



January 13, 2025

The President
The White House
Washington, DC 20500

Dear Mr. President:

I am pleased to submit the enclosed Biennial Report to Congress for Fiscal Years 2017 and 2018 as required by the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act).

The DD Act ensures the rights of individuals with developmental disabilities (DD) to live independently with the choices, decisions, and controls available to all individuals. The DD Act further safeguards the rights of these individuals to participate fully in the human experience, communities, and all the cultural, political, educational, and economic experiences available in the United States and its territories.

Under the oversight of the Administration on Disabilities within the Administration for Community Living, State Councils on Developmental Disabilities, Protection and Advocacy Systems, University Centers for Excellence in Developmental Disabilities Education, Research, and Service, and Projects of National Significance carry out the mission and mandate of the DD Act. This Report addresses those goals and outcomes, coordinated activities, and trends that impact the mission and of DD Act grantees for fiscal years 2017 and 2018.

I hope you will find the Report informative. If you have questions concerning the Report, please do not hesitate to contact me.

Sincerely,

Melanie Anne Egorin, PhD
Assistant Secretary for Legislation

Enclosure



January 13, 2025

The Honorable Claudia Gordon
Chair
National Council on Disability
1331 F Street, NW, Suite 850
Washington, DC 20004

Dear Chair Gordon:

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A handwritten signature in blue ink, which appears to read "Melanie Anne Egorin", is written over the typed name and title.

Melanie Anne Egorin, PhD
Assistant Secretary for Legislation

Enclosure



January 13, 2025

The Honorable Mike Johnson
Speaker of the House
U.S. House of Representatives
Washington, DC 20515

Dear Mr. Speaker:

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Melanie Anne Egorin, PhD
Assistant Secretary for Legislation

Enclosure



January 13, 2025

The Honorable Kamala Harris
Vice President of the United States
President
United States Senate
Washington, DC 20510

Dear Madam Vice President:

I am pleased to submit the enclosed Biennial Report to Congress for Fiscal Years 2017 and 2018 as required by the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act).

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Sincerely,

Melanie Anne Egorin, PhD
Assistant Secretary for Legislation

Enclosure



Biennial Report to the President, Congress, and the National Council on Disability on the Developmental Disabilities Assistance and Bill of Rights Act

Fiscal Years 2017 and 2018

Prepared by
Administration on Disabilities
Administration for Community Living
U.S. Department of Health and Human Services

December 2024

The biennial *Protection and Advocacy for Individuals with Mental Illness (PAIMI) Report* is an appendix to this report.

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Acronyms

ABLE	Achieving a Better Life Experience
ACL	Administration for Community Living
AIDD	Administration on Intellectual and Developmental Disabilities
AoD	Administration on Disabilities
AT	Assistive Technology
CMS	Centers for Medicare & Medicaid Services
CoP	Community of Practice
DD	Developmental Disabilities
DD ACT	The Developmental Disabilities Assistance and Bill of Rights Act of 2000
DSP	Direct Support Professionals
HCBS	Home and Community-based Services
I/DD	Intellectual and Developmental Disabilities
IEP	Individual Education Plan
IRR	Information and Referral
ITACC	Information and Technical Assistance Center for Councils on Developmental Disabilities
MFP	Money Follows the Person
NTI	National Training Initiatives
P&As	Protection and Advocacy Systems
PIE	Partnerships in Employment
PNS	Projects of National Significance
RISP	Residential Information Systems Project
SARTAC	Self-Advocacy Resource and Technical Assistance Center
SOS	The State of the States in Developmental Disabilities
TASC	Training and Advocacy Support Center
UCEDD	University Centers for Excellence in Developmental Disabilities

Introduction

This report summarizes the annual activities for Fiscal Years (FY) 2017 and 2018 of the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act) grantees, funded and administered by the Administration for Community Living (ACL), Administration on Disabilities (AoD). The DD Act requires that the biennial report, which is submitted to the President, Congress, and the National Council on Disability, describe the goals and outcomes of the State Councils on Developmental Disabilities (Councils or State Councils), Protection and Advocacy Systems (P&As), University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDDs), and Projects of National Significance (PNS), and how the programs have:

- Enhanced the ability of people with developmental disabilities (DD) and their families to 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, integration, and inclusion in all facets of community life.
- Brought about advocacy, capacity building, and systemic change activities and other actions on behalf of people with DD and their families, including people who are traditionally unserved or underserved, particularly people who are members of ethnic and racial minority groups and people from underserved geographic areas.
- Brought about advocacy, capacity building, and systemic change activities that affect people with disabilities other than people with DD .

The report also describes how the programs are protecting people with DD from abuse, neglect, sexual and financial exploitation, and violations of legal and human rights. Finally, the report contains information about monitoring of the programs.

The Developmental Disabilities Assistance and Bill of Rights Act

The DD Act promotes for people with DD autonomy in personal choices, inclusion in the design and implementation of programs, and the resources to support the development of services and supports.

Foundationally, the DD Act seeks for people with DD and their families to 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, integration, and inclusion in all facets of community life. The DD Act's findings state that the goals of the Nation include the goal that people with DD have the "information, skills, opportunities, and support to:

- make informed choices and decisions about their lives;

- live in homes and communities in which such people can exercise their full rights and responsibilities as citizens;
- pursue meaningful and productive lives;
- contribute to their families, communities, and states, and the Nation;
- have interdependent friendships and relationships with other persons;
- live free of abuse, neglect, financial and sexual exploitation, and violations of their legal human rights; and
- achieve full integration and inclusion in society, in an individualized manner, consistent with the unique strengths, resources, priorities, concerns, abilities, and capabilities of each individual”¹

Since its enactment in the 1960s, the DD Act has helped to create the changes needed to move people from institutional settings into communities and jobs of their choice. Evidence of this can be found in the current achievements, programs, goals, and plans that are reported for FY 2017 and 2018.

