic downturn. DD networks around the country have engaged in programming that works to ensure that accessible and flexible quality supports and services are available to individuals with developmental disabilities and their families.

Through these efforts, people with disabilities are helped both in the short term and in the long term as ineffective systems are either changed or discarded, meaningfully altering the way individuals with disabilities are supported in the future.

Tennessee DDC

The Tennessee DDC invested in a systems change project known as Person-Centered Thinking Organizations. The effort was designed to provide training, mentoring, technical assistance, & support to agencies wishing to change their business culture by adopting a person-centered philosophy and the use of person-centered tools, based on the premise that skills change behavior and behavior changes values. The goal of the project was to support the implementation of person-centered practices across the state by providing training, developing a community of practice, and providing ongoing support to the organizations implementing the practices.

Additionally, TN has 13 credentialed People Planning Together (PPT) trainers who serve as self-advocates and teach this two-day class to people who receive services from the Department of Intellectual and Developmental Disabilities (DIDD). Other Person-Centered accomplishments included: setting up a policy review committee at central office in order to ensure newly developed policies and procedures are not contrary to a person-centered system; forming a

⁹ Public Law 106-402, Section 101

leadership team, holding support meetings for coaches, and bringing together parents and caregivers from culturally and linguistically diverse backgrounds that have children with special needs.

New Jersey P&A

Disability Rights New Jersey contracted with an organization of self-advocates to reach out to residents of New Jersey's developmental centers regarding community living options. The Seeking Ways Out Together (SWOT) team consisted of former residents of developmental centers who schedule events on the campuses of the developmental centers to meet with current residents to discuss and respond to questions regarding community living. During visits to the institutions, SWOT team members discussed community living through graphics and video and shared their personal stories of transitioning from an institutional to community setting. The team addressed topics such as assistive technology, bullying, and employment options in the community. The team began monthly Circle of Peer Support (CPS) meetings. A CPS is designed for individuals interested in talking about personal feelings with peers who have "been there, done that" as it relates to living in and transitioning from institutional settings to the community. Through community living meetings, the residents participated in interactive discussions through videos, games, and testimonials by former developmental center residents who have moved to the community successfully.

Alabama DDC

The Medicaid Waiver Road Show project presented information to families, self-advocates, and professionals about Medicaid waivers. Participants received information for each of Alabama's six Home and Community-Based Waiver (HCBW) programs regarding eligibility, services offered, the application process, and appeal rights if deemed ineligible. The AL Coalition Against Domestic Violence project provided prevention/educational trainings and workshops specifically geared to people with DD on healthy relationships, domestic violence, and sexual assaults. The trainings focused on students aged 16-21 who were preparing to move from secondary education to the community or college. The Sharing the Care (STC) project had volunteer community workgroups addressing respite problems in four south Alabama communities. STC utilized community volunteers to create resources uniquely needed by their caregiver population, and have found ways to offer a variety of volunteer, faith-based, and peer to peer respite as well as access financial resources that may already exist for the residents in a target community. In each of the four communities, an STC workgroup was formed and strategic plans were developed around four major outcomes. Each community will use the strategic plan to carry out activities that will increase their volunteer base. During FY 2011, more than 2,200 people were been trained in respite options. An unexpected outcome of the trainings was that a fifth site in the STC project was added in Tuscaloosa, with a focus on faith-based options for respite services.

Florida UCEDD

With a focus on in-service training and technical assistance, this project involved comprehensive, community-based training for educators, family members, and other support providers, as well as

brief workshops to promote awareness and expand knowledge in positive behavior support. In addition, project staff provided individualized technical assistance to school district personnel through on-site coaching and phone consultation.

Positive behavioral support (PBS) involves the assessment and reengineering of environments so people with problem behaviors increase social, personal, and professional quality in their lives. PBS is the application of behavior analysis and systems change perspectives within the context of person-centered values to the intensely social problems created by behaviors such as self-injury, aggression, property destruction, defiance, and disruption. It is an approach that blends values about the rights of people with disabilities with a practical science about how learning and behavior change occur. The overriding goal of PBS is to enhance quality of life for individuals and their support providers in home, school, and community settings.

Family Support Initiatives

Family Support Initiatives provide an opportunity for AIDD to support projects that rely on collaborative efforts and community-based solutions to reach unserved and underserved families, and to encourage systemic change and improved community capacity to support families of individuals with developmental disabilities. In 2012, the Family Support Initiatives were no longer in operation due to a lack of federal funding.

Family Support 360 for Military Families

The purpose of these projects was to implement one-stop centers for military families. While many service programs are available in this country, human service systems often fail to meet the diverse needs of an individual with developmental disabilities and his or her family. A family may need several services, and many human service systems address primarily one need, such as health, education, or employment. These systems usually focus on one individual, not the person and his or her family. The AIDD projects worked with military families to assist them with navigating both systems – civilian and military. Collectively, these projects provided a total of 250 comprehensive supports in the form of the development of Individual Family Plans (IFP's) and 447 casual supports in the form of information and referrals (I&Rs). Below are examples of Family Support 360 for Military Family project activities.

New Jersey

This project staff participated in several events, including Specialized Training of Military Families (STOMP) training and The Exceptional Family Member Programs (EFMP) holiday gatherings. In addition, the project staff conducted six-week resource training series for parents, offered a one-day Autism workshop, participated in a coat drive on base, and coordinated a parent-led support group. Navigators planned and executed their first parent training, *Back to School Bootcamp*, which addressed common challenges experienced by families. Staff also worked with EFMP to host two training sessions with Kathie Snow (Disability is Natural). Response to the events was exceptional. A core group of ten family leaders participated in a comprehensive 30-hour resource training for parents, where they were provided with the

information, skills, tools and knowledge to not only advocate on behalf of their own children, but also to support and educate other families. The grantee entity and project co-coordinated a bilingual information clinic that provided information on the IEP process, parent rights, and IEP enhancement. A “Reaching for the Stars” awards ceremony was held for program participants who reached personal goals that included securing a GED or employment, improving school attendance, and improving family relationships.

This project experienced great success as a result of its partnership with Med Group. The FS 360 supported their efforts to engage the community and helped coordinate a forum and fair that boasted more than 100 participants, including base leadership. There were vendors from both on and off base. The USO provided supper and Med Group volunteers manned a child-friendly space.

Washington Partnerships for Action Voices for Empowerment

This project participated in and offered a variety of activities. Staff worked with EFMP to provide the first EFMP Family Resource Fair, connecting families with resources on and off base. They also participated in the Military and Military Kids and Families Summit, a region-wide meeting that opens communication between the community and the military. The Summit included a deployment briefing wherein children participated in an actual deployment line and received information from vendors that would normally interact with families during the various stages of deployment. Quarterly family get-togethers evolved into monthly networking groups with specific themes provided by families.

Georgia

This project developed and piloted the Kids in Crisis program, which was designed to ensure that students are not unfairly removed from education placements to more restrictive settings for behaviors that may be results of their disabilities. The project also developed two new roles, Local Guides and P2P Brokers, to enhance supports. Local Guides provided parents with insight into living in a community with a disability. P2P Brokers were parent leaders who worked FS 360 staff to host events, attend resource fairs, and update the resource database. Statewide support (159 counties) was achieved.

Navigator teams participated in a range of community events that ranged from parent training, to sporting activities (Buddy Ball baseball), to social events (e.g., parents night out). The popular teen dance became an annual event, more community partners joined the garden project, and community socials became quarterly events. In addition, they coordinated a strategic planning retreat for its volunteer board of directors, a group largely comprised of parents of individuals with developmental disabilities.

Mississippi

This project offered summer tutoring to help students best prepare for the new school year. Attendees were also linked with local mental health programs, vocational rehabilitation, and

post-secondary programs for resources and services. Staff conducted a parent meeting to discuss needs and perceived barriers to accessing services. Issues of importance raised by parents included IEP support, social skills training for children, understanding diagnoses, advocating for children, identification of community programs, and peer support.

Staff coordinated a variety of recreational opportunities that ranged from parent nights out, to holiday socials, to a day at the zoo. In addition, the project hosted a number of support group meetings and parent classes. Staff also provided speakers for other organizations' trainings and support groups. In addition, staff observed that advisory council members, who met regularly, developed a sense of project ownership through their involvement in program discussions, decisions, and referrals. Council members also approved a project proposal to select "Navigators" within their organizations to help FS 360 families navigate the agencies' respective service systems.

Family Support Community Access and Demonstration Projects

The purpose of these grants was to reach unserved and underserved families, and to encourage systemic change and improved community capacity to support families of individuals with disabilities via collaborative efforts and community-based solutions. Collectively, these projects provided a total of 146 comprehensive supports in the form of the development of Individual Family Plans (IFP's) and 405 casual supports in the form of information and referrals (I&Rs). Below are examples of two of these project activities.

PACE Center, MN

This project piloted the family-centered intake and planning process with three families from diverse communities (African-American, Hmong, and Somali). Families provided valuable feedback that helped refine services in the second project year. During the needs assessment stage of working with families, project staff discovered that roughly one third of families included more than one individual with developmental disabilities. This was an important note for reporting and outcome evaluation. Families participating in comprehensive assistance were asked to create family stories documenting their strengths. Twelve families completed this goal. Families were trained on the power of a personal story and how they can utilize stories for systems change. Through the project, 30 families in need received computers. Advocates helped families to set up and use their new equipment. In addition, they offered workshops on parent communication, advocating for children (in Spanish), post-secondary transition (in English, Spanish, and Somali), and special education (Hmong and Somali interpreters provided).

Georgia

This project developed and launched its time bank. One Real Community awarded nine mini-grants that funded a variety of activities, from a community art project to the development of a sensory garden at a local high school. Another Real Community held monthly community dinners and developed a Roving Listeners summer youth project that involves monthly youth groups. They also partnered with the State Department of Community Health to offer two Asset

Based Community Development trainings in Atlanta. The project also convened Community Builder retreats and Advisory Committee retreats. In addition, each Real Community hosted its own events.

Partnerships in Employment Systems Change Projects

Partnerships in Employment System Change Projects are a new five-year systems change initiative which began in FY2012 to increase employment and post-secondary outcomes for youth and young adults with intellectual and developmental disabilities. Each project is led by a consortium, including youth and young adults with intellectual disabilities, family members, state agency leaders, university centers, advocates, teachers, service providers, and employers. Projects have defined an operating plan for improving employment and education through new or revised policy development. The project funds a technical assistance provider to assist grantees with solving difficult state level policy issues as well as an independent evaluator to help determine the effectiveness and outcomes of the project. Below are Partnerships in Employment Systems Change project activities.

Wisconsin

This project held various events to include a *Youth Leadership Day*. This was a youth track for students participating in the pilots. The students learned about legislative advocacy and met with their legislators at the State Capitol to discuss employment issues. They also conducted meetings with state Senators Luther Olsen, chair of the Senate Education Committee) and continued to discuss potential legislative changes that would promote *College Workforce Readiness for students with disabilities*. Proposed changes included: 1) requiring a discussion about VR and other agencies providing services to individuals with disabilities no later than 14; 2) adding community-based work assessments to age-appropriate transition assessments; 3) recommendations for strategy related to academic and school-based preparatory experiences, work and career readiness, youth development and leadership, comprehensive community connections and family involvement and engagement; 4) providing child with a summary of his/her academic achievement and functional performance including post-secondary goals and his/her work experiences; and 5) coordinating Individual Learning Plans developed for all students with IEP transition plan for students with disabilities.

Peer to peer mentoring was added to the *Children's Waiver* with a focus on employment skills support. The school pilots made use of the *On the Job Initiative* offered by the Division of Vocational Rehabilitation for paid summer employment for the pilot students. The OJT provided an opportunity for all VR consumers in transition to work for wages before exiting high school providing a longer timeframe (up to 500 hours) and a higher wage subsidy (up to 100 percent reimbursement) to allow an employer to offer competitive employment. *Community Conversations* were held. Outcomes of these meetings included: 1) employees suggesting making an inventory of candidates that they could look at on a website; 2) employers and community members also wanted to hear more directly from the youth; and 3) suggestion that more youth should be out in the community and visible so that the greater community can see that they are willing and able to work.

New York

The grantee worked to develop a *People First Waiver* that significantly affects the state's DD agency funding and delivery of services, including employment. New York's governor included the *NYS Olmstead Plan in his State of the State*. The plan included goals for achieving integrated employment strategies to achieve those goals, performance measures related to transition from segregated to integrated employment settings, and baseline/follow-up data on employment of people with disabilities.

Access-VR ended its supported employment contracts with provider agencies one year earlier than anticipated to align supported employment contracts with contracts for other services (all services to follow the five-year funding cycle). The new contract has allowed provider agencies to request funding to support targeted job supports activities while students are still in high school and allows greater flexibility within NYS for agencies, in partnership with school, to promote intensive transition-to-work models.

OSE and OPWDD worked together to develop a *Job Readiness Curriculum* that is being used across systems. The overall goals were to provide teachers with more effective tools to teach job readiness skills during the high school years and 2) to enhance post-school training offered by OPWDD and ACCESS-VR.

Emergency Preparedness

The purpose of these projects was to design a system whereby individuals with developmental disabilities and their families can be served and assisted during emergency situations. The grantees pool resources, coordinated services and shared expenses in order to effectively train individuals with developmental disabilities and family members to prepare for emergencies, and trained individuals with developmental disabilities and their families on how to prepared for emergency situations and how to return to their regular routine in a timely manner. Below are specific examples of the activities of Emergency Preparedness projects which are slated to end at the end of FY2012.

Delaware

This project developed a "tool-kit" consisting of a personal emergency readiness planner for individuals with developmental disabilities and their families and an accompanying "navigator's guide." The toolkit included prompts to help individuals with various disabilities prepare a plan that addressed their own unique needs during an evacuation or when sheltering in place. Navigators were trained to use this toolkit to assist individuals with disabilities in the preparation of a customized emergency readiness plan.

Hawaii

This project identified and adapted Feeling Safe Being Safe (FSBS) curriculum to best meet the

needs of the target population. Twenty self-advocates have participated in the FSBS train the trainer training, professional development and organizational skills training and completed all the steps to becoming '*Certified Host Trainers for the Hawaii Feeling Safe Being Safe Training*'.

Minnesota

This project trained more than 120 people with severe intellectual and developmental disabilities, including people who have autism spectrum disorder. The trainings included personal safety planning, H1N1 tips for parents and self-advocates, and extreme weather tips. The project also trained more than 100 first responders on how to serve people with autism in emergencies.

New Jersey

This project distributed 90 wrist bands to people with disabilities who may have difficulty communicating. The wrist band contained a USB drive with Self-Directed Emergency Preparedness Plans (S-DEPP) with vital personal and family information. The information was then loaded into a USB drive connected to a wrist band a person would be able to wear in case of an emergency. The idea was for the individual, who may have difficulty speaking or remembering important personal information, to give an emergency shelter worker the USB drive so they can retrieve the necessary information.

North Carolina

This project hosted a secure website through the University of North Carolina which enabled people with disabilities and their families to create PREP plans. The completed website included the template for creating an individual or family PREP Plan, as well as information about the PREP.

Chapter 7: Training and Technical Assistance

AIDD awards a number of training and technical assistance projects to help meet and advance AIDD's mission as mandated by the DD Act. Training and technical assistance is used for multiple purposes:

- Building capacity using a variety of strategies, such as training, for greater productivity and service;
- Assisting a grantees by tackling problems that crosses state lines;
- Assisting individual grantees to carry out its work in a manner that is both responsive to the needs of its clients and efficient in its use of taxpayer dollars;
- Facilitating cross-grantee collaboration to enhance DD Network efforts; and
- Assisting with streamlining administrative processes, collecting information, implementing technology advances and providing expert advice in a wide range of areas.

Technical assistance provides AIDD and its grantees a greater ability to meet ongoing needs and sustain progress toward more successful, fulfilling lives for individuals with developmental disabilities.

In the past two fiscal years, AIDD provided training and technical assistance to each of its grantee programs through contracts with a number of organizations:

- UCEDD Resource Center, implemented under contract by the Association of University Centers on Disabilities (AUCD), which provides technical assistance to UCEDDs;
- Training and Advocacy Support Center (TASC), implemented under contract by the National Disability Rights Network (NDRN), which provides technical assistance to state P&As;
- Information and Technical Assistance Center for Councils (iTACC) awarded to the National Association of Councils on Developmental Disabilities (NACDD), which provides technical assistance to state DDCs;
- BETAH Associates, which provides technical assistance to the PNS family support grantees;
- Institute for Community Inclusion (ICI) which in under contract to provide technical assistance for Project of National Significance Partnerships in Employment Systems Change (PIE) grantees.

Technical Assistance for UCEDDs - Association of University Centers on Disabilities (AUCD)

For more than 20 years, AUCD has served as the AIDD technical assistance contractor for the national network of UCEDDs. AUCD supports its members in research, education and service activities by disseminating information; providing training, research, expert advice and guidance; facilitating electronic information sharing; and serving as a resource for federal and state

policymakers. AUCD also undertakes other activities that promote the viability and use of UCEDD resources and expertise nationally and internationally.

In FY 2011 and FY 2012, AUCD hosted AIDD's annual technical assistance institutes for UCEDD directors which addressed the following topics:

- Updates from various federal agencies, including the Department of Justice, the Department of Education, and , the Centers for Medicare & Medicaid Services;
- Issues related to health-care reform and the Affordable Care Act;
- Early childhood;
- Employment;
- Seclusion and restraint;
- Olmstead.

These institutes were attended by nearly all UCEDD directors who give high ratings on the quality of the events.

Additionally, AUCD carried out the following activities during FY 2011 and FY 2012:

Information dissemination. AUCD led the dissemination of topical information from multiple UCEDDs and others whose work affects the lives of individuals with developmental disabilities. They disseminated the information through multiple channels: electronic newsletters, papers and/or reports, topical pages on the UCEDD Resource Center website, and state-of-the-art Internet technologies such as real-time online discussions, multipoint video conferencing, and web-based audio/video broadcasts on emerging topics that affect individuals with developmental disabilities and their families. AUCD also monitored multiple sources of information on topical areas related to developmental disabilities and UCEDD operations, and disseminated relevant information to the network of 68 UCEDDs through four types of electronic newsletters: *Announcements* (produced 162 issues of the semiweekly newsletter), *Resources* (83 issues of the weekly newsletter), *Funding Opportunities* (87 issues of the weekly newsletter), and the *AUCDigest* (26 issues of the monthly newsletter).

Developing and maintaining UCEDD resource webpage. AUCD maintained and updated the UCEDD Resource Center webpage (www.aucd.org/urc) with:

- AIDD information, the DD Act, related resources, archived UCEDD Resource Center events, meetings, and webinar resources;
- General information about UCEDD grants, guidance on continuation applications and grant modifications, grant management documents and historical documents;
- UCEDD annual report requirements, technical assistance materials and workgroup meeting notes and materials;
- AIDD Monitoring and Technical Assistance Review System resources, tool, schedules, and related resources;
- Guidelines for onsite technical assistance visits;
- Promising practice briefs and Consumer Advocacy Council orientation curriculum.
- National Training Initiative materials;

- Additional AIDD project information and resources including leadership development, inclusive practices, and cultural and linguistic competency.

Convening national training events and maintaining communication. AUCD maintained communication with UCEDDs, workgroups, partners and funders through conference calls, online meetings, video chat, conferences and other means to inform the development of all technical assistance activities. AUCD also disseminated relevant results through compilation, analysis and dissemination of state-of-the-art training, research policies and annual publications of innovative practices.

During FY 2011 and FY 2012, AUCD undertook activities to convene UCEDD leadership and members:

- Convened and facilitated a one- and a half-day annual Directors Technical Assistance Meeting;
- Coordinated and convened network partner collaboration meeting for UCEDDs, DDCs and P&As;
- Planned and implemented for 42 participants a new UCEDD Leadership Institute in collaboration with The National Leadership Consortium on Developmental Disabilities at the University of Delaware to address issues related to /UCEDD senior leadership, and supporting emerging leaders from culturally and linguistically diverse backgrounds;
- Convened meetings of project advisory committee to solicit input regarding national emerging needs and feedback on implementation of technical assistance contract;
- Maintained web portal with links to each of the 68 UCEDD websites and updated a UCEDD directory with contact information for each center, its leadership and key staff;
- Convened and facilitated 1.5-day training sessions to orient 11 new UCEDD Directors and key leaders to their roles.

Designing and implementing technical assistance. AUCD designed and implemented targeted technical assistance to support UCEDDs as they carry out the mandated core functions and address specific topical issues. Technical assistance was administered through training events, workgroups, annual Directors Technical Assistance Meetings, onsite technical assistance visits and web-based outlets.

Technical assistance for reporting requirements. AUCD provided assistance for AIDD reporting requirements and the evaluation of overall program performance through maintenance of the National Information Reporting System (NIRS); annual trainings and regular conference calls with UCEDD data coordinators; annual Directors' Technical Assistance Meetings; rapid response technical assistance; systematic review, including measurement measures, to further develop and revise the AIDD reporting system; and onsite technical assistance. AUCD participated in the following activities:

- Planned and implemented new data coordinator orientations, training a total of 27 staff.
- Supported AIDD's work to revise the UCEDD program performance report and performance measures by conducting a pilot, implementing data management system changes, developing resources, and conducting training.

- Solicited UCEDD input for design changes to NIRS.
- Provided ongoing technical assistance by e-mail and phone to UCEDDs to solve problems, support data entry in NIRS, and develop annual report.
- Provided AIDD with electronic copies of UCEDD annual reports.¹⁰

Technical Assistance for P&As — National Disability Rights Network (NDRN)

The Training Advocacy and Support Center (TASC) contract is designed to improve program performance, statutory compliance and systems change across the P&As. NDRN provides training and technical assistance to the 57 P&As across the United States and its territories that protect the interests of individuals with disabilities. TASC provided training and technical assistance to help P&A staff members enhance their ability to effectively advocate on behalf of all people with disabilities.

NDRN involved the P&As in directing technical assistance toward the most critical needs and in identifying and providing technical assistance resources. NDRN recruited P&A staff, board and committee members to sit on TASC advisory committees that provide advice on technical assistance issues to the contractor and federal staff, and devote time to technical assistance resource development through their members.

In 2012, as a result of NDRN's technical assistance work for P&As:

- 82 percent of participating P&As indicated that they have improved their skills in protecting individuals from abuse and neglect;
- 79 percent have improved their skills for pursuing legal or administrative remedies;
- 81 percent have indicated that they have improved their skills in providing information and referrals;
- 88 percent indicated that they have improved their skills at engaging in advocacy or self-advocacy;
- 55 percent indicated that they have improved their skills at engaging in priority setting or governance activities, including changing questions to meet the client's level of understanding and stressing self-advocacy rather than just advocating.

NDRN carried out a wide range of activities under the TASC contract:

- Staff resources were made available to P&As by e-mail and phone, with experts providing consultation on disabilities law, organizational management and board management. Additionally, staff responded to more than 1500 programmatic issues per year, especially with regard to abuse, neglect, seclusion, restraint, community integration and ADA compliance. Staff also responded to nearly 400 P&A management related issues per year;
- Training meetings and problem-solving conferences were provided to nearly 1,200 trainees per year (e.g., annual CEO Meeting, new CEO training, annual Fiscal Manager Meeting, new fiscal manager training, annual Legal Directors Meeting and a general Annual TASC Conference);

¹⁰ AUCD Contract Year-End Reports, 2011 and 2012.

- Teleconferences and web-based training addressed emerging issues, such as trainings on new provisions in the Individuals with Disabilities Education Act, which was carried out in six sessions with about 60 attendees per session;
- Onsite training to 19 P&As was provided to address specific needs. Onsite trainings were conducted on board member roles, strategic planning and management issues;
- Monthly newsletters were produced, including one monthly newsletter on general P&A issues, a monthly legal issues newsletter, and multiple monthly Q&A fact sheet;
- Maintained a website dedicated to TASC that features a calendar of technical assistance events and resources such as dockets (a compendium of legal advocacy being carried out by other P&As) and manuals in areas of P&A best practices;
- Manuals were developed to provide guidance to P&A managers on issues and best practices (e.g., outreach practices manual, access issues manual, communications handbook, guide to practice for P&A attorneys, information and referral manual);
- Listservs were managed for issues such as legal advocacy, abuse and neglect, and education;
- Three Legal Backup Centers are subcontracted to develop technical assistance resources and provide legal advice and support in highly specialized areas of disabilities law, such as foster care, Medicaid and health care, and conditions in communities and institutions. They have responded to more than 800 requests for technical assistance, supported nearly 100 legal actions, and developed nearly 50 written technical assistance pieces per year;
- NDRN continued its Passport to Advocacy learning program, which structures training for non-attorney advocates.¹¹

Technical Assistance for Councils — National Association of Councils on Developmental Disabilities (NACDD)

Similar to the technical assistance contract for P&As, the Council technical assistance contract works to improve program performance, statutory compliance and systems change across the network of Councils in the United States. The project - Information and Technical Assistance Center for Councils (iTACC) – identifies and implements program-specific and/or cross-cutting initiatives that support the improvement of Council operations and performance.

In FY 2011 and FY 2012, NACDD used federal and non-federal experts to provide technical assistance through a wide array of methods, such as onsite consultations, annual training events and webinars.

AIDD technical assistance institutes. The theme for the 2011 Technical Assistance Institute was Maximizing Effect: Strengthening Council Effectiveness and Accountability and was attended by 149 people. It featured a keynote by Sam Durbin, an advocate and author of “You’re Not the Boss of Me.” Presentations covered topics such as an international view of disability rights, accountability, person-centered planning, effective management, employment first, and youth leadership.

¹¹ NDRN Contract Year-End Reports, 2009 and 2010.

Information dissemination. (iTACC) hosted a website that is the primary information dissemination vehicle to councils, and operated a listserv. In FY 2011, 41 posts were made and in FY 2012, 36 posts were made to the listserv.

Rapid response. Through iTACC, NACDD assisted the DDCs in carrying out congressionally mandated activities by providing DDC members, staff and executive directors with access to information, technical assistance and training resources quickly. In FY 2011, 189 requests were received and completed by iTACC staff and in FY 2012, 266 requests were received and completed by iTACC staff.

Program Performance Report. iTACC assisted with revising the DDC program performance report (PPR) template to improve the reporting process and DDC performance measures. The PPR is an evaluative tool that the DDCs use to assess progress on the Five Year State Plan. iTACC assisted with convening and facilitating workgroup discussions, receiving input from DDCs on draft measures, gathering information, and providing their expertise.

DDC Five-Year Plans. NACDD assisted with revising the DDC Five-Year Plan template to improve the planning process. The Five-Year Plan is a strategic tool that the DDCs use to guide their work. It includes long-term goals and provides guidance to DDCs for using resources. The new template emphasizes the use of national data sets, such as the State of the States in Developmental Disabilities and the American Community Survey; focuses on emerging issues in health care and long-term services and supports, particularly related to the Affordable Care Act; and calls for more relevant competitive, integrated employment opportunities for people with developmental disabilities.¹²

Technical Assistance for Projects of National Significance: Family Support – BETAH Associates

AIDD funds a contract to BETAH Associates to provide technical assistance to AIDD's family support grantees. Awarded in FY 2009, this contract promotes knowledge sharing, collaboration and understanding; builds skills; and facilitates collaborative problem solving among Family Support 360 grantees. Achievements included:

- Provided training and technical assistance to 22 grantees (FY 2011-2012).
- Grantees completed 1,097 family service plans (FY 2011-2012).
- Grantees reported conducting 7,167 information and referral activities (FY 2011-2012).
- The technical assistance website received 2,346. The Family Support 360 Technical Assistance Institute, held May 2nd-4th, 2012, with a theme of Family Support 360: Compassion and Collaboration: A Path to Empowerment. The Technical Assistance Institute received a 3.36 out of 4.00 rating from the grantees, reflecting its effectiveness.¹³

¹² NACDD Contract Year-End Report, 2009 and 2010.

¹³ BETAH Associates Contract; Final Report, January 31, 2013.

Technical Assistance for Project of National Significance: Partnerships in Employment Systems Change (PIE) - Institute for Community Inclusion (ICI)

AIDD funds a cooperative agreement to ICI to provide technical assistance to AIDD's PIE grants. Awarded in 2011, this grant promotes knowledge sharing and resources for systems change, discuss ideas to address employment challenges, promotes collaboration and understanding, and build skills. This project also provides assistance in developing performance benchmarking for the Partnerships in Employment Systems Change grantees. The PIE Annual Meeting was held July 17-18th. Topics discussed at the annual meeting included Issues and Solutions Promoting Increased Employment/Career Development for Youth and Young Adult: Using indicator data to inform system improvement, legal analysis, building local collaborative to inform system improvement, and Making Transition work for Students and their Families.

Information Collection and Dissemination

ICF International supported the Developmental Disabilities Program Information Resources Management (PIRM) contract. ICF ensured that program information resources generated by AIDD and its grantees were collected, analyzed, synthesized and disseminated using techniques that provide maximum utility to AIDD stakeholders. The PIRM contract provided technical assistance for online data collection, statistical and analytical reports, and development and maintenance of the AIDD Internet and intranet sites, as well as publication, production and information dissemination.

AIDD websites

AIDD's internet and intranet sites are crucial for providing information to AIDD grantees, the disability community and the general public. The PIRM contract provided development and maintenance for these sites and ensured that all online content is accessible and section 508 compliant.

Publications

ICF used the material gathered through online data collection and other reporting systems to develop multiple publications and communications materials for AIDD. Under this contract, ICF wrote and/or edited all AIDD publications, including web content; AIDD's newsletter, the *AIDD Update*; and various brochures providing an overview of IADD's programs and successes.

Chapter 8: Interagency Collaboration

Interagency collaboration is an essential part of the work conducted to ensure the successful implementation of the DD Act and positive, productive futures for individuals with developmental disabilities across the United States.

Given the complexity of federal, state and local programs and services that touch the lives of individuals with disabilities, cross-agency dialogue is essential to address the challenges and issues facing this group.

AIDD has undertaken many partnerships and collaborative efforts over the past two fiscal years.

Administration for Community Living

As a result of the Community Living Initiative, collaboration occurred within HHS between the Administration on Aging, the Administration on Intellectual and Developmental Disabilities, and Office on Disability to begin the formation of the HHS Administration for Community Living. The leadership and staff of the aforementioned offices worked during 2011 and 2012 to lay the groundwork for the new division.

Affordable Care Act 2402(a) workgroup.

In 2011 and 2012, AIDD continued participation in the 2402(a) workgroup to develop guidance.

In order to provide guidance to stakeholders on key aspects of home- and community-based services, the HHS Office on Disability has convened a workgroup of representatives from key HHS agencies to implement Section 2402(a) of the Affordable Care Act, "Oversight and Assessment of the Administration of Home and Community Based Services." Section 2402(a) gives the Secretary authority to encourage states to create an HCBS system that is designed to provide individuals, their families, caregivers or other representatives the support and coordination needed to design an individualized, self-directed, community-supported life.

The 2402(a) workgroup developed consensus on several of the key areas of Section 2402(a). These include the following topics:

- Overview of HCBS;
- Participant direction;
- Person-centered planning;
- Quality and system improvements;
- Participant rights and safeguards; and
- Provider qualifications and workforce development.

Expanding Opportunities with the Office of Child Care

In 2011, AIDD continued its participation in Expanding Opportunities with the Office of Child Care (formerly Child Care Bureau), Office of Head Start and the U.S. Department of Education Office of Special Education Programs. Each year, cross-agency teams from three or four states participate to develop and implement plans with the goal of increasing inclusive opportunities for young children with disabilities to improve the quality of early care and educational programs and services in their communities, and to make their findings and resources available to other states. In 2011, AIDD supported staff from the UCEDDs in Arkansas, Mississippi, Nevada, and South Carolina to participate on the state team.

AIDD participated in conference calls to discuss the process for identifying participating states, assisted in review of applications to determine participating states, notified UCEDD and contract staff regarding procedures for participation and support, and implemented an evaluation of the initiative.

Interagency Autism Coordinating Committee

The AIDD Commissioner is a federal member of the Interagency Autism Coordinating Committee (IACC), and staff from AIDD are serving on working groups to assist with updating the IACC Strategic Plan for Autism Spectrum Disorders.

The IACC is a federal advisory committee that coordinates all efforts with HHS concerning autism spectrum disorder. Through its inclusion of both federal and public members, the committee helps ensure that a wide range of ideas and perspectives are represented and discussed in a public forum.

Early Childhood

AIDD staff collaborated with other federal agencies, such as the Administration for Children (ACF) and Families on a variety of early childhood initiatives, providing expertise and recommendations regarding infants and young children with disabilities when needed. For example, staff participated in a cross-agency workgroup led by ACF to develop a resource on screening instruments.

Federal Partners in Transition Workgroup

The workgroup allows federal agency staff to discuss and share information about what their respective agencies are currently doing or planning to do in the area of transition. In collaboration with representatives from the National Council on Disability, the Departments of Education, Justice, Labor and Transportation, the Equal Employment Opportunity Commission and the U.S. Social Security Administration, AIDD and other offices within HHS compiled a Transition Resource Directory that provides descriptions of federally-supported projects and centers that focus on youth transitions.

Federal Partners workgroup meetings

Staff participated in monthly conference calls of various federal agencies in HHS concerned with early childhood issues. In addition, AIDD led an monthly meetings of an inter-agency workgroup that provides funding to the P&As. Agencies included are Rehabilitation Services Administration in the U.S. Department of Education, the Social Security Administration, the Health Resources and Services Administration in HHS, and the Substance Abuse and Mental Health Services Administration, also in HHS. During these calls, the federal partners discuss new and on-going issues with the P&As, federal monitoring processes, and evaluation and accountability efforts.

AIDD/Department of Labor-Office of Disability Employment (ODEP)

The purpose of this MOA is to work collaboratively with ODEP to expand and promote integrated employment as the first employment option for individuals with developmental and other significant disabilities, including intellectual disabilities via both the AIDDs and ODEPs employment initiatives. These two initiatives are complementary efforts that reflect the mutual commitment of ODEP and the AIDD to the concept of Employment First for all individuals with disabilities, regardless of disability label or need for support in finding and retaining employment.

The Competitive Employment Workgroup (CEWG) is an interagency federal partnership workgroup aimed at promoting systems change in the area of competitive integrated employment and is led by Eve Hill, Deputy Assistant Attorney General, Civil Rights Division at the U.S. Department of Justice. AIDD participates in the workgroups and has provided the valuable perspective of the DD Community.

Conclusion: Envisioning the Future

This report offers examples of the successful implementation of each of the core values defined by the DD Act: **Self-determination, Independence, Productivity, and Inclusion and Integration**. AIDD grantees have worked tirelessly to embody these values and achieve their goals of providing a better, more fulfilling life for individuals with developmental disabilities.

AIDD's work to strengthen health care and supports, increase employment opportunities, expand educational opportunities, protect civil rights, promote access to community living, and support the development and use of accessible technologies has successfully supported the opportunity for brighter futures for Americans with developmental disabilities.

AIDD's work supports approaches that shape attitudes, raise expectations, change outdated or broken systems and empower individuals with disabilities to pursue the lives they imagine for themselves. To that end, AIDD provides financial and leadership support to organizations in every state and territory in the United States. These bodies assist individuals with developmental disabilities of all ages and their families with obtaining the support they need to achieve all the aspects of a life envisioned and defined by the DD Act.

AIDD and its network continue to support the changing needs of individuals with developmental disabilities and evaluate their quality of life so that more effective solutions can be devised.

Now, more than ever, these and other collaborations between service systems and the individuals they support, among state and federal government agencies, and across the DD network are essential to ensuring success and a brighter future for all.

Appendix: Program Performance Data

Protection & Advocacy Agencies (P&As) — Selected Data

Areas of Emphasis: Core Outcomes		FY 2011		FY 2012	
<i>Area of Emphasis</i>	<i>Description of Area of Emphasis</i>	<i>Individuals</i>	<i>Number of P&As</i>	<i>Individuals</i>	<i>Number of P&As</i>
Employment	Adults have jobs of their choice	297	39	280	42
Education	Students have education and support they need to reach educational goals	6,580	57	6,248	55
Housing	Have homes of their choice	497	48	451	45
Health	Have needed health services	1,828	54	1,959	53
Child Care	Children in inclusive child care settings	129	23	94	24
Transportation	Have transportation services	103	33	86	28
Quality Assurance	Benefit from P&A quality assurance efforts	103	33	86	28
Complaints of Abuse, Neglect, Discrimination or Rights Remedied	Complaints were addressed and situation were resolved	9,470	56	9,638	56

Developmental Disability Councils (DDCs)— Selected Data – FY 2011

<i>Areas of Emphasis</i>	<i>Description of Area of Emphasis</i>	<i>Number of Individuals</i>	<i>Number of DDCs</i>
Employment	Adults have jobs of their choice	2,122	36
Education	Students have education & support they need to reach their educational goals	26,063	25
Housing	Have homes of their choice	770	19
Health	Have needed health services	10,897	10
Child Care	Children in inclusive child care settings	538	5
Transportation	Have transportation services	16,134	18
Quality Assurance	Benefit from Councils' quality assurance efforts	165,177	41
Formal/Informal Community Services	Individuals benefiting from formal/informal community services	49,261	38

Developmental Disability Councils (DDCs) — Selected Data – FY 2012

<i>DDC Activities</i>	<i>Number of Individuals</i>	<i>Number of DDCs</i>
People trained in area related to goal/objective	162,531	55
People trained in leadership, self-advocacy, and self-determination	45,243	51

People trained in systems advocacy	49,091	51
People active in systems advocacy	65,477	52
People attained membership on public/private bodies and leadership coalitions	3,093	48
Programs/policies created or improved	3,656	50
Number of organizations involved in coalitions, networks, or partnerships	17,459	53
Organization engaged in systems change efforts	13,385	51
Number of public policymakers educated	28,853	53
Members of general public reached	25,072,688	52

**University Centers of Excellence in Developmental Disabilities Education,
Research and Service (UCEDDs) — Selected Data**

<i>Core Functions</i>		<i>FY 2011</i>		<i>FY 2012</i>	
<i>Core Functions</i>	<i>Description of Core Function</i>	<i>Individuals</i>	<i>Number of UCEDDs</i>	<i>Individuals</i>	<i>Number of UCEDDs</i>
Research	Number of researcher activities undertaken	80,5891	56	168,625	62
Technical Assistance	Interdisciplinary pre-service preparation and continuing education	1,190,020	65	483,780	65
Direct Services	Direct or model demonstration services	97,069	51	87,468	57
Information Dissemination	Number of individuals reached through information dissemination	3,363,917	62	7,151,164	64
Trained	Professionals trained	40,676	65	52,062	65

**Appendix: The Protection and Advocacy for
Individuals with Mental Illness (PAIMI)
Program Activities Report For
Fiscal Years 2011 And 2012**

INTRODUCTION

This report summarizes the annual activities for Fiscal Years (FY) 2011 and 2012 of the Protection and Advocacy for Individuals with Mental Illness (PAIMI) Program, grantees funded and administered by the Substance Abuse and Mental Health Services Administration (SAMHSA), Center for Mental Health Services (CMHS), [The Public Health Service (PHS) Act at Subpart 3, 42 U.S.C. 290bb - 31(a) and (b) (7)]. Each PAIMI grantee is required to transmit an annual report to the Secretary of the Department of Health and Human Services (HHS), that describes its program activities, accomplishments, and expenditures during the most recently completed FY [42 U.S.C. 10805(a)(7)]. SAMHSA summarizes the grantee activity information and prepares a report, which includes aggregate data for the Secretary [the PAIMI Act at 42 U.S.C. 10824].