The Developmental Disabilities Network

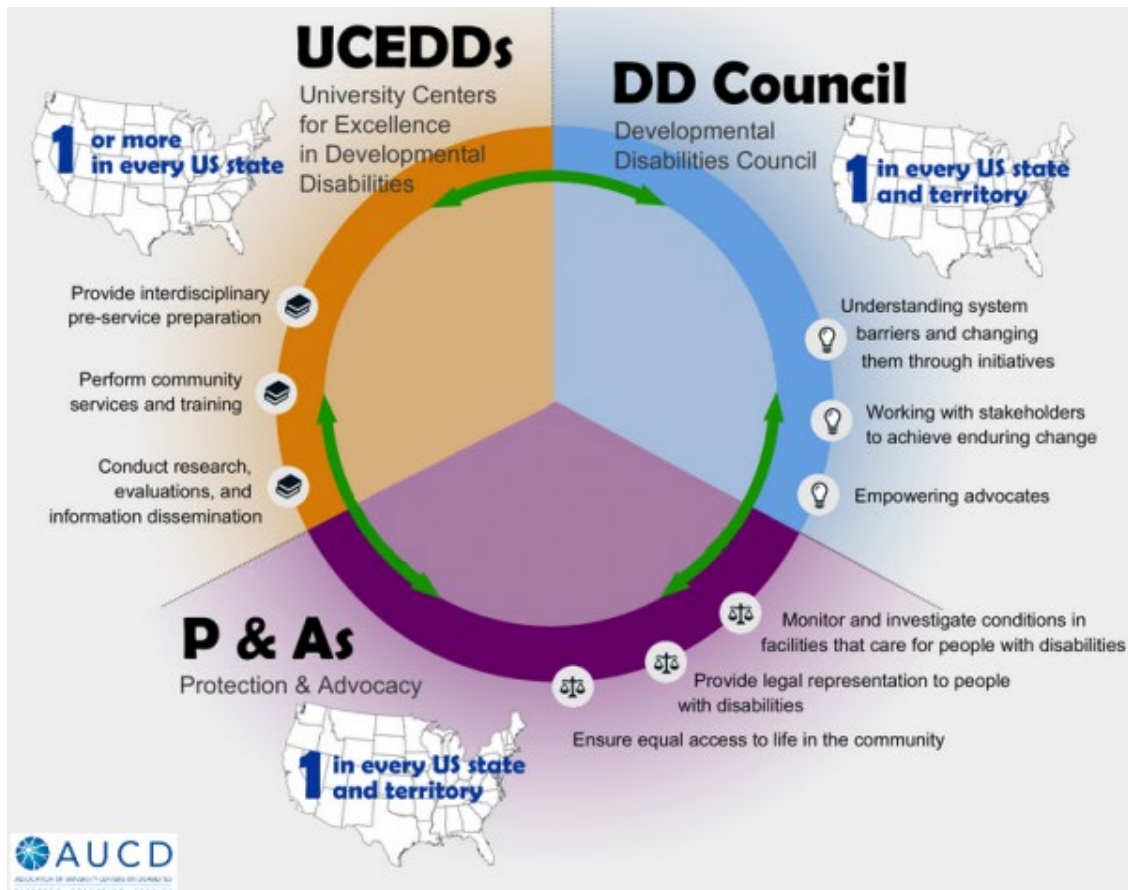
State Councils, P&As, and UCEDDs comprise the core of the DD Network. The DD Act creates this complementary network of services, education, research, protection, advocacy, outreach, capacity building, and leadership development:

- **Councils** work to address identified needs by conducting advocacy, systems change, and capacity-building efforts that promote self-determination, integration, and inclusion. Key activities include conducting outreach, providing training and technical assistance, removing barriers, developing coalitions, encouraging citizen participation, and keeping policymakers informed about disability issues.
- **P&As** are dedicated to the ongoing fight for the personal and civil rights of people with DD. P&As are independent of service-providing agencies within their states and work at the state level to protect people with DD by empowering them and advocating on their behalf. P&As provide legal support to traditionally unserved or underserved populations to help them navigate the legal system to achieve resolution and encourage systems change.
- **UCEDDs** are unique among AoD program grantees in that they are affiliated with universities, allowing them to serve as liaisons between academia and the community. UCEDDs are a nationwide network of independent but interlinked centers, representing

¹ 42 U.S.C. 15001 § (a)(16).

an expansive national resource for addressing issues, finding solutions, and advancing research related to the needs of people with DD and their families.

Figure 1: The Developmental Disabilities Network



By design, the grantee activities align and complement one another to create the opportunities and resources for coordination and collaboration to achieve the goals of the DD Act.

The DD Act also authorizes funding for PNS, which focus on the most pressing issues affecting people with DD and their families. Through PNS, ACL supports the development of national and state policy and awards grants and contracts that enhance the independence, productivity, inclusion, and integration of people with DD.

Monitoring

ACL reviews the programs, procedures, data, and results of grantee activities for compliance and outcomes, periodically adjusting to improve the monitoring process. In collaboration with State Council Executive Directors and staff, ACL developed new performance measures and reporting requirements, which were pilot tested with a subset of Councils. In FY 2017, ACL

started using the new performance measures with all Councils. Information from the pilot informed the transition to the new reporting requirements.

The changes introduced several improvements to the reporting system. For the new performance measure requirements, many Councils introduced pre- and post- surveys for programs as well as satisfaction surveys. Councils also attempted to capture better demographic information for attendees of programs.

Along with performance measure changes, Councils were expected to expand their outreach by identifying “unserved and underserved”² communities and addressing an area of need in their five-year state plan.

State Council on Developmental Disabilities³

Council activities support the DD Act’s purpose of enhancing opportunities for people with DD to make their own choices and live independently, free from abuse, neglect, and exploitation. Governor appointed Councils, consisting of at least 60 percent people with disabilities and family members in equal parts (30% people with disabilities and 30% family), engage in outreach, training and technical assistance, networking and coalition building, information sharing, advocating policy change, encouraging citizen participation, and the promotion of the issues important to people with DD.

Council activities are determined by a five-year state plan, which is developed to address areas of need in each state or territory based on data collection, public surveys, internal research regarding current needs, and national priorities. Programs and initiatives supporting the five-year plan address the most pressing needs. Some state plan activities are a continuation of successful programs while others are novel approaches to continuing issues or the incorporation of successful programs from other states and territories.

The 2017-2018 reporting period marks the start of a new five-year plan cycle. A new requirement for this planning cycle was for Councils to address an area of need for individuals with intellectual and/or developmental disabilities (I/DD) who are unserved or underserved. Many Councils planned to target minority groups through activities such as expanded outreach, efforts to increase the diversification of Council members, requiring contractors to address identified disparities, and increasing language accessibility. Many Councils identified its unserved and underserved communities in terms of race and ethnicity with some focusing on rural communities.

² 42 U.S.C. § 15002(32).

³ Data from FY 2017 and FY2018 are not reported for the Councils due to the transition to new performance reports and data management systems. As the quality and completeness of the new data meet ACL standards, the data will be reported in subsequent years.

Success Stories of State Council on Developmental Disabilities

The DD Act establishes areas of emphasis for grantee programs. When formulating five-year plans and addressing the needs of the state or territory, Councils will select areas of emphasis where state plan activities will be focused.

As part of their accountability to ACL and their constituents, each grantee submits annual performance reports detailing their progress on the goals and initiatives outlined in their approved five-year plans. In these reports, grantees discuss the activities and programs that support these goals and the progress in achieving the stated outcomes. What follows is a selection of success stories from Council activities and programs during fiscal years 2017 and 2018 as relayed from the perspective of the Council.

Advocacy

New Mexico – Successful Outreach Efforts. The New Mexico Developmental Disabilities Planning Council funded a multi-year project through New Mexico Allies for Advocacy INC. (Allies), which continued building the infrastructure capacity of the statewide self-advocacy network. Allies also received a grant from the Governor’s Commission on Disability to continue outreach for the “Know Your Rights” campaign by providing statewide “Fear to Freedom” trainings. The trainings targeted audience of family members to educate them about the upcoming Centers for Medicare & Medicaid Services (CMS) Final Rule for their children with DD.

Nevada – “Hear Me! People with Developmental Disabilities Speak Out” Public Awareness Video. The Nevada Governor’s Council on Developmental Disabilities facilitated seven people with DD (four of whom are Council members) in sharing in-depth conversations about their lives, experiences, relationships, dreams for the future, and the stigmas they encounter. The content, decided solely by people with DD, centered on three core issues: How to act when you meet someone with a disability, things people with DD are tired of hearing, and what people with DD want the world to know. The closed-captioned video featured a qualified American Sign Language interpreter for accessibility. A clip of the video was shown at the Supported Life Institute Conference in May of 2017 to approximately 20 attendees and the entire video debuted at the EPIC⁴ conference in August to an audience of approximately 60 self-advocates and professionals.