HISTORICAL OVERVIEW

The Developmental Disabilities Assistance and Bill of Rights Act of 1975, commonly known as the DD Act, established systems in each state, the District of Columbia, and five territories to protect the legal and human rights of individuals with developmental disabilities [42 U.S.C. 6041]. These entities, the state Protection and Advocacy (P&A) systems, were governor-designated and approved by the Administration on Developmental Disabilities (ADD), within the Administration for Children and Families (ACF). The DD Act authorized formula grants to each eligible state P&A system to support activities on behalf of individuals with developmental disabilities through the Protection and Advocacy for Developmental Disabilities (PADD) Program administered by ADD/ACF. ADD/ACF, the first P&A program, is the lead federal agency on matters pertaining to designation or re-designation of a P&A system. In April 2012, ADD was renamed, reorganized, and relocated. ADD is now known as the Administration on Intellectual and Developmental Disabilities (AIDD), within the Administration for Community Living (ACL).

The PAIMI Act of 1986 [42 U.S.C. 10801 et seq.] extended the DD Act protections to individuals with significant (serious) mental illness (adults) and significant (severe) emotional impairments (children/youth) at risk for, or in danger of abuse, neglect, and rights violations while residing in public or private residential treatment facilities. The same ADD-approved, governor-designated state P&A systems that received PADD Program funding were authorized to administer the PAIMI Program.

The PAIMI Act [42 U.S.C. 10801(b)] mandated state P&A systems:

- 1) To protect and advocate for the rights of residents with significant (serious) mental illness (adults) and significant (severe) emotional impairments (children and youth), residing in public and private care and treatment facilities who are at risk for, or in danger of abuse, neglect, and rights violations by using administrative, legal, systemic, and legislative, or other appropriate remedies on their behalf;
- 2) To investigate reports of abuse, particularly incidents involving serious injuries and deaths related to the inappropriate use of seclusion and restraint; and

- 3) To ensure enforcement of the United States Constitution, federal laws and regulations, and state statutes.

In 1986, there were 56 P&A systems located in each state, the District of Columbia, and five territories (American Samoa, Guam, the Commonwealth of the Northern Mariana Islands, the Commonwealth of Puerto Rico, and the U.S. Virgin Islands). At that time, 45 P&A systems operated as private, non-profit organizations (as designated by the respective state Governors) and 11 were state-operated (Alabama, American Samoa, Connecticut, Indiana, Kentucky, New York, North Carolina, North Dakota, Ohio, the Commonwealths of Puerto Rico, and Virginia). These public/state-operated systems were independent of any agency in the state that provided treatment or services (other than advocacy services, to individuals with mental illness [42 U.S.C.10805 (a) (2)]).

In 2000, the PAIMI Act was amended by the Children's Health Act of 2000 (the CHA at 42 U.S.C. 290 *et seq.*). The CHA established a 57th P&A system for Native Americans, the American Indian Consortium (AIC), which is composed of the Navajo Nation and Hopi tribal councils. The AIC serves the Navajo and Hopi residing on tribal lands, as well as other tribes residing in areas close to the reservations and the Four Corners region of the Southwest (Utah, Arizona, Colorado, and New Mexico). The CHA (42 U.S.C. 290ii) requires that "public or private general hospital, nursing facility, intermediate care facility, or other health care facility that receives support in any form from any program supported in whole or in part with funds appropriated to any federal department or agency shall protect and promote the rights of each resident of the facility. This includes the right to be free from physical or mental abuse, corporal punishment, and any restraints or involuntary seclusions imposed for purposes of discipline or convenience." Each facility covered under the PAIMI Act shall notify the appropriate agency, as determined by the Secretary, of each death that occurs at each such facility, while a patient is restrained or in seclusion, of each death occurring within 24-hours after the patient has been removed from restraints and seclusion, or where it is reasonable to assume that a patient's death is a result of such seclusion or restraint. A notification under this section shall include the name of the resident and shall be provided no later than seven days after the date of the death of the individual involved (*op. cit.* at 42 U.S.C. 290ii - 1). This Act clarified that the state P&A systems had the authority to investigate incidents of restraint and seclusion in these types of facilities.

The PAIMI Act of 2000 also allowed state P&A systems to serve PAIMI-eligible individuals who lived in the community, including their own homes; however, individuals residing in care and treatment facilities must have priority for program services. In 2005, ADD approved a request from the Governor of North Carolina to re-designate the state-operated P&A system to a private, nonprofit entity. In FYS 2011 and 2012, there were 10 state operated P&A systems in Alabama, American Samoa, Connecticut, Indiana, Kentucky, New York, North Dakota, Ohio, and the Commonwealths of Puerto Rico and Virginia.

FUNDING

Each P&A system must submit an annual application or an update of its program priorities, proposed budget, assurances and any other information requested by SAMHSA [PAIMI Act at 42 U.S.C. 10821]. These awards, subject to availability of appropriations, are based on a

formula prescribed by the statute. The formula is based equally on the population of each state in which there is an eligible system and on the population of each state weighted by its relative capital income [42 U.S.C. 10822 (a) (1) (A) (i) and (ii)]. Relative per capita income is the quotient of the per capita income of the state. The quotient of one was assigned to American Samoa, Guam, the Commonwealth of the Northern Mariana Islands, and the U.S. Virgin Islands [42 U.S.C. 10822 (a) (1) (B)]. The Secretary shall use no more than two (2) percent of the amount appropriated, commonly known as the set-aside under the PAIMI Act, to provide technical assistance and training to eligible systems [42 U.S.C. 10825].

The following chart reflects the total annual PAIMI Program grant appropriations, the Technical Assistance (TA) set-aside, and the minimum and maximum grant allotments awarded to the states and the territories in FY 2011 and 2012. In FY 2012, the PAIMI Program grant was reduced by 0.19 percent, a \$68,860 reduction in the total awards to the state P&A systems and a \$1,377 decrease in TA. In FY 2012, California, the largest state P&A system, received \$6,037 less in PAIMI grant funds, the minimum state allotment P&A system grants were reduced by \$800, and the American Indian Consortium, American Samoa, Guam, the Commonwealth of the Northern Mariana Islands, and the U.S. Virgin Islands, each received \$400 reduction.

	FY 2011	FY 2012
Total Annual PAIMI Awards	\$ 36,307,240	\$ 36,238,380
To State P&A Systems	\$ 35,581,095	\$ 35,513,612
Technical Assistance Set-Aside	\$ 726,145	\$ 724,768
Minimum State Award	\$ 429,900	\$ 429,100
Maximum State Award	\$ 3,140,608	\$ 3,134,571
Minimum Territory Award	\$ 230,300	\$ 229,900

[See, Appendix - Table 1]

PAIMI PROGRAM ACTIVITIES

A. Demographic Information

1. Age and Gender

The following chart summarizes the number of PAIMI-eligible individuals or clients served in each FY by age and gender.

	FY 2011	FY 2012
Age in Years		
0-4	34	22
5-12	1,323	1,228
13-18	2,543	2,455
19-25	1,342	1,258
26-64	10,440	10,031
65+	787	920
Unknown	23	23
Total	16,492	15,937
Gender		

Male	9,442	8,999
Female	7,050	6,956
Total Served	16,492	15,955

[See, Appendix, Table 2]

2. **Ethnicity and Race**

PAIMI clients served by the P&A systems self-identified their ethnicity and race. The following chart provides the ethnicity and racial identities reported by individuals served by the P&A systems. The information was self-reported and the individuals/clients served were permitted to select one or more races. The totals may exceed the number of PAIMI-eligible persons served.

Ethnicity	FY 2011	FY 2012
Hispanic/Latino	1,509	1,308
Race		
American Indian/Alaskan Native	419	388
Asian	191	208
Black/African American	3,467	3,386
Native Hawaiian/Pacific Islander	232	419
White/Caucasian	10,954	10,341

[See, Appendix, Table 3]

3. **Living Arrangements**

P&A systems served individuals who resided in various settings. Examples of these living arrangements included:

Arrangement Type	FY 2011	FY 2012
Independently in the community	4,685	4,715
Adult Community residential home	679	631
Psychiatric wards	1,548	1,323
Public and private institutions	3,102	3,059
Legal Detention/Jail	747	794
Homeless	343	372

[See, Appendix, Table 4]

B. Services to Individuals

Under the PAIMI Act, state P&A systems are mandated to protect and advocate for the rights of individuals with mental illness and authorized to investigate complaints of abuse, neglect, and rights violations [42 U.S.C. 10805(a)(1)]. The following table shows the total number of individual PAIMI abuse, neglect and rights violation cases opened, investigated, and closed.

1. **Abuse**

Number and types of closed individual abuse complaints include:

	FY 2011	FY 2012
Abuse Complaints, Investigated and Closed	3,389	2,954
By Complaint Type		
Inappropriate/excessive use of restraints	358	358
Inappropriate/excessive medication	216	220
Involuntary electroconvulsive therapy	12	12
Failure to provide mental health treatment	912	786
Physical assaults resulting in serious injuries	249	128
Sexual assaults	129	120
Staff threats/retaliation/assaults	190	190

[See, Appendix, Tables 5 – 7c]

Case Example from Fiscal Year (FY) 2011

INDIANA – failure to provide adequate psychiatric treatment

A 36-year-old Hispanic male, with limited English language skills, had resided in a local psychiatric hospital for two years awaiting a competency evaluation. The facility never provided him with an interpreter. The P&A interceded and negotiated with the hospital on the client’s behalf. The P&A wanted the client to obtain competent interpreter services, adopted a comprehensive communication policy, and provided an adequate number of interpreters. The P&A intervention resulted in the client receiving translation services that facilitated his ability to communicate with facility treatment staff and residents.

NEW MEXICO – excessive restraint

A young woman resident of a local treatment center was restrained for two hours and 37 minutes for refusing to attend her program. The length of her restraint exceeded the maximum time allowed per state regulations. The P&A staff interviewed her and sent their findings to the facility administrator. An internal investigation by the Director of Quality Improvement and Facility Operations resulted in major systemic changes in the treatment facility’s operations. Examples of these systemic changes included, increased facility staff training (on time limitations in restraint and seclusion), banning staff use of prone restraints, holding treatment team meetings within five-days of a restraint incident, and implementing policies to allow residents private time.

SOUTH DAKOTA – failure to provide appropriate mental health treatment

A 31-year-old male inmate of state minimum-security prison requested P&A assistance to obtain access to medications prescribed prior to his incarceration. The client alleged that prison staff had decreased his medications so much that they were ineffective. The client knew that without medication he would display behaviors that may prolong his sentence. The P&A staff provided him with advice and guidance on how to self-advocate. The client was eventually released from prison and returned to the community where he requested further assistance. P&A staff met with the client’s parole officer and contacted the community mental health provider and social services agency to resolve the client’s medication issue. These efforts resulted in the client’s ability to receive his prescribed medications.

TEXAS – seclusion and restraint/discharge planning

A state-operated psychiatric facility resident contacted the P&A for discharge planning assistance. A review of the client's record included numerous incidents of chair restraint and periods of prolonged seclusion, sometimes up to 20-hours per day. The client's presenting issue was the facility's misapplication of the standard for release from restraint and seclusion. The direct care staff required that the resident be totally calm prior to release. The P&A successfully advocated for a more appropriate behavioral intervention and the development of a safety plan for its client. The number of incidents of restraint and seclusion plummeted prior to the client's discharge. In addition, the P&A conducted in-service training for facility staff on appropriate restraint and seclusion release criteria consistent with state law and regulations.

WASHINGTON – inappropriate use of seclusion and restraint/facility monitoring

The P&A investigated several complaints involving the inappropriate use of Restraint and Seclusion (R&S) on youths residing in a mental health treatment facility. Facility staff used R&S after incidents involving property destruction. Findings in two separate P&A investigations noted that staff failed to follow established R&S state laws and facility policies. P&A intervention resulted in a written agreement requiring the treatment facility to implement action plans to correct 13 problem areas identified by the P&A. To ensure compliance, the P&A will monitor the residential facility's progress.

WEST VIRGINIA - inappropriate use of seclusion and restraint/serious injury

A state hospital resident requested P&A assistance after sustaining bruises and being forcibly injected with a sedative while being restrained by facility staff. The nursing staff confirmed that following the restraint incident, the client received medical care and that a grievance was properly reported to, and investigated by, the administration. P&A staff shared this information with their client who was satisfied with the hospital's response. The P&A staff also educated their client on how to file a grievance.

Case Examples FY 2012

ALABAMA – Failure to provide mental health treatment, abuse & neglect

A 17-year-old youth who resided in a state juvenile correction facility was placed on close observation for prior suicide threats. Facility staff denied the teen's request to have the nurse change the dressing on his injured hand. When the teen refused to leave his cell to participate in regular facility activities, staff promised to take him to the nurse. When the teen left his cell, a staff member reneged on the medical treatment. This upset the teen. He ran from staff, found some plastic material in a facility employee workstation, and placed it over his face. The P&A reviewed the facility's incident report and video surveillance recordings. The P&A investigative findings noted that facility staff deliberately lied to lure the patient from his cell and did not implement the patient's "close observation order" following his suicidal gesture. The facility fired the employee who lied to the patient. To ensure that staff implement the facility's *Suicide Prevention and Intervention* protocol, the P&A recommended that the facility clarify its policies, so that suicidal gesture incidents are no longer viewed as safety violations that lead to disciplinary actions against facility residents.

MICHIGAN – physical abuse

A state ward residing in a residential treatment center was shoved to the ground by a staff person. The young woman sustained a back injury. The P&A intervened on their client's behalf and filed a complaint alleging improper physical restraint with the state licensing agency. The licensing agency substantiated the P&A's allegations. The employee was disciplined and all facility staff were retrained on proper behavior support and de-escalation protocols.

NEW JERSEY – seclusion and restraint, abuse and rights violations

The P&A continued to advocate on behalf of three young female residents placed in three state-operated psychiatric hospitals. The facilities continued to restrain or seclude the women for behaviors attributed to their past traumas (violent sexual and physical abuse). One woman, who facility staff placed in four-point restraints hundreds of times, complained that after each incident, she had flashbacks of abuse by a family member. Although earlier efforts by P&A staff stopped the use of four-point restraints on these women, hospital staff continued mistreating them, e.g., confining one woman for several months to a small "comfort" room with only one exit guarded by facility staff. The hospital did not consider its practice as seclusion and stated that it was the result of a behavioral contract signed by the patient. The three women have one-to-one observation orders that provide them with little privacy or autonomy during their hospitalization.

TENNESSEE – abuse investigations, staff (Non-death related)

The P&A investigated an allegation that a rural boarding school resident was abused by staff. The resident's mother reported that following an incident with school staff, her son's hand was broken and emergency surgery was needed. The facility administration and local law enforcement investigated the incident, which resulted in the arrest and termination of the school employee. The client's mother expressed concern about other facility residents at risk for abuse (the boarding school specialized in behavioral intervention for adolescent boys with emotional impairments and other disabilities). The P&A staff investigation included four unannounced facility visits and resulted in educating boarding school faculty, staff and residents about the P&A's responsibilities.

VIRGINIA – restraint and abuse

An individual, who retained his capacity for informed consent, was voluntarily admitted to a state-operated facility. When he objected to several prescribed psychotropic medications, facility staff restrained him and then gave him an intramuscular injection. During one restraint incident, the individual sustained a laceration above his right eye when he and the staff fell to the floor. The investigation, which substantiated facility staff abuse and violation of their client's rights, resulted in the P&A educating the client on how to self-advocate and to file a grievance/complaint process.

WYOMING – restraint & staff abuse

While reviewing Wyoming State Hospital (WSH) incident reports, P&A staff found several incident reports involving one patient who facility staff placed in prone restraint. The P&A used its probable cause authority and the hospital provided the name of the patient and his guardian. The guardian expressed concern about WSH staff use of inappropriate restraint techniques on the ward and authorized the P&A to investigate the incidents. The P&A investigation included

watching a security video of an incident. During that incident, the patient was held for five minutes, placed in prone restraint (face down on the floor) for an hour, secured to a restraint board, before being transported to another unit where he was placed in bed in four-point restraints. The P&A substantiated the incident of abuse and initiated a conference about its investigative findings of abuse by facility staff with the Wyoming Office of the Attorney General, the Department of Health (DOH), and WSH administration. P&A intervention resulted in WSH and DOH actions to eliminate the use of restraints by facility staff.

2. **Neglect**

Number and types of individual neglect complaints closed per FY included:

	FY 2011	FY 2012
Neglect, Complaints Investigated & Closed By Complaint Type	2,658	2,605
Discharge planning	1,134	1,176
Personal care	292	268
Mental health diagnoses	147	219
Medical diagnoses	193	219
Environmental safety	158	125
Personal safety	127	115
No written treatment plans	138	124

[See, Appendix, Tables 6a & 6b]

Case Examples from FY 2011

KANSAS – personal care

A state psychiatric hospital resident, a veteran with orthopedic issues, requested P&A assistance after hospital staff did not allow him to use his wheelchair. The staff also refused to assist him to get out of bed and complete daily tasks, which impacted his ability to participate in the facility treatment programs and his recovery. A P&A attorney intervened on his behalf and met with the client and hospital staff, including the director of the program. The P&A negotiated an agreement with the state hospital to allow the resident to use his wheelchair and to provide him with assistance when needed. In addition, the Veterans Affairs (VA) doctors informed hospital staff of the client’s medical needs. As a result of P&A intervention, the state hospital services and the VA follow-up care services provided to the client improved. The P&A educated hospital staff on how to better assist other facility residents with similar physical and mobility impairments in activities of daily living.

MARYLAND – discharge planning

The P&A intervened on behalf of a 20-year-old female, Residential Treatment Center (RTC), facility patient. The client, who had multiple RTC placements, remained in the RTC due to inadequate community placement resources. The client’s parents, who were her legal guardians, were not involved in her treatment and did not want her discharged to their home. The P&A staff met with the resident and her therapist, conducted a record review, and discussed placement options with RTC officials. P&A intervention resulted in the client’s discharge from the RTC and placement by the Maryland Mental Hygiene Administration in an appropriate community-

based home with mental health support services.

MASSACHUSETTS – *discharge planning*

The P&A intervened on behalf of a 57-year-old male, state psychiatric hospital resident, whose discharge was delayed. P&A staff reviewed their client's facility record and worked with his health-care proxy/representative payee and brother on appropriate discharge planning. The client had an apartment in the community but his treatment team planned to discharge him to a rest home. The client was medication compliant and had no medical conditions that interfered with his ability to return to his apartment. Vigorous P&A advocacy resulted in the following discharge plan - a brief placement in a step down residence for the client to develop activities of daily living skills before returning to his apartment. The P&A's successful advocacy resulted in a Massachusetts Department of Mental Health decision not to place the man under limited guardianship.

NORTH DAKOTA – *discharge planning/ recovery*

A 28-year-old female requested P&A assistance with discharge planning and alleged that hospital staff did not help her. The hospital staff informed the P&A that it presented options, which the client resisted as she wanted placement in a 24-hour supervised living arrangement. P&A staff met with the client and unit social worker to discuss, discharge planning. The P&A staff also met with the hospital's psychiatric staff and staff from the human service center that served their client's home community. An agreement was reached and the client agreed to be discharged to a crisis facility and receive supportive services from the human service center. P&A involvement resulted in achievement of the client's goal - returning to her home community.

OKLAHOMA – *recovery/housing*

P&A assistance was requested by a PAIMI-eligible woman whose publicly funded housing refused to grant her an accommodation, as recommended by her therapist. The housing office had issued a *notice to vacate*. The client had no other housing options and faced homelessness. P&A staff negotiated with the housing agency to obtain the necessary accommodations, filed a grievance on the client's behalf, and assigned an attorney to accompany the client to the informal grievance hearing. P&A intervention resulted in a settlement. The client received the accommodation she needed and retained her housing and ability to recover in the community.