Outreach

Delaware – Council Outreach Initiatives. The Delaware Developmental Disabilities Council used feedback from Council members to make changes to their outreach efforts. For example, a Hispanic Council member shared Spanish language outreach materials at an event specific to her culture. After the event, she informed the Council that many of the attendees shared that they speak Spanish, but do not read Spanish or English well. The Council agreed to implement

⁴ Equal Partners Interstate Congress

her recommendation that for future events she serve as a translator with staff attending in-person, to assist with answering questions or talk about the Council's outreach materials.

New York – *Using Outreach to Engage Communities.* The New York Developmental Disabilities Council participated in the first Family Support Fair for Chinese American families and self-advocates. The Fair was organized by five Chinese American organizations that help support and provide services to those with DD in their communities. Over 150 parents and self-advocates attended. The Council provided printed informational materials in English and Chinese during the Resource Fair and hired a Mandarin interpreter to verbally communicate information to families and self-advocates at the event.

Employment

California – *Training, Outreach and Capacity Building for Customized Employment.* The California Developmental Disabilities Council worked with Easterseals Southern California (ESSC), who engaged in field testing of the Discovery Fidelity Scale for customized employment to successfully place people with DD into preferred jobs. While this project supported 46 self-advocates and seven family members, it also provided training, outreach, and capacity-building information/resources to 316 professionals and employers, engaging in a series of eight systems change activities with 121 community-based organizations (and 193 people). Through the activities of this project, ESSC leveraged \$149,488; trained staff from provider agencies (and funders) on the customized employment process; and conducted the nation's first field test of the Discovery Fidelity Scale, a process designed to validate whether people with DD achieve better employment outcomes when job discovery is provided with fidelity. This project resulted in the establishment of best practices in achieving positive employment outcomes for people with DD. The research project findings were presented at the National Association of People Supporting Employment First Conference and are slated to be included in an upcoming article⁵ in the Journal of Vocational Rehabilitation.

Rhode Island – *Supporting Entrepreneurism as an Employment Option.* The Rhode Island Developmental Disabilities Council (The RI DD Council) helped people who owned or wanted to own a business by collaborating with businesses, the Small Business Administration, the Center for Women in Enterprise, and the Veterans Business Outreach Center to hold classes and trainings in an integrated environment. The Council then connected budding entrepreneurs with various experts in the business community to help them build their business, write and stick to a business plan, and develop marketing strategies. The Council then hosted the first-ever Small Business Saturday – Shop RI. An event that brought almost 100 businesses to one location and over 1,000 consumers to shop on small business Saturday. The event was fully integrated with almost 20 percent of businesses owned by people with disabilities. With this

⁵ The Discovery Fidelity Scale was updated in December 2018, which included this project's findings. The article in reference can be found in the Journal of Vocational Rehabilitation, vol. 50, no. 1, pp. 23-37, 2019.

major success came requests to grow the class and the event. The RI DD Council successfully obtained significant grant funding to do both.

Education and Early Intervention

Guam – Training Families and Professionals in Early Intervention and Transition Strategies. The Guam Developmental Disabilities Council joined disability network partners in numerous strategies including co-sponsoring the “3rd Annual Island-Wide Conference on Disabilities” which focused on promoting successful transition for children from early intervention to adulthood with a series of trainings for parents, youth with disabilities, and professionals. In 2017, the disability network partners sponsored the “Guam Developmental Disabilities Tri-Agency Summit” that provided opportunities to identify issues and explore solutions to help advance the rights and transform programs and services for people with DD in the community. Through the Summit, strategies were planned aimed at improving and encouraging system change so that people with disabilities exercise their right to make choices, contribute to society, and live independently. The Summit was attended by 60 percent self-advocates and their families and 40 percent service providers who all actively contributed to the planning discussions. Sixty-seven (67) participants determined the top five priority areas as: employment, education and early intervention, health, transportation, and housing. The Council conducted several surveys over various events to obtain information from participants and stakeholders on the effectiveness of activities and the need for improvements in the focus areas.

North Dakota – Replicating a Successful Peer Mentor Program. A Special Education Teacher in Bismarck created a peer mentoring program at her school. Instead of instructional aids, students with DD were partnered with a peer mentor during certain class periods. Students were first trained on disabilities and accommodations for a semester before being a peer mentor. This program has changed the culture of the school. Students have become more accepting, and the school is saving money on instructional aids. Approximately 40 students per year participated in this class. The North Dakota Developmental Disabilities Council funded a grant to take this training statewide. The teacher has taught the process to 10 more schools and the program is being implemented around North Dakota, reaching 20 schools by spring 2019. Rural schools were targeted because the need is so high for instructional aids.

Transportation

Florida – Transportation Voucher Pilot in Hillsborough County. With co-funding from the Florida Department of Transportation, the Florida Developmental Disabilities Council developed a successful urban model that was able to provide 27,813 trips at a cost savings of \$556,260 and became self-sustaining. In Florida’s 2017 legislative session, a six-month Task Force to study and provide recommendations on transportation services specific to people with DD was established and named the Council as one of 10 required members. The Council promoted

recommendations from the 2017 Transportation Task Force in collaboration with self-advocates, and other stakeholders. As a result, the 2018 Legislative Session culminated in two of the four recommendations from the Task Force being funded. Two hundred fifty thousand dollars (\$250,000) was directed toward a study with recommendations to redesign the Agency for Persons with Disabilities (APD) transportation model. Five hundred thousand (\$500,000) was allocated through the Commission for the Transportation Disadvantaged for a new, innovative grant program for people with DD. The grant allocation resulted in a pilot door-to-door, on-demand transportation program for people with DD funded at \$475,000, available to people with DD in Hillsborough, Pinellas, and Manatee counties. The Council assisted the Commission for the Transportation Disadvantaged and Florida Department of Transportation in the development of the funding proposal, served on two selection committees, and have continued to provide technical assistance and support.

Quality Assurance

Texas – *Quality Assurance in Funded Programs.* To evaluate the overall success of reaching their state plan goals, the Texas Developmental Disabilities Council reviewed the achievement of each activity and objective, whether implemented by a grantee or as a staff activity and compared them to the annual work plan. The Council included specific outputs and outcomes in all Requests for Proposals. The grantees were required to describe their evaluation plans in their proposals and use the results to measure specific achievements obtained from their activities. For example, the Epilepsy Foundation’s *Get Fit Texas* measured improvements in strength, flexibility, health habits, body mass index (BMI), Waist-to-Hip ratio, and blood pressure and provided the information to the Council. The Council evaluated the success of the model and then promoted the model to agencies and managed care organizations. Additionally, the Council required all grantees to submit quarterly reports documenting whether the expected outputs and outcomes were reached; reviewed grantee reports and annual continuation applications, provided feedback to grantees as necessary to improve their projects; required grantees to submit and obtain approval for products based on their quality; and followed up with projects after funding ended to determine whether the activities were sustained and if there were long-term outcomes achieved that had not been evident at the end of the project.