Case Examples from FY 2012

GEORGIA – *discharge planning/self-advocacy*

A 41-year-old mental health client participated in a *Certified Peer Specialist* training provided by the P&A. During one training session, the client met with, and informed the P&A Director of Advocacy Education; she was inappropriately discharged from an *Assertive Community Treatment (ACT)* program. The client had received verbal notice from ACT staff of her immediate discharge from the program. This action left the client with no support services for continued management of her mental health needs and jeopardized her significant progress toward health and well-being. The P&A supported the client's efforts to address the inappropriate ACT discharge and lack of referral for services. P&A intervention resulted in the client's access to appropriate mental health supportive services and treatment.

MARYLAND – *failure to provide mental health treatment*

The P&A investigated the failure of state hospital staff to provide necessary treatment to a patient. The patient had attempted suicide twice and requested individual therapy from hospital psychologists several times before and after his suicide attempts. The client was informed; he was not a “priority.” The P&A sent the Director of the Mental Hygiene Administration (MHA) a request to alert the hospital’s administration of the patient’s risk of suicide and to provide him with therapy. As a result of P&A intervention, the hospital assigned a psychologist to provide therapy. The P&A followed-up with MHA and hospital administration, to advocate for increased patient access to individual therapy with a psychologist. The hospital subsequently hired eight psychologists, and now every hospital has the opportunity to request and receive individual therapy.

SOUTH CAROLINA – *neglect/environmental safety*

The P&A assisted an individual who had problems, while living at the Community Residential Care Facility (CRCF), e.g., verbal abuse at the facility. His mental health workers agreed that CRCF was not an appropriate environment for him. They felt the facility staff had not provided him with appropriate care, which caused him to deteriorate. The P&A investigated. The client had an order that relieved his aunt of guardianship responsibilities but also required him to remain in a specific facility indefinitely. The P&A requested and obtained, an amended court order, which allowed the client to live in a least restrictive setting, appropriate to his needs as determined by his treating professionals. The client was moved to a better CRCF and eventually, to a less restrictive setting. The P&A successfully advocated for the client’s re-adjudication of incapacity, a determination that the client had resolved to win. The client chose where he wanted to live.

VERMONT – *discharge planning*

The P&A worked with a client who was involuntarily admitted to the Brattleboro Retreat facility, for a forensic evaluation. After his evaluation, the facility held the client, after obtaining a 90-day Order of Hospitalization and informed the P&A that their client “didn’t really need to be in the hospital.” The P&A investigated and found that the client had no discharge plan. The P&A worked with the client’s social worker who stated; the client’s legal status was placed under the Department of Mental Health, which was responsible for his discharge plan. The development of that plan was related to, recent psychosocial evaluation that recommended 24/7 supervision for the client. The P&A investigated the discharge plan delay, and substantiated that, the client did not require hospitalization, and successfully advocated for the client to receive an appropriate discharge plan.

WYOMING – *environmental safety*

In 2011, the P&A staff investigated conditions at Wyoming State Hospital (WSH), and identified several unsafe conditions in the facility, e.g., mold, dead rodents, asbestos, and impediments to safe fire evacuation, at this facility. In FY 2012, the P&A successfully advocated for, closure of two units at the WSH and the relocation of all patients, previously housed in those units, to more environmentally appropriate facilities.

3. **Rights Complaints**

Number and types of individual rights complaints closed per FY included:

	FY 2011	FY 2012
Total Rights Violation Cases Investigated and Closed	7,086	7,483
By Complaint Type		
Guardianship	367	407
Advanced directive problems	140	151
Failure to provide confidentiality	67	66

[See, Appendix, Tables 7a and 7b]

Case Examples from FY 2011

KENTUCKY – guardianship & discharge planning

A state hospital female resident, requested P&A assistance with discharge planning and placement in the community. The P&A intervened, investigated, and found that a year earlier the state appointed an emergency guardian for their client. While in the guardian’s care, the client was placed in three personal care homes and two psychiatric hospitals, located in different counties. With P&A staff help, the client filed a court petition to either, dissolve the emergency guardianship or to appoint her son as the new guardian. The court ordered the client’s emergency guardian to ensure she was discharged from the state hospital within seven days and to assist with her placement into the community. Subsequently, P&A staff notified the guardian of their intent to inform the judge of the delay in executing the court’s order. This resulted in the guardian's permission to the client's discharge and placement with her son. The client's request for an apartment under the Olmstead Housing assistance was approved. At the client’s final hearing, the court restored her rights and dissolved her emergency guardianship order.

MISSOURI - guardianship

A 21-year-old man requested P&A assistance because his public administrator guardian did not provide him with warm clothing and placed him on phone restrictions. A P&A advocate contacted the guardian who stated; the young man was provided clothes and other monies, interviewed the residence facility staff who refuted the guardian’s statement, and substantiated the information provided by the facility staff. When questioned by the advocate, the guardian insisted, the client must buy clothes from his \$30 monthly allowance and phone restrictions were necessary behavior modifications. When the guardian informed the client, he could not have a pass to visit his family at Christmas; the client expressed his anger and was moved by the guardian. The advocate intervened and spoke with the new residential facility staff. They granted the client a Christmas pass and provided him with warm clothing. The guardian eventually allowed the client one daily phone call.

Case Examples from FY 2012

COLORADO – rights violation

A 39-year-old Native American, with a history of placements in mental health treatment facilities, requested P&A assistance with discharge from the state hospital. The hospital provided the client with only one discharge option – placement in a locked nursing home that had no available beds. For several years, the client remained in this “holding pattern.” P&A staff investigated, conducted a thorough record review, attended treatment planning meetings, consulted extensively with the facility’s treatment team, and worked to obtain their client

culturally-competent services. The client’s treatment team did not support her request to live in the community with appropriate supports. P&A staff met with the hospital superintendent and successfully advocated for the client’s transfer to a recovery-peer oriented treatment team. P&A intervention also provided the client with more independence and time away from her unit.

MAINE – rights violation (recreational activities)

During a P&A monitoring visit to a community psychiatric hospital, several adolescent patients complained they had no access to outdoor recreation (they spent their days indoors) – a violation of state policy. After several informal and unsuccessful meetings to resolve the presenting issues with the facility’s administrators, P&A staff filed a complaint with the state about the hospital’s regulatory violations. This P&A action resulted in the hospital agreeing to develop a secure recreational area for adolescents.

4. Death Investigations

The PAIMI Act authorized state P&A systems to investigate incidents of abuse, neglect, and deaths that occur in public and private care and treatment facilities on behalf of eligible individuals [at 42 U.S.C. 10802 (1), (3), (4), and (5)]. Most states had no mandatory reporting statutes, central registries or other statewide systems to capture incidents of restraint, seclusion, serious injuries and/or fatalities. Despite state data collection limitations, the state P&A systems monitored and investigated the use of restraint and seclusion in residential care and treatment facilities, especially incidents involving serious injury or death. States with mandatory reporting requirements and central registries often send all state death reports to the P&A system, whose staff must then review the information to determine those incidents that require an investigation. Deaths reported and investigated by state P&A systems included:

Deaths Reported	FY 2011	FY 2012
Source of Report		
States	2,475	2,636
Centers for Medicare & Medicaid Services (CMS)	7	4
Other	96	138
Deaths Reported Total	2578	2778
Deaths Investigated	FY 2011	FY 2012
By incident type		
Seclusion (S)	3	40
Restraints (R)	16	14
Non S or R related	290	469
Deaths Investigated Total	309	523

[See, Appendix, Table 7c.]

Case Examples from FY 2011

COLORADO – restraint

The P&A investigated a death at the Colorado Mental Health Institute at Pueblo (CMHI – P). After placing a resident in five-point restraints in a prone position, facility staff did not monitor his breathing. The staff was unable to release the patient’s leather restraint straps, turn him on his back and initiate cardio pulmonary resuscitation before the patient died. After the incident,

CMHI – P implemented systemic changes, e.g., the use of prone restraints was prohibited, the inclusion of scissors in restraint bags, and continuous face-to-face monitoring of all residents placed in restraints.

NEW JERSEY – medical neglect

A 62-year-old Greystone Park Psychiatric Hospital resident died while sitting in the hallway floor next to her unit’s medication room. The P&A investigative findings noted discrepancies between the unit’s surveillance videotape and hospital staffs’ documentation of the incident. For example, the video showed the only physical contact between the patient and unit staff occurred when a Licensed Practitioner Nurse (LPN) attempted to arouse the patient with a kick. The LPN notified two Registered Nurses (RN) who assessed the patient’s condition as motionless and unresponsive, but did administer cardio pulmonary resuscitation. The P&A investigation substantiated the staffs’ neglect before referring its findings to the hospital’s nursing administration and employee relations for review and appropriate corrective action.

TENNESSEE – prone restraint

An inmate died after he was placed in prone restraints by Correction Officers (CO) under observation of a nurse. The CO did not respond when the inmate complained of his inability to breathe. The inmate stopped breathing when the officers finally turned him on his back. Resuscitation efforts were unsuccessful. Subsequently, the coroner ruled the death a homicide. The P&A investigated and substantiated that the inappropriate use of restraint by the CO and possible failure by the RN to recognize potential drug interactions. The P&A provided the prison administration with the following recommendations: ensure that equipment and outside lighting are maintained nightly; develop and implement a medication review policy (i.e., for possible interactions, any risks associated with the use of prone restraint); require medical treatment when prisoner complains or exhibits signs of respiratory distress; and, train all prison staff involved in this incident on the risks of *Sudden In-Custody Death Syndrome*. The P&A monitored the facility’s compliance with these recommendations.

Case Examples from FY 2012

NEW JERSEY - suicide

This P&A reviewed the state Department of Human Services (DHS), death investigation report of a 28-year-old, Trenton Psychiatric Hospital (TPH) patient who completed suicide while under staff supervision. The P&A conducted a secondary death investigation and noted discrepancies in DHS’ findings. For example, the patient’s direct care worker, who was assigned to supervise him every 15 minutes, reported that the required patient checks were performed. In fact, the worker was eating and watching television when the patient died. During his six-month hospitalization at TPH, the patient attempted suicide, eloped repeatedly, was moved from unit to unit, and received little or no treatment. The P&A reported its findings, and several other TPH incidents that appeared to be a pattern of neglectful practices to the U.S. Department of Justice, Civil Rights Division, and the Centers for Medicare and Medicaid Services.

WISCONSIN – restraints & seclusion

Seven months after stopping his medications, a man was placed in a state psychiatric institution. Shortly after admission, he was restrained several times for attempting to leave his unit (by

rushing towards the door) and often spent his nights in a seclusion room. Following an incident, facility staff forced him to the floor, placed him in a "burrito wrap" body restraint, transported him to the unit's seclusion room where he was left in a prone (face down) position. For several hours, staff checked his condition by observing him from the window of the locked seclusion room. One staff member entered the patient's room, turned him over and noticed his skin was blue (due to a lack of oxygen). Despite staff efforts to resuscitate him, the patient died. The P&A investigated, i.e., reviewed the hospital's incident reports, peer review records, etc. The medical examiner attributed the patient's death to the prone restraint. The state Division of Quality Assurance also investigated the incident. The hospital was cited by the state and federal government for inadequate care and monitoring of vital systems during restraint interventions. The P&A met with the hospital's administrative, clinical, and security staff and advocated that the hospital prohibit staff use of prone restraint, prone transfers and "burrito wrap" holds. P&A's intervention resulted in systemic changes in the facility, e.g., the removal of the "burrito wrap" from all units and limited use of prone transfers to emergencies.

5. Intervention Strategies

The P&A systems are authorized by the PAIMI Act [at 42 U.S.C. 10805 (a) (1) (C)] to pursue administrative, legal, and other remedies to ensure protection for individuals with mental illness. An individual's initial complaint may involve multiple issues and P&A systems often use several strategies to resolve them. The total strategies used often exceeded the number of complaints investigated and closed in a FY, as clients' initial complaints frequently include multiple issues and various strategies are used to resolve them.

	FY 2011	FY 2012
By Type		
Short term assistance	6,668	6,331
Abuse & Neglect Investigations	2,395	2,162
Technical assistance	3,035	2,659
Administrative Remedies	374	737
Negotiation/Mediation	1,740	1,599
Legal	333	287
Total Strategies Used	14,545	13,775

[See, Appendix Table 8]

Case Examples from FY 2011

ARIZONA – technical assistance/administrative hearing

A guardian was provided technical assistance after a PAIMI-eligible received a notice of action to terminate a supportive behavioral health housing placement. No alternative housing placement was provided and the individual faced possible homelessness. With P&A assistance, the guardian successfully advocated for the individual and learned how to file an appeal. P&A intervention resulted in the individual's continued placement in supportive housing.

CALIFORNIA – short-term assistance/investigation

The P&A helped a PAIMI-eligible individual with multiple disabilities (visual impairments, HIV positive) who complained of "squalid" conditions in his room and board facility. The facility did

not provide daily meals or any additional domestic services the individual required. The P&A investigated the service providers and helped their client file an adult protective services (APS) complaint. APS substantiated the client’s allegations. The client moved to a better boarding situation. P&A intervention alerted APS to neglectful service providers and the improved the living conditions of their client.

Case Examples from FY 2012

NEW YORK – abuse & neglect investigations

A PAIMI eligible Five Points Correctional (FPC) facility inmate requested P&A assistance. The NYS inmate was placed on FPC’s Special Housing Unit managed by the NYS Office of Mental Health (OMH). OMH dropped the inmate from the unit’s caseload and refused to provide him with a requested psychiatric evaluation. The P&A investigated OMH’s failure to provide psychiatric treatment (the inmate has had a diagnosis of paranoid schizophrenia). The client participated in the Community Orientation and Re-Entry Program (a discharge planning program for inmates with serious mental illness). OMH omitted this information from the inmate’s current mental health records. The P&A’s investigative findings were sent to the OMH Risk Management Director. P&A involvement resulted in the inmate’s placement on the OMH caseload, where he was evaluated by a nurse practitioner and prescribed psychiatric medication. This P&A investigation insured that prisoners received the mental health services mandated by state law.

OHIO – negotiation, short-term assistance

When the P&A was notified that a nursing home closing might leave 33 PAIMI-eligible residents without services, its staff visited the facility residents, determined their preferred living arrangements and then helped them obtain appropriate placements. P&A intervention resulted in the successful transfer of the 33 residents, to community homes of their choice with appropriate support services.

C. Class Action Litigation

To ensure compliance with federal or state laws and regulations and when immediate action is needed to protect a group of individuals, state P&A systems may use class litigation [42 U.S.C. 10805 (a)(1)(B)]. This type of litigation is the strategy of last resort. This complex strategy often takes years to resolve the presenting problem, and requires special staff expertise, resources and time. These types of cases generally involve a range of issues that impact the lives of individuals or groups of individuals with mental illness and other disabilities and their families. Class action activities reported by the P&A systems on behalf of PAIMI-eligible individuals included:

	FY 2011	FY 2012
Class Actions Filed	61	57
Individuals Impacted	3,194,230	3,581,553

[See, Appendix, Table 9]

Case Example from FY 2011 & 2012

CALIFORNIA – recovery

In November 15, 2010 (FY 2011), the District Court for the Eastern District of California approved an interim agreement that required Sacramento County to hire an expert to evaluate its adult outpatient mental health services and make recommendations for a more recovery-oriented model. In May 2010, the P&A and the two private legal entities jointly filed this legal action and alleged; the county's plan to close outpatient mental health clinics that served approximately 5,000 individuals, violated the integration mandate of the Americans with Disabilities Act (ADA) and state law because it placed thousands of people with mental health needs at risk of unnecessary institutionalization. The U.S. Department of Justice filed a Statement of Interest in support of plaintiffs' request that the court stop the county from proceeding with its plans to drastically change the mental health service system. In July 2010, the plaintiff's request was granted. This prevented the county from ending contracts with existing non-profit mental health providers and opening its own clinics staff with county employees. On January 24, 2012, the county signed a Consent Decree. The Court ordered the county to develop a plan to provide a continuum of care through the county-operated and county-funded adult outpatient mental health system and to consolidate the two county outpatient clinics. [See, *Napper et al v. County of Sacramento, et al* Case 2:10-cv-0871119-JAM-EFP Document 80, Filed 07/01/10].

PENNSYLVANIA – right to treatment

The P&A settled a legal action filed on behalf of individuals detained or sentenced to serve time in the city of Philadelphia's jails. The lawsuit alleged that overcrowded facilities violated the Constitution. The P&A focused on the needs of individuals with serious mental illness incarcerated in these overcrowded institutions. Since this case was filed, the city's jail population and the need to place more than one inmate in a cell (triple-celled) were reduced substantially. Under the settlement, which benefitted prisoners with mental illness, the city of Philadelphia agreed: 1) not to triple-cell prisoners with mental illness without psychiatric evaluations; 2) not to allow triple-celling of such individuals for extended time periods; and 3) to assure prisoners with mental illness do not miss therapeutic activities during lockdowns due to staff shortage, if there are no security issues.

SOUTH CAROLINA – right to treatment

This P&A represented inmates with serious mental illness in the custody of the South Carolina Department of Corrections (SCDOC). While incarcerated, these inmates did not receive minimally adequate mental health care or treatment. The P&A and the inmates were represented by, pro bono, private counsel. The trial was held in 2012. P&A intervention will impact 2,400 inmates with SMI in SCDOC custody (*T. R. Protection & Advocacy for People with Disabilities, Inc. et al. v. South Carolina Department of Corrections, et al*).

D. Group Advocacy

The majority of P&A systems advocated on behalf of groups of PAIMI-eligible individuals. These types of activities were not directed toward individuals, but for the resolution of a range of systemic issues impacted specific groups or larger populations throughout a state. Some systemic advocacy activities included legal actions to protect the rights, health and safety of vulnerable facility residents (see, C. Class Action). Sometimes individual complaints resulted in

group advocacy. Generally, P&A non-case directed advocacy activities focused on implementing changes in administrative policy, procedures, or practices in state agencies, residential treatment facilities and other service providers.

	FY 2011	FY 2012
Non-Litigation Advocacy		
Number of events	442	368
Total Number of Individuals Impacted	19,018,946	14,895,684
Policy Change		
Number of events	626	307
Total Number of Individuals Impacted	16,300,029	14,097,977

[See, Appendix Table 9]

Case Examples from FY 2011

KANSAS - youths

During a monitoring visit at a private psychiatric hospital, the P&A staff found the facility’s restraint and seclusion protocols used by its adolescent treatment programs was not consistent with state and federal requirements, e.g., hospital protocols restricted patients to their rooms (seclusion) for certain behaviors. The P&A notified the facility of these violations and requested immediate suspension of these program practices. The hospital administrators met with the P&A staff, acknowledged their facility practices constituted seclusion and restraint, and immediately discontinued their use in the adolescent treatment programs.

MICHIGAN – investigation, rights protection

During a monitoring visit of a state psychiatric institution, the P&A staff learned; facility staff conducted unauthorized regular searches of all facility residents and their personal property without probable cause. State law allowed searches when staff had reason to believe a resident may have contraband or when a resident returned to the hospital following a leave of absence. The P&A filed a complaint that substantiated these illegal searches. The state hospital immediately stopped the searches. P&A group advocacy affected the rights of the hospital’s 280 residents.

UTAH – state prisons

The P&A collaborated with a coalition of service providers and state prison officials on behalf of individuals with mental illness released from prison without access to mental health services. While incarcerated, these individuals were unable to apply for or be reinstated to receive public benefits. The P&A advocated that the discharge plans of individuals include assistance with applying for benefits, at least 30-days before their release from prison.

Case Examples from FY 2012

NEBRASKA – facility monitoring

A P&A case advocate conducted bi-weekly visits to the state’s only remaining state psychiatric hospital - the Lincoln Regional Center (LRC). During these visits, the advocate noted hospital’s

conditions (i.e., safety, cleanliness, security, etc.), reviewed records, conducted intakes, met with and provided information to residents (i.e., patient grievance procedures, etc.). The advocate raised concerns to the hospital administrator and participated in the hospital's Women's Council meetings.