Childcare

Maryland – *Partnering and Advocating for Access to Childcare.* The Maryland Developmental Disabilities Council had great policy success in 2017 with the establishment of a dispute resolution process for families of children with disabilities to use when their child faced discrimination in keeping childcare or enrolling in childcare because of his or her disability. The childcare associations that represent all childcare providers in Maryland were not always supportive of the Council’s efforts and had significant concerns. However, the Council continued to work with them, amended language, and educated and advocated for children

and their families. In the end, after legislation passed to establish a work group to develop the process, more than one childcare provider thanked the Council for their continued partnership, efforts, and commitment to better outcomes for children and families. These types of partnerships are critical to the sustainability of the Council's work. This is one example of how important it is for the Council to successfully navigate the complexities of policies, laws, regulations, and competing priorities of different associations to ensure more access and opportunity for children with disabilities in childcare.

Formal and Informal Community Supports

New Jersey – Improved Funding for Direct Support Professionals. The New Jersey Developmental Disabilities Council funded the Coalition for a Direct Support Professional (DSP) Living Wage (Coalition). This funding permitted the Coalition to study DSP wage issues in New Jersey and across the country. The Council developed materials to promote DSP living wage issues and to educate people with DD, their families, providers, DSPs, and the legislature. As a result of their education and messaging on the DSP workforce crisis, the New Jersey legislature approved increased funding in the contracted system with providers that afforded a one-time salary/bonus adjustment to most DSPs working within the DD service system.

Oklahoma – Supporting Parents with Disabilities. The Supporting Parents with Disabilities Project completed its second full year of work during FY 2017. What started with a small focus grew exponentially as new issues arose – and for this reason, the Oklahoma Developmental Disabilities Council will likely be investing in this for several more years. During the Council's review of parent training programs offered by state agencies, it was found that people with disabilities were specifically excluded from participating in these programs. Additionally, it was found that state law allows parental disability to be considered as a sole reason for removing a child from parent custody – without any requirement for due process. To address these issues, the Council funded the development of a first ever database of parents who have disabilities. In addition, the Council funded the purchase and placement of accessible baby care equipment at the state's Assistive Technology Act project, Oklahoma ABLE Tech, for long-term loan to parents.

Protection and Advocacy Systems

P&As ensure that people with DD can exercise their rights to make choices, contribute to society, and live independently by empowering them and advocating on their behalf. P&As provide legal support to traditionally unserved or underserved populations and encourage systems change through legal opinions and policy recommendations.

P&As engage in a range of efforts to promote the rights of people with disabilities. Table 1 illustrates the impact of P&A activity on people with DD. Outreach and self-advocacy training was a priority activity. Popular outreach topics included explanation of Achieving a Better Life

Experience Act (ABLE) accounts to ease the financial strain of people with disabilities by making tax-free saving accounts available to cover qualified disability expenses.

Table 1: P&A Activities by the Number of People Served, Places, or Investigations

Activity	FY 2017	FY 2018	Total
Public and private places/services made more accessible	12,882 places/services	13,007 places/services	25,889 Places/services
Abuse and neglect investigations	3,482 investigations	1,525 investigations	5,007 investigations
People with disabilities receiving information, technical assistance, and referral services	25,115 people	26,647 people	51,762 people
People with disabilities trained to become active participants in making decisions that affect their lives	383,754 people	50,261 people	434,015 people
People whose rights were advanced through class and/or systemic impact litigation	1,506,981 people	1,965,001 people	3,471,982 people
People with disabilities whose rights were enforced, protected, or restored as a result of non-litigation group advocacy	6,451,767 people	4,740,950 people	11,192,717 people
People with disabilities who received a lower level of services due to lack of P&A resources	4,330 people	958 people	5,288 people
People with disabilities impacted by one or more provision(s) in law modified or prevented	4,241,952 people	2,136,934 people	6,378,886 people

P&As use a range of legal advocacy strategies to protect the rights of individuals with DD. Many results are achieved through information and referrals, technical assistance in self-advocacy, short-term assistance, investigation and monitoring, negotiations, mediation or alternate dispute resolutions, and administrative hearings. P&A systems also often provide training and technical assistance to service providers, state legislators, and other policymakers on the rights of individuals. They also conduct self-advocacy training and raise public awareness of legal and social issues affecting individuals with ID/DD and their families (Table 2). Only a small percentage of cases go to litigation. In 2017-18, individual client's case resolved through litigation was about 4 percent and group cases resolved through litigation was about 8 percent.

Additionally, P&A systems provide group advocacy services that includes work on behalf of groups of people with disabilities pursued through the interventions of systemic litigation, legislative and regulatory advocacy, and systemic advocacy (non-litigious and non-legislative). These actions are aimed at reforming the policies or mode of operations of a system of services such as the disabilities service system.

Table 2 People Served by P&A Strategy and Year

Strategy	FY 2017	FY 2018	Total
Number of people served to address complaints	14,618 complaints	14,032 complaints	28,650 complaints
Number of Group Advocacy Cases	1,623 cases	1,774 cases	3,397 cases
Information and referral (IRR)	22,327 IRR	17,711 IRR	40,038 IRR
People receiving technical assistance	NA	6,580 technical assistance	6,580 technical assistance
People with disabilities who received advocacy training	NA	29,514 training	29,514 training
People with disabilities who received rights training	35,732	36,654 training	72,386 training

P&As provide substantial advocacy and legal services on education issues, working to ensure students with DD receive an appropriate education in an inclusive setting. Table 3 illustrates the prevalence of education complaints filed with P&As during the reporting period. The number of home and community-based services (HCBS) and housing complaints addressed demonstrates the strides in increased opportunities for people with DD to make decisions for themselves about where and with whom they live.

Table 3: Number and Percentage of Complaints by Problem Area by Year; with 2-year totals

Problem Areas-Complaints	2017		2018		Total	
	n	%	n	%	n	%
Total Abuse	1,008	6.3	1,050	6.7	2,058	6.5
Access to Admin. Or Judicial process	37	0.2	38	0.2	75	0.2
Access to Records	17	0.1	12	0.1	29	0.1
Advance Directives	18	0.1	15	0.1	33	0.1
Architectural Accessibility	78	0.5	63	0.4	141	0.4
Total Assistive Technology	73	0.5	45	0.3	118	0.4
Aversive (including ECT)	0	0.0	2	0.0	2	0.0
Civil Commitment	21	0.1	16	0.1	37	0.1
Criminal Justice	83	0.5	80	0.5	163	0.5
Custody/Parental rights	40	0.2	35	0.2	75	0.2
Total Education	6,470	40.2	5,979	38.4	12,449	39.4
Employment Discriminations	289	1.8	290	1.9	579	1.8
Employment Preparation	34	0.2	47	0.3	81	0.3
Financial Benefits	105	0.7	204	1.3	309	1.0
Forensic Commitment	12	0.1	11	0.1	23	0.1