NEW YORK – best practice guidelines

The P&A addressed issues experienced by parents with mental illness, whose children are placed in state custody (e.g., child welfare, etc.). The P&A worked with a coalition of attorneys, advocates, and mental health professionals to improve how the New York City Administration Children's Services (ACS) worked with parents with mental health disabilities. In August 2011, the P&A participated on the Mental Health Subcommittee of the Adoption and Safe Families Act (ASFA) Coalition that provided a forum for discussion of issues from the perspectives of mental health services professionals, disability rights advocates and attorneys representing parents and children in the child welfare system. The coalition worked to develop guidelines for ACS caseworkers with parents with mental health disabilities whose children were in the city's legal custody. The coalition proposed "best practice principles" for guiding caseworker training and manual development.

RHODE ISLAND – state hospital residents

Despite repeated attempts, the state hospital's Internal Investigation Unit (IIU) was unable to substantiate allegations that patients were abused when restrained. The P&A advocated and the hospital administration agreed to install a camera in the restraint room on one hospital unit. The P&A advocated for hospital policies that protected the residents' rights to informed consent, privacy and confidentiality. P&A intervention resulted in a decrease in restraint-related abuse complaints. The P&A continued to advocate for hospital policy changes. For most of FY 2011, the restraint room camera was inoperable. In FY 2012, P&A staff monitored the camera's status, scheduled regular meetings with state officials, and continued its efforts to further advocate and protect hospital patients' rights until the unit's camera was repaired.

WASHINGTON – mental health competency

For several years, the P&A successfully encouraged state actions to resolve jail competency evaluation delays. As a result, the state passed a new law that improves "the timeliness, efficiency, and accountability of forensic resource utilization associated with competency to stand trial." It included performance targets for state hospitals to complete their competency evaluation/services. For example, seven days for admission to a state hospital for evaluation, treatment, or civil conversion; seven days for completion of an evaluation and report for a defendant in jail; and 21 days for completion of an evaluation and report for a defendant in the community who makes reasonable efforts to cooperate with the evaluation. These performance targets run from the date the state hospital receives the referral, charging documents, discovery, and criminal history information and do not create any new entitlement or cause of action related to the timeliness of competency services.

E. Education and Training Activities

Each state P&A system received requests for information and referral services from its constituents via telephone, e-mail, letter, face-to-face, and walk-in visits. The systems also provided information by conducting public education, training, and activities. Many state

PAIMI Programs met with and provided civil rights informational training to their state legislators, consumers, stakeholders, and advocacy groups. Other P&A systems conducted mental health law classes for attorneys, graduate students, current and former recipients of mental health services, and mental health service professionals. P&A system provided information to the public by various means, e.g., the media (newspapers, radio/television public service announcements), agency newsletters, websites, publications, investigative reports, and list serves. Some P&A systems within sparsely populated states or with large rural populations used technology to provide information through webcams, videoconferences, teleconferences, webinars, Facebook, and Skype. PAIMI program public education, training, and awareness activities included:

<i>Educational or Training Activities</i>		
	FY 2011	FY 2012
Information and Referral Requests	40,170	35,785
Public Awareness Events	2, 123	2,340
Public Awareness Attendees	3,878,922	2,970,549
Educational Trainings	2,006	1,922
Total Trained	75,815	142,224

[See, Appendix, Table 10]

Example from FY 2011

MAINE

After a local television station presented a PAIMI Advisory Council (PAC) member with a prestigious award, she asked the station managers to attend a listening session conducted by individuals involved in the mental health field. Her goals were to educate the station’s personnel, to sensitize the reporters to the negative public attitudes and other issues experienced by individuals with mental illness and their family members, and to encourage the promotion of public awareness and community integration by station personnel. The PAC member invited representatives from the P&A, National Alliance on Mental Illness (NAMI-Maine), and the state mental health authority to the meeting, which included robust discussions. TV station staff eagerly received the information and hopefully future reporting will reflect efforts to reduce negative public attitudes.

Example from FY 2012

MASSACHUSETTS

For several years, Fenway Park, the Red Sox’ home stadium, underwent extensive renovations. The P&A was involved in this process. For example, in FY 2011, it continued to provide guidance and feedback on the stadium’s physical, architectural, visual and communication access issues and etiquette tips on how to interact with and accommodate fans with mental health and other disabilities. The P&A trained the Boston Red Sox staff on Title III of the Americans with Disabilities Act (ADA), specifically the legal requirements applicable to public places and reasonable accommodations for Red Sox fans with disabilities. Over 400 Red Sox personnel, e.g., the ushers, ticket takers and security guards that interact with the 76,000 Red Sox game fans, attended the P&A training. The P&A continues to work with the Boston Red Sox to ensure

access for people with disabilities.

F. Accomplishments, Impediments, and Unmet Advocacy Needs

1. Accomplishments

P&A system intervention improved the quality of life for individuals with mental illness and resulted in systemic changes. Examples of these accomplishments included:

MAJOR ACCOMPLISHMENTS

Example from FY 2011

COLORADO

This P&A conducted 53 investigations of incidents of abuse, neglect and rights violations on behalf of PAIMI-eligible individuals in detention and state correctional facilities. The clients served were detained in jails in the counties of Adams, Boulder, Denver, Huerfano, Jefferson and Summit, as well as, several Colorado Department of Corrections operated facilities. The P&A also investigated incidents and advocated for residents of Colorado's two mental health institutes, two private hospitals, two Department of Youth correctional facilities, three nursing homes and two residential facilities for children.

GUAM

The P&A focused on systemic change in how services were provided to minors diagnosed with significant emotional impairments. The P&A, Guam Superior Court and legislature ensured, the island's system of care provider ('Fama-gu-on'ta) develop and provide services for minors, especially those placed in residential treatment facilities. P&A efforts resulted in the availability of more island residential mental health treatment services and the subsequent return home of minors previously treated off island.

MICHIGAN

The P&A reached a settlement of the *Michigan Protection and Advocacy Services v. Caruso* (treatment of inmates with mental illness) case that increased state identification of inmates with serious mental illness (from 8 to approximately 20 percent); provided training to more than 9,000 correctional facility staff (i.e., how to identify mental illness) and increased annual funding for mental health services. P&A intervention facilitated the processing of inmates request for, and access to, mental health services.

VIRGINIA

The P&A conducted a systemic investigation focused on identifying patients in state-operated, high-security forensic facilities, who were deemed clinically appropriate for a less restrictive placement, but never transferred. The P&A used the state's complaint system and obtained a favorable decision from the Virginia Human Rights Committee. The decision required the Department of Behavioral Health and Disability Services to develop and implement a plan that facilitated the timely transfer of forensic inmates. The P&A monitored implementation of the plans.

Example from FY 2012

TENNESSEE

The P&A and representatives from the Tennessee Department of Mental Health and Substance Abuse Services met to discuss issues related to the well-being of individuals with mental health disabilities. This meeting resulted in the signing of a Memorandum of Understanding (MOU). The MOU delineates the areas of collaboration between the two entities, i.e., cross-training opportunities, joint program initiatives, information sharing, identification of trends and intervention strategy planning.

2. Impediments

Example from FY 2011

GEORGIA

The P&A identified; the majority of Georgians with mental health and other disabilities residing in state institutions were racial minorities. The P&A focused on the state's discriminatory practice of placing those individuals in congregated and segregated settings, far from any diverse racial communities.

IDAHO

This P&A reported an increase in challenges to its congressionally mandated access authority as a major external impediment. The challenges to P&A access authority to records, facilities and individuals drain this minimum allotment, grantee's resources and impede timely investigation of incidents of abuse and neglect, especially when such acts result in serious injury or death to Idahoans placed in public and private residential care and treatment facilities.

NEBRASKA

Insufficient resources impeded this P&A system's ability to conduct regular and effective monitoring of all community-based, residential and treatment facilities that serve Nebraskans with mental illness. Nebraska is a large state with a significant number of isolated, congregate facilities located in small sparsely populated frontier and rural communities. Resource limitations affected the P&A's ability to hire, train new staff, and provide the resources needed to visit these facilities.

SOUTH CAROLINA

Budget cuts negatively impacted mental health service delivery in South Carolina's departments of mental health and corrections, as well as county jails.

TEXAS

The P&A experienced access authority challenges by the *Texas Open Government Act (TOGA)*. TOGA provides an entity, the means to protect information from disclosure by requesting an opinion from the Texas Attorney General (AG) on whether the information falls under the act's disclosure exceptions. The AG's Open Records Division (ORD) received regular briefings from P&A attorneys on their access authority, which preempts inconsistent state law provisions. TOGA increased P&A's expenditure of considerable resources to defend its congressional

mandated access authority. The ORD attorneys' rulings on P&A access authority were often in favor of the other party. Subsequently, the P&A had to challenge the ORD ruling in federal court.

Example from FY 2012

ARIZONA

During FY 2010, the Arizona Department of Behavioral Health Services (BHS) revised its death reporting process, which affected the reporting of behavioral health system facility deaths. Information previously made available to the P&A was now included in the “Quality of Care Concern Process” – a peer review. Data compiled by the BHS was now protected by the peer review process and no longer available. In FY 2012, the State of Arizona changed its reporting requirements for deaths of persons with mental illness. The state also eliminated rules that required some licensed facilities to report certain types of incidents and accidents from the rules, pending approval by the Arizona Office of Behavioral Health Licensing. The revised state protocols impacted the number of incidents involving seclusion, restraint, any resulting serious injuries, and deaths reported by behavioral health services providers.

NORTH DAKOTA

As the North Dakota economy improved, due to the oil industry the state’s infrastructure was impacted. The state’s transportation (roads), housing (shortages and skyrocketing cost), educational (teacher shortages, overcrowded schools), medical (shortages of professionals), and mental health (acute shortage of psychiatrists, psychologists, mental health case managers, etc.) systems were adversely impacted. The influx of oil industry workers has made it difficult for P&A staff to serve North Dakotans with mental health and other disabilities who reside in the more rural, remote areas in this large, sparsely populated frontier state. For example, P&A staff had difficulty securing a hotel room at a reasonable rate in or near “oil country”. The P&A’s Williston office, in ‘the heart of the oil boom’, is located in an office building currently for sale. When its lease expired in June 2013, the P&A stated it would be difficult to find affordable, accessible office space in that community.

3. Outreach/Advocacy Services to Unserved and Underserved Populations

The P&A systems reached out to underserved and unserved populations, such as rural, homeless, ethnic and racial minorities. The following vignettes describe those efforts:

Example FY 2011

HAWAII

The P&A focused its outreach activities on two minority communities – Filipinos and Micronesians – the state’s fastest growing immigrant populations.

IDAHO

P&A outreach activities focused on the Hispanic community. For example, its staff participated in the *Mujeres Unidas de Idaho* annual conference and attended its monthly luncheons. They also collaborated with Catholic Charities, an organization with close ties to the Hispanic community.

Example from FY 2012

WYOMING

Although Wyoming has few ethnic and racial minorities (13 – 14 percent), the P&A continued outreach efforts to recruit members from the Hispanic, African American, and American Indian (Shoshone and Arapahoe) communities to serve on its governing board and the PAIMI Advisory Council. In FY 2012, the P&A updated its program materials and their accessibility on its website. For example, information was provided in Braille and Shoshone, Arapahoe and Spanish. The P&A used mass media to disseminate information to all Wyomingites, including the unserved and underserved.

GOVERNANCE

1. The Governing Authority

The DD Act of 1975 [42 U.S.C. 15043 (a), amended in 2000], which created the state P&A systems, mandated that private, non-profit, entities have a multimember governing authority (board) to oversee the system [42 U.S.C. 15044]. The DD Act required: the governing boards be selected according to the policies and procedures of the system; that board members include individuals who broadly represent or are knowledgeable of the needs of individuals served by the system; that the majority of board members include persons with disabilities who are current or former recipients of disability services, their family members, guardians, authorized representatives and advocates; that the system set term limits to ensure rotating membership on the board; and that board vacancies be filled within 60-days [respectively, at 42 U.S.C. 15044 (a) (1) (A), (B) (i), (ii) and (C) (3) and (4)]. There were 47 private non-profit P&A systems. State-operated P&A systems may, but are not required, to have a governing authority.

Consistent with the DD Act, the PAIMI Act [42 U.S.C. 10805(c)] also required that private P&A systems have a multimember governing authority (board) [42 U.S.C. 10805(c) (1) (A)]. Each board was responsible for the planning, designing, implementing and functioning of its system [42 U.S.C. 10805(c) (2) (A)]. The board must work jointly with its PAIMI Advisory Council (PAC) [42 U.S.C. 10805(c) (2) (B)] and establish policies and procedures for the selection of its members [42 U.S.C. 10805(c) (1) (B)]. The DD Act included provisions for the Board terms of appointment, size, and composition. The PAIMI Act and Rules also require the Advisory Council Chair, who must be a current or former recipient (C/FR) of mental health services or a family member, sit on the governing board of private, non-profit P&A systems. The board must make continuing efforts to ensure its members include racial and ethnic minorities [respectively at, 42 U.S.C. 10805(a) (6) (C) and 42 CFR 51.22(b) and (c)].

The PAIMI Advisory Council

Each state P&A system is mandated to establish a PAIMI Advisory Council (PAC) [PAIMI Act at 42 U.S.C. 10805(a) (6) (C)] to advise the system on policies and priorities to be carried out in protecting and advocating for the rights of individuals with mental illness [at 42 U.S.C. 10805 (a) (6) (A)]. The composition of the PAC is also mandated [PAIMI Act at 42 U.S.C. 10805(a) (6) (B)]. The Advisory Council chair must be a current or former mental health recipient or a family member of such an individual [42 U.S.C. 10805(a) (6) (C) and the PAIMI Rules at 42 CFR at 51.23(b) (2)].

Each PAIMI Advisory Council is required to provide independent advice and recommendations to its state P&A system, to work jointly with the governing authority in the development of policies and priorities, and to submit a section of the system's annual report [PAIMI Rules at 42 CFR 51.23 (a) (1) - (3)]. Council terms of appointment must be staggered, of reasonable duration and at least 60 percent of its members must be current or former recipients of mental health services or their family members, meet at least three times a year, include ethnic and racial minorities, and receive information related to the system's budget, staff, current program policies, priorities and performance outcomes [PAIMI Rules at 42 CFR 51.23(b) (2), (3) and (c)].

The PAC, whose size varied per state P&A system, is mandated to provide the governing board with advice and recommendations on the annual PAIMI programmatic activities and priorities to be funded in a FY. The PAC is expected to convene a minimum of three (3) meetings each calendar year and set staggered terms for its members [42 CFR at 51.23 (b)(3)]. The PAIMI Act requires the Chair of the PAIMI PAC, sit on the governing board of private, non-profit state P&A systems [42 U.S.C. 10805 (a) (6) (A), 42 CFR at 51.22 (b) (3)]. However, any advisory council member may serve on the governing board [42 CFR at 51.22(d)].

By January 1 of each year, each P&A system is required to submit an annual PAIMI Program Performance Report (PPR) to the Secretary HHS [42 U.S.C. 10805 (a)(7)]. The Advisory Council is also required to submit a section of that annual PPR as mandated by the PAIMI Act (42 U.S.C. 10824) and the PAIMI Rules (42 CFR 51.8).

The council's report must:

- Describe its membership and its PAIMI Program activities;
- Explain its relationship to the P&A governing board in the previous calendar year;
- Independently assess the P&A system's PAIMI Program;
- Include whether the program accomplished its priorities, goals, and objectives for the previous FY.

In addition to attending meetings, PAIMI Advisory Council members participated in numerous activities sponsored or endorsed by the PAIMI Program, e.g., attended in-state and out-of-state trainings, served on P&A governing board committees, engaged in systemic and legislative advocacy; and participated in special projects.

TRAINING AND TECHNICAL ASSISTANCE

SAMHSA provided training and technical assistance (T/TA) to the state P&A systems through an interagency agreement (IAA) administered by the AIDD. AIDD, which oversees the PADD Program, is the first federal protection and advocacy program and is the lead on federal P&A system for issues pertaining to designation, re-designation, regulations, etc. SAMHSA supports the IAA with funds specifically set-aside for T/TA and limited to a maximum of two percent of the annual PAIMI Program appropriation. The Rehabilitation Services Administration (RSA), within the Office of Special Education and Rehabilitation Services, U.S. Department of Education, administers the Protection and Advocacy for Individual Rights (PAIR) Program, the Client Assistance Program (CAP), and the Protection and Advocacy for Assistive Technology (PAAT) Program. RSA has a separate IAA with AIDD. This consolidation of federal P&A

program set-aside funds maximizes each agencies limited resources and contributes to a federal partnership among the three agencies that fosters cooperation, information sharing, strategic planning, coordination and integration of P&A system activities.

The Training Advocacy and Support Center (TASC) of the National Disability Rights Network (NDRN) was the contractor selected by the AIDD to serve the P&A systems. Under the contract, TASC is responsible for T/TA various tasks, some general, and others agency specific, e.g., the annual PAIMI Advisory Council training. TASC activities under FYS 2011 and 2012 contract included the following topics: investigation protocols for incidents of abuse and neglect cases involving deaths; seclusion and restraint; community integration (Olmstead); Medicaid funding; consumer self-advocacy; the role of PAIMI Advisory Councils; access to jails, prisons, and juvenile detention facilities; housing; and outreach strategies for unserved and underserved populations, i.e., ethnic, racial minorities, urban, rural, prisons, jails, and detention centers. TASC also assisted P&A systems prepare legal briefs when their PAIMI Act investigative and access authority were challenged.

Under the IAA, TASC prepared three publications, [*TASC Update* (monthly), *LegalEASE* (monthly) and *the P&A News* (quarterly)] that were reviewed and edited by SAMHSA, AIDD and RSA and approved by AIDD before they were disseminated to the state P&A systems.

Under the IAA, TASC staff:

- Maintained a website accessible to the public and a webpage accessible only to the federal partners and the state P&A systems;
- Developed model guidelines, training manuals, and legal advocacy materials, i.e., *LegalEASE (monthly)* and *Case Dockets*;
- Analyzed public policy;
- Established relationships with state P&A system staff;
- Served as liaison to the state P&A system staff;
- Facilitated information exchanges and requests for assistance from the P&A system staff;
- Subcontracted with national legal organizations, e.g., the Bazelon Center for Mental Health Law, the Center for Public Representation, and other legal experts for P&A system consultation services;
- Promoted the use of the *Protection & Advocacy Standards* which were developed in 2009;
- Identified and disseminated samples of model P&A system policies and procedures;
- Developed P&A system self-assessment procedures, a project started in 2009; and
- Planned and conducted training on current disability, legal, and advocacy issues, e.g., the Annual Conference, the P&A executive director and fiscal management training.