Government Benefits Services	758	4.7	690	4.4	1,448	4.6
Guardianship/Conservatorship	624	3.9	666	4.3	1,290	4.1
Home and Community Based Services	2,197	13.7	2,104	13.5	4,301	13.6
Total Healthcare	1,636	10.2	1,631	10.5	3,267	10.3
Total Housing	384	2.4	304	2.0	688	2.2
Immigration	7	0.0	5	0.0	12	0.0
Juvenile Justice	14	0.1	14	0.1	28	0.1
Total Neglect	973	6.1	1,015	6.5	1,988	6.3
Post-Secondary Education	64	0.4	52	0.3	116	0.4
Non-Medical Insurance	4	0.0	3	0.0	7	0.0
Privacy Rights	36	0.2	57	0.4	93	0.3
Public Accommodations	153	1.0	199	1.3	352	1.1
Rehabilitation Services	109	0.7	45	0.3	154	0.5
Suspicious Death	232	1.4	311	2.0	543	1.7
Transportation	123	0.8	164	1.1	287	0.9
Unnecessary Institutionalization	176	1.1	118	0.8	294	0.9
Voting	8	0.0	4	0.0	12	0.0
Other	202	1.3	292	1.9	494	1.6
Total Complaints	16,075	99.4*	15,561	100.0	31,636	99.7*

*Due to rounding, total percentage does not sum to 100 percent.

Considering the living arrangements of people with ID is critical as it helps inform policy development and resource allocation. It helps identify gaps in housing options, access, and integration into the community. It also assists with monitoring trends over time and provide an indication of an increasing need of community-based housing as well as inform long term planning and sustainability of services as the population ages and grows.

Table 4 identifies the living arrangements of clients who were represented in FY 2017 and 2018 with a majority residing in the home of a parent or other family member.

Table 4: Number of Clients Represented by Living Arrangements and Year

Place of Residence or Living Conditions	2017		2018		Total	
	n	%	N	%	n	%
Independent	1,273	8.7	1,263	9.0	2,536	8.9
Parental or other family home	9,622	65.8	9,128	65.0	18,750	65.4
Community Residential Home for Children/Youth (0-18 Years)	116	0.8	113	0.8	229	0.8
Community Residential Home for Adults	1,661	11.4	1,753	12.5	3,414	11.9
Non-medical community base residential facility for children	36	0.2	44	0.3	80	0.3
Foster care	90	0.6	91	0.6	181	0.6

Nursing homes, including Skilled nursing facilities (SNF)	247	1.7	237	1.7	484	1.7
Intermediate Care Facilities	156	1.1	244	1.7	400	1.4
Public and private general hospitals including emergency room	56	0.4	72	0.5	128	0.4
Public Institutional Living Arrangement	550	3.8	473	3.4	1,023	3.6
Private Institutional Living Arrangement	365	2.5	319	2.3	684	2.4
Psychiatric wards (public or private)	92	0.6	67	0.5	159	0.6
Jail	127	0.9	89	0.6	216	0.8
State Prison	58	0.4	40	0.3	98	0.3
Federal Detention Center	6	0.0	5	0.0	11	0.0
Federal Prison	4	0.0	0	0.0	4	0.0
Veterans Administration Hospital	0	0.0	0	0.0	0	0.0
Other Federal Facility	2	0.0	1	0.0	3	0.0
Homeless	55	0.4	48	0.3	103	0.4
Unknown	102	0.7	47	0.3	149	0.5
Total	14,618	100.0	14,034	100.0	28,652	100.0

Success Stories of Protection and Advocacy Systems

Each year, the P&As provide performance reports detailing progress on the goals and initiatives undertaken. P&As report on monitoring efforts, persons served, collaborations, and successful cases in their chosen areas of emphasis. The information that follows is a selection of success stories from P&A activities and programs during fiscal years 2017 and 2018.

Education

Nebraska – Advocating for a Student with a Traumatic Brain Injury While Working with the School and Justice System. A 10-year-old student with a traumatic brain injury was being restrained and secluded while attending a small rural school. Law enforcement was involved because of incidents at the school, and he was involved in the juvenile justice system. He had recently received probation for nine years from the court system. A Nebraska P&A advocate in Western Nebraska worked with the mother and the probation officer. She attended Individual Education Plan (IEP) meetings to advocate for an appropriate behavior plan, testing, and to educate the school and probation officer about children with brain injuries and mental health issues. Through this process, the client's probation officer realized the nature of the client's disabilities and that the Judge's order of nine years of probation was inappropriate. The probation officer petitioned the court for the nine-year probation to be dropped after testing was completed. The judge agreed with the petition. Additionally, the mother gained knowledge through this process that helped her become a stronger advocate for her son. When this case was closed, the client was attending school successfully.

North Carolina – *Investigating Abuse in the Classroom.* A student was enrolled in a public school with an IEP that failed to recognize or accommodate for his deafness. The student's family initially contacted the North Carolina P&A regarding an incident of abuse at the school which was captured on video. The P&A obtained the video and confirmed that the teacher's assistant (TA) in the classroom slapped the student on his back, and the teacher turned the camera away at the critical moment so that the slap was not filmed. The teacher did not report the TA's behavior. It was apparent from the student's behavior that this was not an isolated incident. The P&A monitored the criminal proceedings against the TA and teacher. The TA was convicted of assault on a person with a disability and spent 30 days in jail. The teacher was convicted of failure to report child abuse and received two years of probation, a \$500 fine, and 100 hours of community service. The teacher was also prohibited from working with children under the age of 16 for the next two years. The P&A filed a complaint about the teacher with the state Board of Education, and a second complaint with the Behavior Analyst Certification Board, which licensed the teacher to provide behavior analysis and therapy services in both North and South Carolina. Both Boards revoked the teacher's licenses. Additionally, the P&A negotiated with the school system to provide the student with significant compensatory education services, an IEP that acknowledges his deafness, placement in a non-segregated school with appropriate supports and services, and an improvement to his communication system.

Wisconsin – *Collecting Data on Seclusion and Restraint to Advocate for Statewide Systems Change.* In 2017, The Wisconsin P&A obtained and compiled data from 423 school districts (out of 450 in the entire state), which disclosed that there had been 23,101 incidents of seclusion or restraint used on 4,630 students, 74 percent of whom were identified as being students with disabilities. The Wisconsin P&A used these data to educate policymakers – Department of Public Instruction officials, school boards, school administrators and legislative representatives – on the need for legislation to address the high incidence of use of restraint and seclusion on students with disabilities. In collaboration with the above groups, the Wisconsin P&A recommended changes to state law that would provide for 1) statewide reporting by school districts to the Wisconsin Department of Public Instruction; 2) requiring incident reports to be provided to the affected student's parent; 3) requiring parental agreement to include seclusion and restraint in a student's IEP; 4) requiring debriefing following incidents; and 5) expansion of the law to require private schools receiving state funds to report seclusion and restraint use to parents

Housing

Ohio – *Safeguarding Housing Rights on an Individual Basis.* During the past fiscal year, the Ohio P&A provided short-term assistance to 20 people who requested assistance with their housing rights. The P&A provided information to one individual on housing rights to prepare the client for effective self-advocacy. Another client, who required a live-in aid, contacted the P&A after

being told both would be evicted from their residence. The landlord stated that the financial history of the live-in aid was the reason for the eviction. The P&A provided information on individual rights and housing discrimination. Since the individual was the one paying rent, and not the live-in aid, the financial history of the aid should not have mattered. The P&A assisted the client in informing the landlord of their rights, and the landlord adjusted the lease and allowed the live-in aid to reside with the client – ensuring he had access to live in the community.