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Table 1 – State PAIMI Allotments

2011

States	Federal Award FY 2012
Alabama *	\$451,372
Alaska	\$429,100
American Indian Consortium	\$229,900
American Samoa *	\$229,900
Arizona	\$633,443
Arkansas	\$429,100
California	\$3,134,571
Colorado	\$429,546
Connecticut *	\$429,100
Delaware	\$429,100
District of Columbia	\$429,100
Florida	\$1,642,108
Georgia	\$933,039
Guam	\$229,900
Hawaii	\$429,100
Idaho	\$429,100
Illinois	\$1,102,843
Indiana *	\$610,362
Iowa	\$429,100
Kansas	\$429,100
Kentucky *	\$429,100
Louisiana	\$429,100
Maine	\$429,100
Maryland	\$456,215
Massachusetts	\$521,358
Michigan	\$941,212
Minnesota	\$450,085
Mississippi	\$429,100
Missouri	\$551,979
Montana	\$429,100
Nebraska	\$429,100
Nevada	\$429,100
New Hampshire	\$429,100
New Jersey	\$686,332
New Mexico	\$429,100
New York *	\$1,591,215
North Carolina	\$880,448
North Dakota *	\$429,100
North Mariana Islands	\$229,900
Ohio *	\$1,069,448
Oklahoma	\$429,100
Oregon	\$429,100
Pennsylvania	\$1,099,025
Puerto Rico *	\$618,294
Rhode Island	\$429,100

South Carolina	\$444,614
South Dakota	\$429,100
Tennessee	\$595,224
Texas	\$2,204,946
Utah	\$429,100
Vermont	\$429,100
Virgin Islands	\$229,900
Virginia *	\$657,158
Washington	\$562,766
West Virginia	\$429,100
Wisconsin	\$510,809
Wyoming	\$429,100
Total P&A Award	\$35,513,612
Technical Assistance	\$724,768
Total P&A Award	\$36,238,380

2012

States	Federal Award FY 2012
Alabama *	\$451,372
Alaska	\$429,100
American Indian Consortium	\$229,900
American Samoa *	\$229,900
Arizona	\$633,443
Arkansas	\$429,100
California	\$3,134,571
Colorado	\$429,546
Connecticut *	\$429,100
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Virgin Islands	\$229,900
Virginia *	\$657,158
Washington	\$562,766
West Virginia	\$429,100
Wisconsin	\$510,809
Wyoming	\$429,100
Total P&A Award	\$35,513,612
Technical Assistance	\$724,768
Total P&A Award	\$36,238,380

Table 2 – Client Age and Gender
2011

State	Clients Served	Age						Unknown	Served Total	Gender	
		0-4	5-12	13-18	19-25	26-64	65+			Male	Female
Alabama*	360	0	18	137	29	165	11	0	360	231	129
Alaska	115	0	0	1	4	105	5	0	115	56	59
American Indian Consortium	33	0	5	17	3	8	0	0	33	23	10
America Samoa*	49	0	2	5	7	33	2	0	49	15	34
Arizona	231	0	4	16	12	194	5	0	231	113	118
Arkansas	90	0	11	30	5	39	5	0	90	52	38
California	1,266	0	20	74	78	947	147	0	1,266	647	619
Colorado	121	0	5	8	14	90	4	0	121	86	35
Connecticut*	96	0	2	5	11	77	1	0	96	61	35
Delaware	194	0	7	24	10	146	7	0	194	89	105
District of Columbia	120	0	0	3	12	95	10	0	120	64	56
Florida	206	0	16	38	12	128	12	0	206	125	81
Georgia	184	0	2	21	18	137	6	0	184	106	78
Guam	31	0	0	8	2	21	0	0	31	14	17
Hawaii	255	2	33	39	12	162	7	0	255	172	83
Idaho	134	0	5	16	11	98	4	0	134	67	67
Illinois	834	1	65	170	64	479	44	11	834	482	352
Indiana*	168	0	3	10	18	131	6	0	168	113	55
Iowa	70	0	6	13	8	41	2	0	70	44	26
Kansas	587	0	42	50	33	443	19	0	587	289	298
Kentucky*	173	0	27	48	15	69	14	0	173	90	83
Louisiana	115	0	11	23	5	74	2	0	115	74	41
Maine	225	0	21	44	11	141	8	0	225	104	121
Maryland	152	0	6	32	22	82	10	0	152	90	62
Massachusetts	138	1	9	19	14	87	8	0	138	81	57
Michigan	140	0	16	28	15	64	17	0	140	94	46
Minnesota	482	4	40	74	52	295	17	0	482	256	226
Mississippi	162	0	28	75	8	48	3	0	162	107	55
Missouri	240	0	2	12	27	192	7	0	240	141	99
Montana	159	0	17	61	11	65	5	0	159	93	66
Nebraska	73	0	0	0	6	59	8	0	73	32	41
Nevada	89	0	4	5	15	64	1	0	89	43	46
New Hampshire	637	0	28	75	44	433	34	23	637	316	321
New Jersey	376	0	7	45	25	256	43	0	376	235	141
New Mexico	169	0	2	20	10	123	14	0	169	103	66
New York*	488	0	86	143	26	217	16	0	488	293	195
North Carolina	323	0	19	68	25	201	10	0	323	207	116
North Dakota*	191	1	39	42	13	87	9	0	191	115	76
North Mariana Islands	26	2	2	1	2	16	3	0	26	13	13
Ohio*	984	3	50	62	67	719	83	0	984	488	496
Oklahoma	879	0	76	84	46	646	27	0	879	464	415
Oregon	82	0	4	2	13	59	4	0	82	43	39

Table 2 – Client Age and Gender
2011 cont.

Pennsylvania	780	13	135	152	73	364	43	0	780	447	333
Puerto Rico*	127	0	19	16	11	78	3	0	127	83	44
Rhode Island	300	0	14	33	29	199	25	0	300	170	130
South Carolina	131	0	7	85	6	31	2	0	131	84	47
South Dakota	170	0	18	27	13	106	6	0	170	91	79
Tennessee	102	0	10	31	13	44	4	0	102	69	33
Texas	1,491	4	190	286	132	815	64	0	1491	903	588
Utah	343	1	18	26	32	252	14	0	343	168	175
Vermont	149	0	0	11	15	115	8	0	149	79	70
Virgin Islands	38	0	21	0	0	11	1	5	38	21	17
Virginia*	158	0	0	11	13	120	14	0	158	102	56
Washington	534	0	12	33	38	357	94	0	534	305	229
West Virginia	74	0	3	8	6	56	1	0	74	47	27
Wisconsin	201	0	13	29	21	136	2	0	201	128	73
Wyoming	75	0	7	6	5	51	6	0	75	49	26
Total	16,492	34	1,323	2,543	1,342	10,440	787	23	16,492	9,442	7,050
Percentages	100%	0%	8%	15%	8%	63%	5%	0%	100%	57%	43%

Table 3 – Client Ethnicity and Race
2011

State	Clients Served	American Indian/ Alaska	Asian	Black/ African American	Native Hawaiian or Pacific	White/ Caucasian	** Other	Hispanic/ Latino	Not Hispanic/ Latino	Total
Alabama	359	1	2	181	0	172	3	1	358	359
Alaska	114	16	0	7	1	85	5	1	113	114
American Indian Consortium	33	33	0	0	0	0	0	0	33	33
American Samoa	54	0	2	1	49	2	0	0	54	54
Arizona	194	3	2	12	0	177	0	37	157	194
Arkansas	88	1	0	35	0	51	1	2	86	88
California	1,086	20	35	228	9	725	69	180	906	1086
Colorado	93	2	0	12	0	77	2	28	65	93
Connecticut	78	0	2	18	0	58	0	18	60	78
Delaware	172	0	4	65	0	103	0	22	150	172
District of Columbia	120	1	2	93	0	19	5	5	115	120
Florida *	206	3	1	28	0	169	5	18	188	206
Georgia	178	0	3	88	0	82	5	6	172	178
Guam *	31	0	2	0	26	3	0	0	31	31
Hawaii	265	12	36	9	25	102	81	10	255	265
Idaho	134	4	3	1	0	125	1	12	122	134
Illinois *	806	22	18	302	0	424	40	85	721	806
Indiana	167	0	0	38	129	0	0	6	161	167
Iowa *	70	0	0	0	0	68	2	1	69	70
Kansas	562	13	1	54	0	473	21	19	543	562
Kentucky	173	0	0	38	16	117	2	2	171	173
Louisiana *	113	0	1	62	0	49	1	4	109	113
Maine	225	4	1	2	0	197	21	4	221	225
Maryland	152	0	4	88	0	55	5	4	148	152
Massachusetts	123	2	4	26	0	91	0	15	108	123
Michigan	139	3	1	38	0	91	6	1	138	139
Minnesota	471	23	9	102	0	337	0	11	460	471
Mississippi	161	2	0	81	0	78	0	3	158	161
Missouri	238	4	0	73	0	161	0	2	236	238
Montana	158	9	0	0	1	147	1	3	155	158
Nebraska	72	0	1	1	4	65	1	1	71	72
Nevada	76	2	1	15	0	57	1	13	63	76
New Hampshire	620	2	10	8	1	599	0	15	605	620
New Jersey	367	0	3	95	0	269	0	34	333	367
New Mexico	169	0	0	5	0	164	0	90	79	169
New York	440	1	1	130	1	273	34	48	392	440
North Carolina	316	7	6	128	1	174	0	7	309	316
North Dakota	195	29	2	8	1	153	2	4	191	195
North Mariana Islands	30	0	4	0	20	6	0	0	30	30
Ohio	977	3	3	288	0	683	0	17	960	977
Oklahoma	855	89	5	171	1	589	0	24	831	855
Oregon	78	6	0	5	0	67	0	6	72	78
Pennsylvania	732	3	9	191	0	529	0	48	48	0

Table 3 – Client Ethnicity and Race
2011 cont.

Puerto Rico*	0	0	0	0	0	0	0	127	127	0
Rhode Island	300	3	3	17	0	277	0	300	27	273
South Carolina	131	2	0	54	0	75	0	131	3	128
South Dakota	170	31	2	2	2	127	6	160	13	147
Tennessee	102	0	0	31	0	71	0	102	1	101
Texas	1,434	6	4	335	1	1088	0	1442	448	994
Utah	324	4	1	13	0	306	0	331	17	314
Vermont	141	3	2	4	0	132	0	136	4	132
Virgin Islands	38	2	2	30	1	3	0	38	2	36
Virginia*	152	0	4	76	0	72	0	6	6	0
Washington	534	16	16	62	0	440	0	534	68	466
West Virginia	74	3	0	8	0	63	0	74	3	71
Wisconsin	193	6	0	53	0	126	8	206	13	193
Wyoming	75	4	0	1	1	69	0	75	5	70
Total	15,686	419	191	3,467	232	10,954	423	13,768	1,509	12,259

Table 4 – Living Arrangements
2011

State	Clients Served	Independent Living	Parental or Family Home	Community Residential Home for Children/ Youth 0-18 yrs	Adult Community Residential Home	Non-Medical Community Child/Youth 0-18 yrs	Foster Care	Nursing Facility	Intermediate Care	Public & Private General Hospital	Other Health Facility
Alabama*	360	20	58	4	86	0	4	5	3	0	0
Alaska	115	68	8	7	1	0	0	0	0	0	0
American Indian Consortium	33	5	18	0	0	0	3	0	0	2	0
American Samoa*	49	6	15	2	2	4	0	0	0	5	2
Arizona	231	140	28	0	12	0	2	1	0	3	0
Arkansas	90	13	19	1	11	0	0	2	2	0	0
California	1,265	631	191	5	52	0	1	36	0	18	1
Colorado	121	12	18	0	1	3	0	8	0	2	3
Connecticut*	96	25	10	0	11	0	0	1	1	20	0
Delaware	194	75	38	1	13	0	4	4	0	0	0
District of Columbia	120	17	9	0	1	0	1	7	0	0	0
Florida	206	37	30	0	5	1	4	6	3	0	1
Georgia	184	22	11	1	15	0	0	0	0	1	0
Guam	31	5	11	1	0	0	0	0	0	0	0
Hawaii	255	64	85	29	0	0	4	0	0	0	0
Idaho	134	58	33	1	7	0	0	5	1	0	0
Illinois	834	218	259	2	30	0	0	88	3	18	1
Indiana*	168	12	13	1	5	0	0	0	0	1	0
Iowa	70	21	18	1	3	0	0	6	0	0	0
Kansas	587	347	94	2	17	0	0	52	3	0	0
Kentucky*	173	6	57	14	0	1	6	5	2	0	6
Louisiana	115	14	35	0	2	0	1	9	2	31	0
Maine	225	75	48	0	0	11	0	3	0	2	0
Maryland	152	14	10	3	4	0	0	1	0	1	0
Massachusetts	138	14	27	0	3	0	0	1	0	0	0
Michigan	140	23	41	3	16	0	0	17	0	1	0
Minnesota	482	118	114	12	67	0	33	0	13	1	3
Mississippi	162	14	81	5	7	4	7	0	0	0	0

Table 4 – Living Arrangements
2011 cont.

Missouri	240	57	18	0	21	2	0	34	2	2	1
Montana	159	24	23	1	4	0	3	4	0	0	1
Nebraska	73	9	1	0	32	0	0	1	0	0	0
Nevada	89	40	10	1	0	0	0	0	0	0	0
New Hampshire	637	244	160	7	7	5	0	1	0	4	0
New Jersey	376	32	59	2	6	0	1	5	0	0	0
New Mexico	169	16	11	7	4	0	0	0	0	0	0
New York*	488	149	41	43	25	19	0	0	2	81	1
North Carolina	323	12	37	1	1	26	3	1	0	6	0
North Dakota*	191	50	80	0	3	0	2	4	0	0	0
North Mariana Islands	26	9	15	0	1	0	0	0	0	0	0
Ohio*	984	334	123	19	28	2	0	71	1	24	1
Oklahoma	879	500	247	1	10	0	10	14	0	13	0
Oregon	78	10	7	1	4	0	0	1	0	0	0
Pennsylvania	759	265	195	6	8	48	5	29	2	8	3
Puerto Rico*	128	57	39	3	6	1	2	1	0	1	1
Rhode Island	305	72	86	1	20	0	0	65	0	5	0
South Carolina	145	10	30	0	4	0	5	1	0	0	0
South Dakota	176	21	48	0	2	3	0	2	0	1	0
Tennessee	73	9	41	1	3	0	0	3	0	0	0
Texas	1,390	155	475	16	27	24	40	12	3	6	0
Utah	464	278	62	0	10	0	0	10	0	2	0
Vermont	117	40	0	1	11	0	0	1	1	0	0
Virgin Islands	47	15	19	2	3	0	0	0	0	0	0
Virginia*	143	10	10	7	5	3	0	0	0	0	0
Washington	463	154	39	15	0	0	2	4	0	3	26
West Virginia	80	14	14	0	3	0	0	3	0	0	0
Wisconsin	189	53	44	2	12	1	0	2	0	0	2
Wyoming	33	2	1	1	0	0	0	1	0	0	0
Total	15,954	4,715	3,314	233	631	158	143	527	44	262	53
Percentages	101%	30%	21%	1%	4%	1%	1%	3%	0%	2%	0%

Table 4 – Living Arrangements
2011

State	Psych Wards	Public & Private Institutional Living	Jail Detention	State Prison	Homeless	Federal Facility	Unknown
Alabama*	3	129	40	5	2	1	0
Alaska	6	3	0	0	18	4	0
American Indian Consortium	2	2	1	0	0	0	0
American Samoa*	2	4	0	5	0	0	2
Arizona	10	14	3	9	8	1	0
Arkansas	0	42	0	0	0	0	0
California	25	192	37	19	55	3	0
Colorado	36	7	10	18	2	1	0
Connecticut*	0	3	19	0	6	0	0
Delaware	44	2	3	7	3	0	0
District of Columbia	18	49	6	0	12	0	0
Florida	2	81	34	0	2	0	0
Georgia	1	118	11	2	2	0	0
Guam	4	9	1	0	0	0	0
Hawaii	65	0	0	2	6	0	0
Idaho	2	12	4	3	8	0	0
Illinois	24	146	17	11	11	3	5
Indiana*	2	89	17	28	0	0	0
Iowa	0	18	2	1	0	0	0
Kansas	26	29	5	0	10	2	0
Kentucky*	14	52	1	0	0	9	0
Louisiana	6	6	9	0	0	0	0
Maine	18	54	4	0	10	0	0
Maryland	3	105	5	0	6	0	0
Massachusetts	0	91	0	1	1	0	0
Michigan	11	17	8	2	1	0	0

Table 4 – Living Arrangements
2011 cont.

Minnesota	22	58	9	12	2	18	0
Mississippi	0	39	2	2	1	0	0
Missouri	9	59	8	19	7	1	0
Montana	0	89	7	3	0	0	0
Nebraska	0	73	0	0	0	0	0
Nevada	0	26	1	3	8	0	0
New Hampshire	0	118	9	13	24	0	45
New Jersey	9	247	14	1	0	0	0
New Mexico	106	7	17	0	1	0	0
New York*	0	73	8	7	28	5	6
North Carolina	0	211	2	21	2	0	0
North Dakota*	3	29	3	8	9	0	0
North Mariana Islands	0	0	1	0	0	0	0
Ohio*	301	105	46	8	12	1	0
Oklahoma	5	20	24	13	22	0	0
Oregon	42	10	0	1	1	1	0
Pennsylvania	18	100	16	38	18	0	0
Puerto Rico*	3	1	7	1	1	4	0
Rhode Island	17	17	7	3	8	4	0
South Carolina	0	27	63	4	1	0	0
South Dakota	5	81	3	8	2	0	0
Tennessee	3	10	3	0	0	0	0
Texas	399	44	166	4	19	0	0
Utah	7	44	31	6	14	0	0
Vermont	27	9	4	14	3	6	0
Virgin Islands	1	2	3	0	2	0	0
Virginia*	3	99	5		1	0	0
Washington	2	114	87	0	16	1	0
West Virginia	0	40	1	4	1	0	0
Wisconsin	16	7	9	34	6	1	0
Wyoming	1	26	1	0	0	0	0
Total	1,323	3,059	794	340	372	66	58
Percentages	8%	19%	5%	2%	2%	0%	0%

Table 5 – Abuse
2011

States	Number of Abuse Complaints Closed	Inappropriate/Excessive				
		Medication	Physical Restraint	Chemical Restraint	Mechanical Restraint	Seclusion
Alabama*	77	1	13	0	0	1
Alaska	15	2	5	0	1	0
American Indian Consortium	6	0	0	0	0	0
American Samoa*	6	0	0	0	0	0
Arizona	6	3	1	0	0	1
Arkansas	30	0	5	0	2	0
California	125	21	13	1	5	0
Colorado	21	4	1	0	1	1
Connecticut*	43	0	1	0	0	2
Delaware	36	3	3	0	0	0
District of Columbia	33	8	4	3	1	1
Florida	39	0	4	3	1	0
Georgia	74	5	2	4	1	0
Guam	8	1	0	0	0	0
Hawaii	22	2	0	0	1	2
Idaho	12	1	0	1	0	1
Illinois	175	31	16	8	1	5
Indiana*	60	3	10	1	1	1
Iowa	5	0	0	0	2	0
Kansas	45	2	4	0	1	2
Kentucky*	12	0	4	0	0	0
Louisiana	12	0	0	0	0	3
Maine	53	2	11	0	1	2
Maryland	32	0	4	0	0	3
Massachusetts	37	0	1	1	1	0
Michigan	15	0	6	0	2	1
Minnesota	44	0	2	0	1	0
Mississippi	34	1	2	0	0	2
Missouri	78	26	1	0	1	0
Montana	36	0	5	9	1	3
Nebraska	14	0	0	0	0	0
Nevada	9	1	1	0	0	0
New Hampshire	88	11	1	0	2	0
New Jersey	137	29	0	0	4	0
New Mexico	43	2	6	0	0	0
New York*	201	1	0	13	0	0
North Carolina	139	0	1	5	0	2
North Dakota*	44	0	10	0	1	0
North Mariana Islands	1	0	0	0	0	0
Ohio*	209	5	9	2	3	3

Table 5 – Abuse
2011 cont.

Oklahoma	31	2	1	0	0	6
Oregon	17	0	3	0	0	0
Pennsylvania	167	5	19	0	1	1
Puerto Rico*	10	0	0	0	0	0
Rhode Island	6	0	0	0	0	0
South Carolina	86	0	15	0	0	6
South Dakota	26	5	4	1	1	0
Tennessee	26	1	3	1	0	0
Texas	123	7	18	5	0	1
Utah	60	7	9	2	0	2
Vermont	53	2	9	3	5	3
Virgin Islands	2	0	0	0	0	0
Virginia*	40	3	11	0	1	0
Washington	168	21	5	2	1	26
West Virginia	14	0	2	0	0	1
Wisconsin	35	1	1	0	0	5
Wyoming	14	1	2	0	1	0
Total	2,954	220	248	65	45	87
Percentages	100%	7%	8%	2%	2%	3%

Table 5 – Abuse
2011

States	Involuntary				Failure to Provide Mental Health Treatment
	Medication	ECT	Aversive Behavior Therapy	Sterilization	
Alabama*	1	0	0	0	7
Alaska	0	0	0	0	3
American Indian Consortium	0	0	0	0	1
American Samoa*	1	0	0	0	2
Arizona	2	0	3	0	8
Arkansas	0	0	0	0	6
California	10	0	0	0	35
Colorado	2	0	0	0	6
Connecticut*	11	0	0	0	15
Delaware	1	0	0	0	1
District of Columbia	0	0	0	0	0
Florida	1	0	0	0	14
Georgia	0	0	0	0	13
Guam	0	0	0	0	3

Table 5 – Abuse
2011 cont.