Health

Rhode Island – Ensuring Equal Access to Treatment The Rhode Island P&A represented a client with DD who needed exploratory tests under anesthesia to determine the best course of treatment for a cardiac tumor. The group home was reluctant to have the client undergo the tests and any needed follow-up surgery due to his anxiety. The P&A reassured the client about the need for the tests and represented the client in mental health court where the judge signed an order approving the tests. When the P&A learned the group home requested that the surgeon scheduled to perform the preliminary tests also conduct the surgery at the same time, the P&A advocated for the client to have access to the same course of treatment that any other individual (without a disability) would receive. As a result, the client was able to decide for himself whether to undergo the proposed procedure.

Additionally, the P&A represented another client, who had been adjudicated to not be competent and did not have a family to provide consent for cataract surgery. The client expressed her desire to have the surgery. She had a limited understanding of the benefits, but not all the risks. At deposition, the doctor explained the procedure was low risk and also testified that the client's quality of life would be greatly improved by her increased vision. P&A staff made the client's wishes known to the court, which ruled that the client have the procedure.

Childcare

Wisconsin – Increasing Access and Addressing Barriers in Underserved Communities. The Wisconsin P&A led a project to increase access to HCBS for African American children with disabilities and their families. The project resulted in the increased enrollment of Milwaukee African American children in the community, long-term supports, and greater awareness about HCBS among families and community professionals. This program reached over 4,000 people at 57 community events where 97 African American families received P&A legal and advocacy services. The P&A trained 170 family members and 550 professionals who served African American children including school social workers and psychologists, youth agency staff, childcare staff, clinicians, and other community professionals. A total of 6,000 Family Guides were developed and disseminated. Additionally, the P&A developed collaborative relationships with a wide range of community partners committed to increasing access and working with

both Milwaukee County and the Wisconsin Department of Health Services (DHS) to address systemic barriers and advance policy changes.

Recreation

Georgia – Advocating for Service Supports for Greater Community Access. The Georgia P&A represented a young woman with complex DD, who had been on the Comprehensive Supports Waiver Program for almost a year. However, during the time she had been receiving services through the waiver, she had not been able to go out into the community and live a meaningful life due to inadequate staffing. Thus, she requested six to seven hours per week of community access individual (CAI) support services and 28 hours a week of community living support services (CLS) through the waiver. The Department of Behavioral Healthcare, Developmental Disabilities and Hospitals (DBHDD) denied her request. In collaboration with Atlanta Legal Aid, the P&A filed a request for an administrative appeal with the Office of State Administrative Hearings (OSAH) on her behalf regarding DBHDD's denial. After a series of negotiations with DBHDD, and before the hearing, DBHDD agreed to provide the CAI and CLS hours requested.

Self-Advocacy

Maryland – Supporting Client Rights in Choice of Housing and Services. The Maryland P&A helped a woman get her choice of services so she could be discharged from a hospital and avoid another nursing facility admission. The woman has cerebral palsy, uses a wheelchair, and needed assistance with activities of daily living. She shared an apartment with an abusive partner, went to a nursing facility and then was hospitalized. When she was ready to be discharged, she needed a safe place to live and receive appropriate support services. This required increasing her Community First Choice personal care services and enrolling in Developmental Disability Administration (DDA) services for residential support. However, her Coordinator of Community Services (CCS or case manager) was working with her sister instead of her and was not moving quickly enough to avoid another nursing facility stay. The P&A successfully established that the woman would otherwise be homeless and thus was in DDA's highest priority category. The P&A helped the woman choose a new CCS and persuaded the CCS to take direction from the woman instead of her sister, with whom she frequently disagreed. The woman has successfully moved to a new provider agency.

Virginia – Supporting Self-Advocacy on an Individual Basis. The Virginia P&A received complaints from a man and his residential provider against his Day support provider, the local community services board. Day support staff were verbally abusive. The complainants asked for guidance on how to handle these issues at an upcoming meeting with the day support staff and other staff from the community services board. The P&A recommended that before the joint meeting convenes, the man identify what he wants and practice communicating those desires so that he could advocate for himself as much as possible. This strategy worked and was more

impactful coming from him directly. Having the man advocate for himself, even though it was difficult for him, made all the difference to open the lines of two-way communication.

Guardianship

Oregon- Rights-Based, Individual Advocacy for Guardianship Creates Radical Improvement for Client. A client was concerned that his civil liberties were being violated by his guardian while he lived in a group home for people with DD where his life was highly regulated. The client was not able to go into the community for more than 30 minutes per day, was not able to pursue employment through Vocational Rehabilitation or otherwise, was not able to get together with friends or contact friends by phone and was not able to have privacy (door taken off his room). These restrictions were imposed by the client's guardian and agreed upon by the housing provider. The Oregon P&A's client believed he could make his own decisions and wanted to live without these restrictions. During the P&A's investigations, the PA communicated with the client, staff from the group home, medical providers, the LTCO staff, and the guardian's attorney. The P&A then moved to terminate the guardianship and negotiated greater liberties for the client while awaiting trial. Before the trial date, the guardian agreed to enter into a Settlement Agreement whereby the P&A's client made his own independent decisions during a probationary period. Further, the P&A designed a monthly report that included the client's independent decisions as well as the concerns of the guardian. Acting upon the terms of the Settlement Agreement, the client moved out of the group home where he had lived for seven years. The client found an apartment, secured full-time employment, joined, and regularly worked out at a fitness center, and managed his own meals as well as apartment cleaning. The client thrived in the community and was able to get together with and phone his friends while having an appropriate level of privacy. The P&A drafted the guardianship termination order based on the client's success during this period.

Community Living

New Hampshire – Monitoring and Advocating for Community Versus Institutional Living. The New Hampshire P&A advocated against the re-opening of an institution for people with DD that had closed due to dangerous conditions identified by the P&A. In 2016, the facility's parent company began efforts to reopen the facility without any evidence that conditions would improve or that residents would be integrated into the community. The P&A attended the hearings and advocated for people with disabilities to live in home and community-based settings, rather than an institution. In FY 2017, that facility withdrew its request to reopen.

University Centers for Excellence in Developmental Disabilities Education, Research and Services

The UCEDDs are unique among DD Act grantees in that they are affiliated with universities and serve as liaisons between academia and the community. First established in 1963, UCEDDs now

comprise a nationwide network on 68 Centers. The DD Act authorizes funding for each UCEDD to support infrastructure and operational needs. UCEDDs are then required to leverage funding from other sources, such as state and private organizations, to carry out their core functions:

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

Table 5: The Number of UCEDD Accomplishments by Year

Accomplishment Description	FY 2017	FY 2018	Total
Continuing education events	2,628	2,119	4,747
Continuing education hours	54,242	43,873	98,115
Continuing education participants	196,216	219,955	416,171
Continuing training events	63,214	48,103	111,317
Continuing training participants	422,057	794,691 ⁶	1,216,748
Participants in demonstration services	13,334	25,119	38,453
Direct model services	126,461	103,055	229,516
Interdisciplinary preservice participants	68,851	52,097	120,948
Participants in other model services	112,309	112,772	225,081
Participants in research and evaluation activities	129,514	162,696	292,210
Participants in technical assistance programs	399,501	491,633 ⁷	891,134
Information dissemination products	7,705	8,216	15,921

Each UCEDD develops a five-year plan that incorporates core functions into programs, projects, and objectives to address issues, find solutions, and advance research in specified areas of emphasis important to the populations served. Areas of emphasis are selected through community surveys, needs assessments and research related to the needs of people with DD , and their families. The UCEDD’s Consumer Advisory Committee, a majority of whom are people with disabilities and family members, meets throughout the year to help guide the selection of areas of emphasis, ensure continuity of progress through the plan, and provide the vision and approach to tackling these issues.