Hawaii	2	0	0	0	0
Idaho	1	0	0	0	2
Illinois	14	0	0	0	34
Indiana	0	0	0	0	4
Iowa*	0	1	0	0	4
Kansas	1	0	0	0	18
Kentucky*	0	0	0	0	2
Louisiana	0	0	0	0	11
Maine	3	0	0	0	0
Maryland	0	0	0	0	5
Massachusetts	1	0	0	0	22
Michigan	0	0	0	0	69
Minnesota	1	2	0	0	27
Mississippi	1	0	0	0	2
Missouri	2	0	0	0	27
Montana	2	0	0	0	8
Nebraska	1	0	0	0	4
Nevada	0	0	0	0	2
New Hampshire	2	2	0	0	37
New Jersey	5	0	0	0	8
New Mexico	0	0	0	0	11
New York*	11	0	0	0	8
North Carolina	3	3	4	0	89
North Dakota*	9	0	0	0	6
North Mariana Islands	4	0	0	1	0
Ohio*	8	1	0	0	67
Oklahoma	0	0	0	0	15
Oregon	0	1	0	0	18
Pennsylvania	3	2	2	0	9
Puerto Rico*	0	0	6	3	0
Rhode Island	1	0	0	0	9
South Carolina	1	0	0	0	43
South Dakota	0	0	0	0	11
Tennessee	0	0	0	0	22
Texas	12	0	0	0	65
Utah	0	0	1	0	10
Vermont	1	0	0	0	19
Virgin Islands	0	0	0	0	0
Virginia*	6	0	0	0	31
Washington	5	0	0	0	38
West Virginia	2	0	0	0	2
Wisconsin	0	0	0	0	19
Wyoming	0	0	0	0	20
Total	131	12	16	4	912
Percentages	4%	0%	0%	0%	27%

Table 5 – Abuse
2011

States	Complaints Concerning								
	Failure to Provide Medical Treatment	Physical Assault		Sexual Assault	Staff Threats of Retaliation	Coercion	Financial Exploitation	Suspicious Death	Other
		Serious Injuries Related	Serious Injuries Not Related						
Alabama*	4	1	11	4	8	0	0	0	1
Alaska	1	0	0	2	0	0	2	0	0
American Indian Consortium	0	0	1	1	0	0	0	0	0
American Samoa*	0	0	0	0	0	0	2	0	0
Arizona	2	0	2	0	7	0	1	0	0
Arkansas	0	2	2	3	1	0	1	0	0
California	15	4	11	4	14	15	14	3	0
Colorado	3	1	2	3	3	0	0	2	0
Connecticut*	1	0	1	0	3	0	2	1	0
Delaware	2	0	2	2	1	0	6	2	0
District of Columbia	4	1	4	3	1	0	4	3	1
Florida	0	1	4	3	1	0	5	0	0
Georgia	3	2	13	7	9	2	0	8	0
Guam	0	0	0	0	0	0	0	0	0
Hawaii	4	1	0	9	0	1	0	2	0
Idaho	1	0	0	2	3	0	0	1	0
Illinois	16	2	14	6	19	2	15	1	0
Indiana	6	1	0	1	0	0	1	3	0
Iowa*	0	0	1	0	1	0	0	0	0
Kansas	1	2	10	2	3	3	8	1	0
Kentucky*	0	0	2	0	1	0	1	11	0
Louisiana	4	2	5	1	3	0	8	0	0
Maine	20	0	0	0	2	0	8	0	0
Maryland	2	1	12	1	3	0	0	1	1
Massachusetts	5	0	1	3	1	4	0	3	0
Michigan	2	0	4	2	11	0	0	1	0
Minnesota	7	0	0	0	1	0	6	0	0
Mississippi	4	0	2	0	3	2	1	0	0
Missouri	12	1	7	3	1	0	0	4	0
Montana	5	3	1	7	1	1	0	0	3
Nebraska	4	1	2	4	0	0	1	0	0
Nevada	0	0	0	0	0	0	0	0	0
New Hampshire	7	1	0	0	4	1	12	0	0
New Jersey	13	3	21	1	6	0	0	37	1
New Mexico	3	1	2	0	4	0	0	0	0
New York*	2	127	0	16	2	1	2	0	2

Table 5 – Abuse
2011 cont.

North Carolina	17	0	6	1	13	2	1	3	0
North Dakota*	1	0	7	3	5	2	18	0	0
North Mariana Islands	0	0	0	0	0	0	0	0	0
Ohio*	21	4	6	12	16	296	17	4	6
Oklahoma	3	0	3	0	2	2	2	0	0
Oregon	1	1	1	0	0	3	0	0	0
Pennsylvania	6	61	7	5	16	1	3	0	0
Puerto Rico*	1	0	1	0	0	0	0	0	0
Rhode Island	3	0	1	0	0	0	0	1	2
South Carolina	2	6	0	1	0	0	1	0	0
South Dakota	3	0	0	1	1	0	0	0	0
Tennessee	8	2	11	0	0	0	0	3	0
Texas	1	4	31	4	3	0	9	0	0
Utah	6	2	0	2	1	0	1	1	0
Vermont	3	3	3	3	4	2	1	0	1
Virgin Islands	1	1	1	0	1	1	1	0	0
Virginia*	3	0	1	0	0	0	0	0	2
Washington	11	3	10	6	5	2	5	0	0
West Virginia	0	3	1	0	1	0	1	1	1
Wisconsin	8	0	1	0	5	0	4	0	0
Wyoming	1	1	0	1	0	1	0	2	0
Total	253	249	228	129	190	344	164	99	21
Percentages	7%	7%	7%	4%	6%	10%	5%	3%	1%

Table 6a – Neglect
2011

States	Number of Neglect Complaints Closed	Failure to Provide for Appropriate										
		Resident/ Inpatient Admission	Transport To/From Treatment Facility	Discharge Planning	Mental Health Diagnostic	Medical Diagnostic	Personal Care	Safety Environment	Personal Safety	Written Treatment Plan	Rehabilitation Vocational Programming	Other
Alabama*	224	98	1	83	3	5	3	1	6	2	1	21
Alaska	1	0	0	1	0	0	0	0	0	0	0	0
American Indian Consortium	2	0	0	0	0	0	2	0	0	0	0	0
American Samoa*	6	0	0	1	0	0	4	0	0	0	1	0
Arizona	41	0	0	4	25	3	2	1	4	2	0	0
Arkansas	15	1	0	7	1	0	3	1	0	0	0	2
California	79	4	2	24	7	7	13	3	11	4	4	0
Colorado	28	1	0	13	8	2	0	0	2	2	0	0
Connecticut*	26	1	0	16	0	4	1	0	2	2	0	0
Delaware	9	0	0	3	0	1	2	0	1	0	1	1
District of Columbia	42	0	1	20	1	4	13	0	2	1	0	0
Florida	43	6	0	16	3	3	6	4	5	0	0	0
Georgia	109	0	0	62	1	2	2	7	4	3	27	1
Guam	6	0	0	3	0	1	1	0	0	0	1	0
Hawaii	17	0	0	8	4	3	1	0	1	0	0	0
Idaho	10	1	0	9	0	0	0	0	0	0	0	0
Illinois	238	18	2	130	20	9	22	6	11	8	12	0
Indiana	11	0	0	4	0	0	2	0	3	2	0	0
Iowa*	1	1	0	0	0	0	0	0	0	0	0	0
Kansas	58	3	2	19	4	9	9	2	1	8	1	0
Kentucky*	2	0	0	0	1	1	0	0	0	0	0	0
Louisiana	53	0	0	4	1	6	15	2	1	20	1	3
Maine	26	2	1	16	0	1	2	0	3	1	0	0
Maryland	16	0	0	12	1	0	0	0	0	0	1	2
Massachusetts	33	6	0	17	3	2	3	0	2	0	0	0
Michigan	58	1	0	17	13	5	20	0	2	0	0	0
Minnesota	79	7	3	17	5	2	27	1	8	6	3	0
Mississippi	11	0	0	6	1	1	3	0	0	0	0	0
Missouri	47	1	0	6	4	16	12	2	4	2	0	0

Table 6a – Neglect
2011 cont.

Montana	65	0	0	4	3	6	1	39	7	0	0	5
Subtotal	1356	151	12	522	109	93	169	69	80	63	53	35

Table 6a – Neglect
2012

States	Neglect Complaints Closed	Failure to Provide Appropriate										
		Residential/ Inpatient/ Admission	Transport To/From Treatment Facility	Discharge Planning	Mental Health Diagnostic	Medical Diagnostic	Personal Care	Safety Environment	Personal Safety	Written Treatment Plan	Rehabilitation Vocational Programming	Other
Alabama*	147	76	0	30	2	7	2	6	10	2	0	12
Alaska	3	0	0	3	0	0	0	0	0	0	0	0
American Indian Consortium	3	2	0	1	0	0	0	0	0	0	0	0
American Samoa*	4	0	0	0	0	0	2	2	0	0	0	0
Arizona	34	0	0	5	13	8	6	0	1	1	0	0
Arkansas	16	0	0	9	0	0	2	0	4	1	0	0
California	67	6	0	14	13	15	8	4	6	1	0	0
Colorado	41	1	0	18	5	4	0	5	1	7	0	0
Connecticut*	16	1	0	12	0	1	1	1	0	0	0	0
Delaware	35	2	0	13	0	1	2	7	4	6	0	0
District of Columbia	34	0	0	19	0	3	5	1	2	4	0	0
Florida	67	3	1	38	0	10	5	4	6	0	0	0
Georgia	48	1	0	38	0	2	0	4	0	1	2	0
Guam	10	10	0	0	0	0	0	0	0	0	0	0
Hawaii	10	1	0	1	2	1	1	0	3	0	0	1
Idaho	8	0	0	6	0	0	1	0	1	0	0	0
Illinois	237	28	1	115	12	14	28	14	9	8	8	0
Indiana	38	0	0	14	1	2	9	2	9	0	1	0

Table 6a – Neglect
2012 cont.

Iowa	3	0	0	1	0	0	1	0	1	0	0	0
Kansas	49	2	3	14	2	4	9	2	0	13	0	0
Kentucky*	5	0	0	3	0	0	0	0	1	1	0	0
Louisiana	20	0	0	2	3	5	3	0	0	1	6	0
Maine	19	3	0	16	0	0	0	0	0	0	0	0
Maryland	27	1	0	18	1	4	0	2	1	0	0	0
Massachusetts	39	5	1	28	0	1	0	0	1	0	0	3
Michigan	22	0	0	8	1	1	11	0	0	1	0	0
Minnesota	61	7	2	13	1	1	24	0	2	10	1	0
Mississippi	67	0	0	7	4	11	22	4	10	9	0	0
Missouri	15	1	0	7	2	0	1	1	3	0	0	0
Montana	51	2	0	5	2	5	0	27	4	0	0	6
Subtotal	1196	152	8	458	64	100	143	86	79	66	18	22

Table 6b – Neglect
2011

States	Number of Neglect Complaints Closed	Failure to Provide for Appropriate										
		Residence Inpatient Admission	Transport To/From Treatment Facility	Discharge Planning	Mental Health Diagnostic	Medical Diagnostic	Personal Care	Safety Environment	Personal Safety	Written Treatment Plan	Rehabilitation Vocational Programming	Other
Nebraska	0	0	0	0	0	0	0	0	0	0	0	0
Nevada	26	1	0	21	2	1	0	0	0	0	0	1
New Hampshire	54	2	2	29	1	0	1	0	0	19	0	0
New Jersey	47	0	0	38	1	3	3	0	2	0	0	0
New Mexico	18	0	0	3	0	0	12	0	0	0	3	0
New York*	36	4	5	4	2	2	3	3	0	12	1	0
North Carolina*	113	18	1	48	5	2	11	26	0	2	0	0
North Dakota*	52	0	0	7	0	3	24	1	0	16	1	0
North Mariana Islands	5	0	0	2	1	0	0	2	0	0	0	0
Ohio*	62	5	1	15	4	6	21	1	2	0	7	0
Oklahoma	2	0	0	0	0	0	0	1	0	1	0	0
Oregon	7	0	0	2	2	2	1	0	0	0	0	0
Pennsylvania	71	5	0	35	0	8	5	7	1	10	0	0
Puerto Rico*	26	7	0	5	3	2	2	5	2	0	0	0
Rhode Island	16	1	0	10	1	0	1	0	2	0	0	1
South Carolina	11	1	0	6	1	2	0	0	1	0	0	0
South Dakota	82	0	0	68	4	2	3	0	4	1	0	0
Tennessee	6	0	0	0	0	2	1	1	2	0	0	0
Texas	400	3	0	215	2	40	14	0	8	1	117	0
Utah	24	0	0	5	1	0	5	1	2	8	2	0
Vermont	32	2	0	12	3	0	2	4	2	2	3	2
Virgin Islands	0	0	0	0	0	0	0	0	0	0	0	0
Virginia*	43	0	0	35	1	2	0	0	0	0	4	1
Washington	77	11	1	24	1	13	7	4	14	0	1	1
West Virginia	13	0	0	7	0	2	1	0	1	1	0	1
Wisconsin	43	0	0	20	3	5	5	2	4	2	2	0
Wyoming	36	0	0	1	0	3	1	31	0	0	0	0
Subtotal 6b	2,658	211	22	1,134	147	193	292	158	127	138	194	42

Table 6b – Neglect
2011 cont.

Subtotal 6a	1356	151	12	522	109	93	169	69	80	63	53	35
Total 6a & 6b	4014	362	34	1656	256	286	461	227	207	201	247	77

Table 7a – Rights Violations
2011

States	Number of Rights Complaints Closed	Discrimination in:		Denial of:				
		Housing	Employment	Reimbursement and Entitlement	Guardianship	Rights Protect or Legal Assistance	Privacy	Recreational Opportunities
Alabama*	31	1	0	1	4	2	0	1
Alaska	38	5	1	29	1	0	0	0
American Indian Consortium	10	1	1	2	2	0	0	0
American Samoa*	7	0	1	1	1	0	2	2
Arizona	43	2	0	3	2	23	4	2
Arkansas	45	10	1	0	1	1	1	0
California	591	157	44	180	69	20	17	3
Colorado	27	5	0	3	0	3	5	3
Connecticut*	16	3	1	0	0	6	0	0
Delaware	82	7	0	33	4	5	2	1
District of Columbia	8	2	0	0	0	0	1	0
Florida	110	15	0	8	10	42	1	2
Georgia	7	1	0	2	0	1	1	0
Guam	15	0	0	1	6	0	0	0
Hawaii	208	9	2	41	2	4	0	7
Idaho	77	0	0	63	4	0	0	0
Illinois	406	11	63	17	30	12	10	11
Indiana	15	0	0	2	0	2	0	3
Iowa*	37	4	12	1	4	6	2	0
Kansas	208	63	14	27	9	13	2	0
Kentucky*	18	1	0	1	2	4	1	3
Louisiana	29	0	0	5	3	4	1	2
Maine	106	35	17	4	9	2	2	1
Maryland	6	0	0	3	0	3	0	0
Massachusetts	74	9	12	4	0	7	0	5
Michigan	72	13	3	1	5	11	3	4
Minnesota	142	9	7	4	19	10	2	2
Mississippi	59	2	1	4	3	2	0	0
Missouri	80	6	2	30	20	2	10	2

Table 7a – Rights Violations
2011 cont.

Montana	27	4	1	0	1	8	2	2
Nebraska	2	0	0	1	1	0	0	0
Nevada	53	4	0	12	2	28	1	1
New Hampshire	126	14	8	17	2	3	0	0
New Jersey	69	1	8	1	1	0	3	5
New Mexico	14	0	0	1	7	3	0	0
New York*	143	27	9	33	0	8	4	0
North Carolina	80	4	3	15	6	33	0	7
North Dakota*	67	1	4	5	0	10	0	0
North Mariana Islands	7	0	1	4	0	0	0	0
Ohio*	377	38	38	32	30	116	12	17
Oklahoma	240	26	7	94	2	14	1	1
Oregon	23	7	1	4	3	4	0	0
Pennsylvania	794	104	50	275	9	135	7	3
Puerto Rico*	71	5	7	3	15	0	0	0
Rhode Island	36	14	1	0	3	2	0	0
South Carolina	25	5	0	1	1	2	1	0
South Dakota	53	2	1	12	4	0	2	0
Tennessee	50	1	7	0	0	1	0	5
Texas	455	14	30	10	23	34	10	16
Utah	147	0	0	30	29	83	0	0
Vermont	39	6	3	1	0	8	2	3
Virgin Islands	5	0	1	0	0	2	0	0
Virginia*	47	4	2	1	5	0	3	2
Washington	282	49	21	39	13	47	27	23
West Virginia	17	3	0	1	0	2	2	2
Wisconsin	46	3	8	1	0	6	1	2
Wyoming	13	0	0	0	0	1	2	0
Total	5,875	707	393	1,063	367	735	147	143
Percentages	100%	12%	7%	18%	6%	13%	3%	2%

Table 7b – Rights Violations
2011

States	Number of Rights Complaints Closed	Denial to:		Failure to Provide:			Problems with Advance Directives	Denial of Parental Rights
		Visitors	Access to Records	Confidentiality	Informed Consent	Education		
Alabama*	31	0	0	1	0	20	0	1
Alaska	38	0	1	0	0	1	0	0
American Indian Consortium	10	0	0	0	0	2	0	2
American Samoa*	7	0	0	0	0	0	0	0
Arizona	43	0	5	2	0	0	0	0
Arkansas	45	0	3	1	0	26	0	1
California	591	0	14	3	3	50	8	23
Colorado	27	0	2	2	1	1	0	2
Connecticut*	16	1	2	0	1	1	0	1
Delaware	82	0	3	0	0	22	3	2
District of Columbia	8	0	1	0	3	0	1	0
Florida	110	1	1	1	20	9	0	0
Georgia	7	0	0	0	0	2	0	0
Guam	15	1	1	0	0	5	1	0
Hawaii	208	0	0	0	0	85	58	0
Idaho	77	1	1	0	0	8	0	0
Illinois	406	3	9	10	1	205	6	18
Indiana*	15	0	0	1	0	7	0	0
Iowa	37	0	1	0	0	7	0	0
Kansas	208	12	4	3	24	37	0	0
Kentucky*	18	1	0	0	2	2	0	1
Louisiana	29	0	3	2	0	8	1	0
Maine	106	0	0	0	1	34	0	1
Maryland	6	0	0	0	0	0	0	0
Massachusetts	74	1	0	1	0	35	0	0
Michigan	72	0	0	1	0	30	0	1
Minnesota	142	0	1	2	2	78	3	3
Mississippi	59	0	0	0	2	43	2	0
Missouri	80	3	1	0	0	4	0	0
Montana	27	0	0	0	1	6	0	2

Table 7b – Rights Violations
2011 cont.