ACL funding supports the organizational foundation of UCEDDs, which allows these grantees to pursue other sources of support to conduct various activities. UCEDDs leverage funding from a variety of sources, including federal, state, and local agencies; private foundations; donations;

⁶ The large increase in FY 2018 is due to the Minnesota UCEDD reporting 432,330 training participants. This number was verified by ACL.

⁷ The large increase in FY 2018 was due to the Pennsylvania UCEDD reporting 92,869 participants in their Assistive Technology project. This number was verified by ACL.

and fee-for-service earnings. ACL may award additional grants to UCEDDs through National Training Initiatives.

Success Stories of University Centers for Excellence in Developmental Disabilities Education, Research and Services

As part of each UCEDD's accountability to their constituents, the ACL and the DD Act, performance reports detailing progress on the core functions, goals and initiatives undertaken to support the five-year plan are submitted annually. What follows is a selection of success stories from the activities and programs of UCEDDs from fiscal years 2017 and 2018.

Arts

Indiana (Indiana University) – *Big Ideas, Creative Approaches in Education*. Through its Center on Education and Lifelong Learning and the Indiana Resource Center for Autism, the Indiana UCEDD co-sponsored the summer day camp *Yes And* for teens on the autism spectrum and educators. The camp, which was featured nationally on National Public Radio (NPR), focuses on improvisational theatre as a way to develop social communication skills and transform the teaching environment. Camp *Yes And* combines direct support for teens with a deep professional learning experience for educators, including K-12 general and special education teachers, speech-language pathologists, school psychologists and social workers, and arts educators. Additionally, center staff co-facilitate staff development workshops to introduce improv to camp educators' colleagues at the school and district levels.

Autism

Minnesota (University of Minnesota) – *Reaching Underserved Communities Through Collaboration*. The Minnesota UCEDD collaborated with the Minnesota Department of Human Services (DHS) to create a series of short films that raise community awareness of autism and the resources available to families. The target communities were Somalis, Hispanic, Hmong, African American, and American Indian. These short films were created with and for each of the five communities and will be used to help families get the resources they need. During 2018, over 30 interviews were filmed. Editing of the raw footage and release of the films for online dissemination by the Minnesota DHS was completed during calendar year 2018.

Direct Support

New Jersey (Rutgers University) – *Quality Assurance and Technical Assistance for the Direct Support Workforce*. In initiatives to enhance the Direct Support Workforce, the New Jersey UCEDD collaborated with a number of public and private provider agencies and networks in a variety of initiatives to strengthen recruitment, retention, and supports for direct support professionals. The UCEDD conducted training and technical assistance activities focused on statewide use of the College of Direct Support where the UCEDD serves as the statewide College of Direct Support (CDS) Administrator and manages the CDS Administrator listserv aimed at providing updates and technical assistance to CDS users in New Jersey. The Center

provided 1,200 hours of technical assistance in Direct Support Workforce Development to more than 1,100 participants in FY 17. The UCEDD surveyed 783 members of the College of Direct Support Technical Assistance (CDSTA) listserv to evaluate their satisfaction with the technical assistance received through the College of Direct Support in FY 17. Ninety-two percent of respondents reported Strongly Agreed or Agreed that their knowledge increased and that they were Highly Satisfied or Satisfied with the technical assistance provided.

Education

Georgia (University of Georgia) – *Providing Full Inclusion in Post-Secondary Education.* The Georgia UCEDD led efforts for the full inclusion of students with I/DD on campus by providing the academic home for Destination Dawgs: Inclusive Post-Secondary Education at the University of Georgia. The inaugural cohort of five students began on January 5, 2017, and their first semester concluded on April 26, 2017. They resumed classes on August 14, 2017. This program served students with DD to enrich their education, increase their ability to live independently and engage in a self-directed life, achieve competitive and integrated meaningful employment, and have the opportunity to gain life-long friendships. Destination Dawgs was designed as a fully inclusive program to meet the definition of a model postsecondary program.

Employment

Iowa (University of Iowa) – *Collaborating with State Organizations to Improve Employment Outcomes.* The Iowa UCEDD's Money Follows the Person (MFP) Employment Services Specialist held an Employment Gathering in the fall of 2017. This was attended by over 50 people from 14 Community Rehabilitation Providers (CRPs). Technical Assistance was provided on developing useful and robust Positive Personal Profiles, understanding the Iowa Workforce Development system as well as the newly developed Service Delivery Agreement between Iowa Vocational Rehabilitation Services and the Department of Education. Additionally, the Deputy Treasurer of Iowa provided information regarding Iowa's new ABLE accounts.

Throughout the year the Employment Services Specialist provided individual consultation to MFP members seeking employment. Working with Iowa Vocational Rehabilitation, Iowa Workforce Development, CRPs and the MFP member or families, as well as other team members, she partnered to ensure that services and supports are planned and delivered in an effective and timely manner. She worked with 37 members in 2017.

North Dakota (Minot State University) – *Moving People into Community-Based Competitive Employment.* The North Dakota UCEDD's most prominent project, Expanded Supported Employment (ESE), addresses the employment of people with DD. The UCEDD collaborated with the North Dakota Vocational Rehabilitation program and the North Dakota Developmental Disabilities Division on ESE. This partnership collectively implemented a project designed to move people with DD from unemployed, day services and/or under-employed segregated work

to customized community employment. Four state provider agencies worked with the partners to learn and then implement the procedures for customized employment. Twelve people with DD were moved into community-based competitive employment. The project was so successful that the state agencies funded it for three additional years to train and support all adult DD service providers in the state. In addition, the North Dakota Department of Human Services worked on regulations regarding funding streams for agencies who took the training, implemented customized employment, and helped people with DD get community jobs.

Health

Arkansas (University of Arkansas) – *Teaching Adult Nutrition, Healthy Food Purchasing and Meal Preparation. Nutrition Is for Everyone (NIFE)*, The Arkansas UCEDD demonstrated an example of leveraged funds (and expectation of all UCEDDS) in obtaining a grant from the Walmart Foundation for NIFE. Arkansas NIFE provided nutrition education to people with DD and their support system to increase the number of servings of fruits and vegetables they consume. The UCEDD's project partnered with a number of organizations, with the most prominent being the Hunger Relief Alliance and Special Olympics. Special Olympics provided access to people with DD. The Hunger Relief Alliance is the Arkansas affiliate of Share Our Strength's No Kid Hungry Campaign, which uses the Cooking Matters curriculum to teach about nutrition, healthy food purchasing, and preparation of nutritious meals. When NIFE started using the curriculum with people with DD, it became apparent that the curriculum needed to be modified for this population. The Arkansas NIFE program adapted the materials for people with DD and field-tested the curriculum with that group, as well as developed menus that could be prepared with only a microwave oven. Share Our Strength was in the process of reviewing the modified curriculum to be used nationally.