Nebraska	2	0	0	0	0	0	0	0
Nevada	53	0	0	1	0	4	0	0
New Hampshire	126	0	0	1	0	80	0	1
New Jersey	69	4	0	1	0	43	0	2
New Mexico	14	0	0	1	1	0	1	0
New York*	143	0	8	7	2	34	5	6
North Carolina	80	0	0	0	0	10	0	2
North Dakota*	67	0	0	0	0	47	0	0
North Mariana Islands	7	0	0	0	0	2	0	0
Ohio*	377	3	15	7	3	38	12	16
Oklahoma	240	0	1	1	1	88	0	4
Oregon	23	0	0	1	2	1	0	0
Pennsylvania	794	3	1	2	0	165	8	32
Puerto Rico*	71	0	2	0	0	39	0	0
Rhode Island	36	0	0	1	1	14	0	0
South Carolina	25	0	0	0	0	15	0	0
South Dakota	53	0	0	0	0	32	0	0
Tennessee	50	0	0	0	0	36	0	0
Texas	455	0	6	2	40	259	0	11
Utah	147	0	0	0	0	0	0	5
Vermont	39	1	1	2	1	9	1	1
Virgin Islands	5	0	0	0	1	1	0	0
Virginia*	47	0	2	0	0	2	25	1
Washington	282	2	5	9	1	11	5	30
West Virginia	17	1	0	1	0	5	0	0
Wisconsin	46	0	0	0	0	24	0	1
Wyoming	13	0	0	0	0	10	0	0
Total	5,875	38	94	67	114	1,697	140	170

Table 7b – Rights Violations
2012

States	Number of Rights Complaints Closed	Denial to:		Failure to Provide:			Problems with Advance Directives	Denial of Parental Rights
		Visitors	Access to Records	Confidentiality	Informed Consent	Education		
Alabama*	50	0	1	0	1	20	0	2
Alaska	41	0	0	1	0	0	0	0
American Indian Consortium	18	0	0	0	0	14	0	0
American Samoa*	9	2	0	0	0	0	0	1
Arizona	35	0	6	1	0	0	0	0
Arkansas	60	0	1	0	0	32	0	1
California	1,045	1	13	7	2	71	4	13
Colorado	30	0	1	1	5	1	0	4
Connecticut*	10	0	0	0	0	1	1	0
Delaware	84	1	1	0	0	16	1	5
District of Columbia	14	0	0	0	4	0	0	0
Florida	76	0	0	1	1	15	1	0
Georgia	31	0	0	0	0	3	0	0
Guam	13	0	0	0	0	5	0	0
Hawaii	149	0	1	0	0	61	48	0
Idaho	106	0	2	0	2	12	0	1
Illinois	539	1	18	6	3	210	4	21
Indiana*	27	1	0	0	0	6	0	0
Iowa	59	0	0	0	1	13	0	0
Kansas	440	1	2	14	44	48	1	8
Kentucky*	8	0	0	0	0	0	0	1
Louisiana	47	0	1	1	0	19	1	0
Maine	88	0	0	0	0	32	0	0
Maryland	32	3	0	0	0	0	0	1
Massachusetts	55	0	0	0	1	29	1	0
Michigan	66	0	1	0	0	35	0	0
Minnesota	216	3	2	2	1	71	35	3
Mississippi	98	0	0	0	0	73	2	0
Missouri	99	4	2	0	1	4	0	0
Montana	18	0	1	0	2	7	0	1

Table 7b – Rights Violations
2012 cont.

Nebraska	5	0	0	0	0	0	0	0
Nevada	52	0	0	1	0	4	0	0
New Hampshire	329	0	5	1	0	61	0	6
New Jersey	69	0	1	0	6	31	1	0
New Mexico	55	3	3	0	1	9	0	0
New York*	89	0	6	0	1	10	1	4
North Carolina	77	1	1	0	0	10	0	2
North Dakota*	61	0	0	0	0	42	0	0
North Mariana Islands	17	0	0	1	0	2	0	0
Ohio*	617	0	14	7	15	48	16	12
Oklahoma	379	0	2	2	0	81	1	28
Oregon	20	2	0	0	2	2	0	0
Pennsylvania	634	1	5	3	2	150	10	23
Puerto Rico*	53	1	0	1	0	20	0	0
Rhode Island	44	0	0	0	0	18	1	0
South Carolina	33	0	0	0	0	17	0	1
South Dakota	55	0	1	0	0	35	0	0
Tennessee	56	0	0	0	0	38	0	13
Texas	632	0	6	3	49	328	0	12
Utah	221	0	0	7	0	0	1	5
Vermont	36	0	0	0	0	1	9	0
Virgin Islands	7	0	0	0	0	1	0	0
Virginia*	23	2	1	0	0	2	8	0
Washington	248	1	3	4	2	9	4	26
West Virginia	37	1	0	1	1	7	0	0
Wisconsin	64	0	1	0	0	27	0	0
Wyoming	7	0	0	1	0	0	0	0
Total	7,483	29	102	66	147	1,223	151	194

Table 7c – Rights Violations
2011

States	Total	Deaths Reported			Death Investigations Conducted			
		State	Center for Medicare & Medicaid	Other	Total	Seclusion	Restraint	Not Related to S/R
Alabama*	1	0	0	1	1	0	0	1
Alaska	4	0	0	4	4	0	0	4
American Indian Consortium	0	0	0	0	0	0	0	0
American Samoa*	0	0	0	0	0	0	0	0
Arizona	1	0	0	1	0	0	0	0
Arkansas	0	0	0	0	0	0	0	0
California	11	1	1	9	9	1	3	5
Colorado	0	0	0	0	6	0	0	6
Connecticut*	11	11	0	0	1	0	0	1
Delaware	17	17	0	0	17	0	0	17
District of Columbia	5	0	0	5	3	0	0	3
Florida	6	1	0	5	6	0	0	6
Georgia	7	7	0	0	9	0	0	9
Guam	0	0	0	1	1	0	0	1
Hawaii	0	0	0	0	0	0	0	0
Idaho	2	0	0	2	1	0	0	1
Illinois	18	14	1	3	11	0	2	9
Indiana	2	0	0	2	3	0	0	3
Iowa*	0	0	0	0	0	0	0	0
Kansas	0	0	0	0	0	0	0	0
Kentucky*	15	14	1	0	15	0	0	15
Louisiana	2	0	0	2	2	0	0	2
Maine	1	0	1	0	0	0	0	0
Maryland	83	83	0	0	10	0	0	10
Massachusetts	344	344	0	0	2	0	1	1
Michigan	21	6	0	15	21	0	1	20
Minnesota	0	0	0	0	0	0	0	0
Mississippi	0	0	0	0	0	0	0	0

Table 7c – Rights Violations
2011 cont.

Missouri	215	207	0	8	15	0	0	15
Montana	0	0	0	0	0	0	0	0
Nebraska	0	0	0	0	0	0	0	0
Nevada	0	0	0	0	0	0	0	0
New Hampshire	0	0	0	0	0	0	0	0
New Jersey	51	50	1	0	51	0	0	51
New Mexico	0	0	0	0	0	0	0	0
New York*	1316	1316	0	0	17	0	0	17
North Carolina	103	102	0	1	7	0	1	6
North Dakota*	2	0	0	2	0	0	0	0
North Mariana Islands	1	0	0	1	1	0	0	1
Ohio*	193	192	1	0	1	0	1	0
Oklahoma	0	0	0	0	0	0	0	0
Oregon	0	0	0	0	0	0	0	0
Pennsylvania	40	40	0	0	40	0	0	40
Puerto Rico*	1	0	0	1	1	0	0	1
Rhode Island	1	0	0	1	1	0	0	1
South Carolina	0	0	0	0	0	0	0	0
South Dakota	0	0	0	0	0	0	0	0
Tennessee	3	0	0	3	3	0	1	2
Texas	17	0	0	17	17	0	3	14
Utah	1	1	0	0	1	0	0	1
Vermont	7	0	0	7	7	2	0	5
Virgin Islands	0	0	0	0	0	0	0	0
Virginia*	58	57	0	1	3	0	1	2
Washington	0	0	0	0	4	0	1	3
West Virginia	0	0	0	0	1	0	0	1
Wisconsin	15	10	1	4	15	0	1	14
Wyoming	2	2	0	0	2	0	0	2
Total	2578	2475	7	96	309	3	16	290
Percentages	100%	96%	0%	4%	100%	1%	5%	94%

Table 8 – Intervention Strategies
2011

States	Total Intervention Strategies	Short Term Assistance	Abuse Neglect Investigation	Technical Assistance	Administrative Remedies	Negotiation/ Investigations	Legal Remedies
Alabama*	324	222	60	1	9	27	5
Alaska	55	23	3	0	19	7	3
American Indian Consortium	15	3	0	1	4	0	7
American Samoa*	59	16	11	7	2	22	1
Arizona	309	13	6	287	0	3	0
Arkansas	88	55	3	17	7	6	0
California	1,456	1408	13	5	8	14	8
Colorado	83	18	26	16	0	19	4
Connecticut*	78	53	4	10	10	1	0
Delaware	113	57	5	16	20	9	6
District of Columbia	85	34	12	17	15	7	0
Florida	197	72	51	42	5	24	3
Georgia	186	13	90	8	1	73	1
Guam	24	10	4	0	1	8	1
Hawaii	257	110	49	31	29	36	2
Idaho	143	51	11	75	5	0	1
Illinois	862	312	410	41	16	76	7
Indiana	53	23	22	6	0	2	0
Iowa*	61	39	7	1	1	5	8
Kansas	404	98	5	279	3	5	14
Kentucky*	116	54	16	46	0	0	0
Louisiana	128	97	14	5	3	4	5
Maine	182	63	3	9	18	81	8
Maryland	73	10	51	8	0	3	1
Massachusetts	151	115	5	7	0	23	1
Michigan	240	38	62	25	7	18	90
Minnesota	371	215	2	101	18	34	1
Mississippi	103	48	36	3	1	11	4
Missouri	199	12	31	51	10	85	10
Montana	184	103	71	2	4	0	4

Table 8 – Intervention Strategies
2011 cont.

Nebraska	23	1	20	0	0	1	1
Nevada	99	63	0	34	2	0	0
New Hampshire	254	85	6	148	3	7	5
New Jersey	256	42	153	35	2	20	4
New Mexico	143	94	23	9	2	13	2
New York	566	174	185	123	22	42	20
North Carolina	384	341	14	0	5	23	1
North Dakota*	425	128	153	7	15	117	5
North Mariana Islands	17	0	7	2	1	6	1
Ohio*	953	613	167	105	3	58	7
Oklahoma	298	259	4	1	6	25	3
Oregon	85	37	9	0	0	29	10
Pennsylvania	780	218	7	549	2	3	1
Puerto Rico*	101	15	18	2	10	54	2
Rhode Island	94	22	24	34	2	7	5
South Carolina	103	31	54	1	2	15	0
South Dakota	157	69	6	6	7	66	3
Tennessee	105	28	50	9	0	15	3
Texas	1,120	494	81	106	40	353	46
Utah	342	269	44	6	2	21	0
Vermont	145	77	56	6	4	0	2
Virgin Islands	26	17	4	1	0	2	2
Virginia*	143	65	14	10	14	25	15
Washington	627	0	7	619	0	1	0
West Virginia	57	36	3	6	0	12	0
Wisconsin	564	91	157	99	14	203	0
Wyoming	79	14	46	0	0	19	0
Total	14,545	6,668	2,395	3,035	374	1,740	333
Percentages	100.0%	45.8%	16.5%	20.9%	2.6%	12.0%	2.3%

Table 9 – Group Advocacy Strategies
2011

States	Non-Litigation Advocacy		Class Action Litigation		Legislative & Regulatory Advocacy	
Alabama*	10	48,380	0	0	35	902,761
Alaska	3	152	1	300	1	0
American Indian Consortium	1	8,500	0	0	1	8,500
American Samoa*	2	150	0	0	2	2
Arizona	4	209,808	2	209,808	2	209,808
Arkansas	2	2,133	0	0	0	0
California	16	7,816,758	6	55,850	6	2,050,000
Colorado	2	500	0	0	2	4,500
Connecticut*	7	791,719	1	4,000	2	113,207
Delaware	21	1,490	0	0	10	16,410
District of Columbia	3	30,000	3	4,800	3	10,500
Florida	23	35,250	0	0	117	5,662,886
Georgia	29	1,456,812	4	1,456,812	8	1,456,812
Guam	2	0	0	0	0	0
Hawaii	0	0	2	12,200	2	1,000
Idaho	0	0	0	0	4	74,000
Illinois	1	535,115	3	58,500	5	535,115
Indiana	6	1,095	1	4,476	2	85,791
Iowa*	9	336,139	0	0	3	336,043
Kansas	1	744,000	0	0	2	744,000
Kentucky*	10	874,000	3	874,000	80	874,000
Louisiana	14	2,294	1	250	12	188,691
Maine	14	56,000	1	12,500	48	56,000
Maryland	2	750	1	1,000	1	100,000
Massachusetts	14	894,056	0	0	7	50,716
Michigan	0	0	0	0	2	513,000
Minnesota	2	223	0	0	8	7,470
Mississippi	5	550	0	0	3	4,000
Missouri	7	940	1	3,000	0	0
Montana	0	53,000	0	0	2	53,000

Table 9 – Group Advocacy Strategies
2011 cont.

Nebraska	6	244	0	0	17	23,000
Nevada	1	20,000	0	0	0	25,000
New Hampshire	0	0	1	160	75	100,000
New Jersey	3	6,000	4	25,550	2	16,500
New Mexico	1	150	0	0	4	79,340
New York	1	833	7	10,000	2	4,000
North Carolina	3	7,000	0	0	10	50,000
North Dakota*	0	0	0	0	10	11,487
North Mariana Islands	0	0	0	0	0	0
Ohio*	11	585	3	140,200	30	115,424
Oklahoma	7	6,796	0	0	2	1,500
Oregon	1	800	0	0	3	900
Pennsylvania	4	44,270	1	1,500	4	36,302
Puerto Rico*	5	171	0	0	2	600,000
Rhode Island	5	35,080	0	0	5	46,000
South Carolina	1	168,913	1	2,400	1	4,185
South Dakota	0	0	0	0	0	100
Tennessee	45	933,000	0	0	5	340,000
Texas	1	70,120	1	4,000	4	220,000
Utah	10	1,050	0	0	12	90,339
Vermont	30	1,600	0	0	22	4,250
Virgin Islands	1	28,025	0	0	3	28,000
Virginia*	0	0	0	0	0	0
Washington	14	116,245	12	281,000	32	29,068
West Virginia	3	151,042	1	31,924	4	151,042
Wisconsin	71	3,526,708	0	0	0	263,000
Wyoming	8	500	0	0	7	2,380
Total	442	19,018,946	61	3,194,230	626	16,300,029

Table 10 – Public Awareness & Educational Training Activities
2011

States	Information & Referral	Public Awareness Events	Public Awareness Recipients	Education Trainings	Persons Trained
Alabama *	540	15	1,099	26	1,226
Alaska	655	3	215	13	196
American Indian Consortium	3,815	2	525	3	324
American Samoa *	833	3	307	7	1,200
Arizona	258	28	4,892	10	303
Arkansas	557	62	6,317	19	762
California	318	208	15,993	161	5,549
Colorado	521	1	5,000	2	55
Connecticut *	338	14	3,125	37	793
Delaware	270	8	1,710	40	892
District of Columbia	10	4	646	42	642
Florida	2,484	66	370,559	27	3,133
Georgia	592	19	4,915	73	2,200
Guam	42	78	57,661	134	1,991
Hawaii	654	281	6,336	60	1,123
Idaho	442	13	1,463	16	423
Illinois	681	42	6,049	141	3,797
Indiana	403	3	600	36	274
Iowa*	26	3	1,085	3	369
Kansas	34	5	35,455	136	5,020
Kentucky *	783	58	1,524	42	500
Louisiana	496	46	2,097	41	1,423
Maine	536	9	275	82	2,378
Maryland	162	1	23	59	1,585
Massachusetts	2,186	9	489,100	18	5,173
Michigan	2,363	21	300,000	23	565
Minnesota	133	4	870	38	2,290

Table 10 – Public Awareness & Educational Training Activities
2011 cont.

Mississippi	334	24	3,294	41	1,196
Missouri	739	34	7,102	15	676
Montana	388	16	370	6	870
Nebraska	186	4	200	10	228
Nevada	779	31	957	10	305
New Hampshire	343	22	1,650	19	566
New Jersey	768	45	12,350	10	220
New Mexico	503	17	3,140	20	471
New York *	936	35	937	23	647
North Carolina	572	149	7,200	13	355
North Dakota *	417	18	761	13	280
North Mariana Islands	112	18	2,374	21	484
Ohio *	51	10	745	16	379
Oklahoma	475	8	3,260	18	1,372
Oregon	1,042	7	185	5	95
Pennsylvania	200	14	4,786	37	1,417
Puerto Rico *	506	52	1,883,613	32	2,107
Rhode Island	272	15	1,091	6	418
South Carolina	614	0	0	8	203
South Dakota	478	97	4,168	11	312
Tennessee	681	96	557,541	21	1,677
Texas	2,580	93	5,340	139	6,102
Utah	629	34	6,524	43	2,539
Vermont	889	19	320	23	143
Virgin Islands	11	14	34,375	11	1,375
Virginia *	3,155	9	217	59	1,484
Washington	1,403	73	9,940	40	2,806
West Virginia	280	19	2,637	5	148
Wisconsin	445	0	0	19	1,545
Wyoming	250	144	6,004	23	1,209
Total	40,170	2,123	3,878,922	2,006	75,815

Table 10 – Public Awareness & Educational Training Activities
2012

States	Information & Referral	Public Awareness Events	Public Awareness Recipients	Educational Trainings	Total Persons Trained
Alabama *	681	4	1,040	4	1,260
Alaska	540	3	215	3	189
American Indian Consortium	3	4	1,544	6	378
American Samoa *	122	51	20,000	5	620
Arizona	315	59	15,054	17	727
Arkansas	398	17	5,744	5	125
California	154	347	19,073	148	4,411
Colorado	709	7	35,600	4	130
Connecticut *	525	30	30,000	15	405
Delaware	458	8	1,710	40	892
District of Columbia	10	4	646	42	642
Florida	2,484	66	370,559	27	3,133
Georgia	592	19	4,915	73	2,200
Guam	42	78	57,661	34	1,991
Hawaii	654	281	6,336	60	1,123
Idaho	442	13	1,463	16	423
Illinois	681	42	6,049	141	3,797
Indiana *	403	3	600	36	434
Iowa	26	3	1,085	6	274
Kansas	34	35	1,240,654	136	5,020
Kentucky *	783	58	1,524	42	500
Louisiana	496	46	2,097	41	1,423
Maine	541	3	250	79	2,098
Maryland	166	17	800	88	3,074
Massachusetts	2,458	15	617,864	18	1,954
Michigan	2,428	6	1,230	31	818
Minnesota	121	9	1,870	39	2,340
Mississippi	237	24	8,034	28	8,034

Table 10 – Public Awareness & Educational Training Activities
2012 cont.

Missouri	978	31	8,000	15	457
Montana	441	18	717	18	717
Nebraska	230	51	294,610	5	114
Nevada	698	79	2,394	6	477
New Hampshire	455	0	0	21	1,358
New Jersey	781	31	6,665	17	799
New Mexico	734	24	5,460	24	729
New York *	861	15	933	31	849
North Carolina	1,468	56	3,000	8	490
North Dakota *	386	22	21,067	17	325
North Mariana Islands	183	43	8,000	56	2,331
Ohio *	65	39	1,328	15	530
Oklahoma	500	9	3,080	20	2,238
Oregon	1,043	14	235	7	175
Pennsylvania	10	7	1,550	19	1,111
Puerto Rico *	506	32	2,107	53	4,332
Rhode Island	282	8	1,425	4	92
South Carolina	560	22	10,993	29	805
South Dakota	327	81	3,308	13	331
Tennessee	589	78	11,529	42	1,141
Texas	2,305	18	2,999	99	4,548
Utah	464	24	9,693	33	66,282
Vermont	718	20	269	18	156
Virgin Islands	14	19	1,246	12	336
Virginia *	2,825	34	1,060	17	1,567
Washington	918	33	101,806	54	506
West Virginia	283	22	6,883	10	153
Wisconsin	464	19	1,075	28	628
Wyoming	194	239	5,500	47	232
Total	35,785	2,340	2,970,549	1,922	142,224