Missouri (University of Missouri)– *Expanding a Dental Care Program to a Wellness Campaign*. The Missouri UCEDD provides another example of the use of leveraged funds. Their project goal was to ensure an oral health care system for people with DD that provides easy access to quality dental care, resulting in better oral health, better dental care, and lower costs. The UCEDD partnered with the Jackson County Developmental Disabilities Board funded through the Health Care Foundation of Greater Kansas City. A training to increase the capacity of dental professionals to serve people with DD was revised and trainings were scheduled for fall FY 2018. In addition, video-based training for people and families was developed to help increase the number of people with DD who engage in preventive oral health practices. Also notable, the Developmental Disabilities Health Initiative (DDHI) is looking to change policies and practices that improve nutrition and increase participation in physical activity among people with DD in Jackson County. In 2017, the UCEDD offered a Community Health Worker (CHW) training to provider organizations. Previously trained CHWs working for DD services providers piloted a LifeCourse Health Portfolio tool. Use of the tool showed a statistically significant increase in health-related goal attainment for people with DD. In addition, a DD Health Disparities module

was delivered to 50 CHWs and disability and public health professionals at the Department of Health and Senior Services. An evaluation of the training showed statistically significant gains in knowledge and self-efficacy in supporting people with DD in health-related goals.

Recreation

California (University of California Los Angeles) – *International Distribution of Our Successful Program.* The Program for the Education and Enrichment of Relational Skills (PEERS) is world-renowned for providing evidence-based social skills treatment to preschoolers, adolescents, and young adults with autism spectrum disorder (ASD), attention deficit/hyperactivity disorder (ADHD), anxiety, depression, and/or other socio-emotional challenges. PEERS, published in 2017, expanded its international use when Dr. Laugeson's book, "The Science of Making Friends," was translated into Japanese. Prior to the launch of the book, a validation of PEERS was conducted at Osaka University in Japan where they found similar findings to Dr. Laugeson's research studies in North America. PEERS Certified training has been conducted in 25 countries and translated into 12 languages. To date, PEERS is used in 35 countries.

Mississippi (University of Southern Mississippi)– *Creating Recreational Opportunities to Promote Socialization, Self-Confidence, and Problem-Solving Skills.* The Mississippi UCEDD funded Project STICK which aimed to increase the availability and accessibility of inclusive recreational activities targeting people with DD of all ages in south Mississippi. Operating since 2014, Project STICK offers a variety of recreational opportunities including Adventure Therapy, which included high and low ropes courses, Quidditch, kayaking, live stream video gaming, and art-based activities. All Project STICK activities were designed to promote recreation and socialization which also helped participants develop self-confidence and problem-solving skills. During 2017-18, Project STICK provided 90 inclusive recreational activities for 1,203 people, of whom 662 were people with DD . Additionally, Project STICK staff partnered with Special Olympics of South Mississippi to host the Area III Summer Games in which 92 athletes demonstrated their skills in four sports: croquet, horseshoes, soccer, and softball.

New Mexico (University of New Mexico) – *An Inclusive Camp Experience with Opportunities as Camp Assistants.* Camp Rising Sun is a recreational residential summer camp for children, kids, and teens (separate week-long camps) on the autism spectrum and their neurotypical peers. There were 71 campers that participated in the Children's Camp and 68 campers participated in the Teen Camp. Nine young adults on the autism spectrum participated as camp assistants. For all the parents that responded to a post-camp impact survey, they either strongly agreed or agreed that they were satisfied with the experience the camp provided to their child. A delegation from Russia also attended the June 2017 camps in Albuquerque.

Transition

Delaware(University of Delaware) – *Building Successful and Self-Sustaining Transition Programs.* The Delaware UCEDD continued to pioneer a continuum of innovative programs

focused on transition-age youth (ages 14-22). Activities such as Disability Mentoring Day connected students to mentored worksite experiences; more extended experiences bring high school students to campus in programs focusing on employment readiness or college exploration. These campus immersion experiences, which are supported by the Division of Vocational Rehabilitation using Workforce Innovation and Opportunity Act funds, have been incredibly impactful in expanding students' self-determination and self-advocacy. The UCEDD also continued to operate the Career and Life Studies Certificate Program (CLSC), a two-year postsecondary certificate program for people with intellectual disabilities. Launched with federal Transition and Postsecondary Programs for Students with Intellectual Disabilities funding, CLSC self-sustained for two years following cessation of federal funding. In 2017, the UCEDD extended the program to include residential opportunities in University of Delaware dormitories and the establishment of a Living Learning Community in which students with and without DD will choose to live together.

National Training Initiatives – Additional Grants

The DD Act authorizes the funding of National Training Initiatives (NTI) to address national emerging needs through the UCEDD network. During this reporting period, ACL funded NTI grants to address diversity and improve the cultural competence in the field.

Minority Serving Institution Partnerships

Grants were awarded each year during fiscal years 2017 and 2018 to UCEDDs to establish a partnership with a minority-serving institution, community college, or another training program that serves underrepresented populations. UCEDDs and partners in Arizona, Mississippi, and Tennessee jointly planned and co-designed training experiences and utilized a variety of innovative knowledge exchange and transfer strategies. The goals included the promotion of interdisciplinary approaches to research, training, and services and building a pipeline for students to undergraduate and graduate training programs in the disability field.

Diversity Fellowships

These NTI grants aimed to grow the diversity of the UCEDD trainee enrollment and build a cohort of trainees in the UCEDD network from diverse backgrounds. The grants created a forum for knowledge exchange and transfer at the UCEDD and created a sustainability plan to promote further development of Diversity Fellowship programs beyond the funding period. To achieve this goal, the Diversity Fellowship programs employed traditional and non-traditional methods for marketing and maintaining the project over time in collaboration with national organizations, including the UCEDD Resource Center and the network of UCEDDs. The programs participated in an Association of University Centers on Disabilities coordinated national forum for knowledge exchange and transfer across the UCEDD network.

During fiscal years 2017 and 2018, grants were awarded to 13 UCEDDs, supporting 23 Diversity Fellows. Each Fellow had the opportunity to make systemic change through a capstone project

in community-based activities, organizations, policy and/or programs. For example, the Diversity Fellow from the Institute of Human Development and Disability at the University of Georgia worked with the successful *Destination Dawgs* program, which supported a complete, inclusive post-secondary experience for students with DD. This Fellow piloted a culturally competent curriculum for peer mentors interacting with students with DD in the program. The curriculum emphasized cultural competency, intersectionality, and person-centered planning.

Projects of National Significance

PNS target emerging national issues by identifying barriers, measuring the scope of need, analyzing data, creating novel solutions, and building coalitions of organizations to address the issues. During the current reporting period, employment remained a significant focus of ongoing PNS activity and updates to HCBS emerged as a new focus.

During fiscal years 2017 and 2018, ACL funded \$16,732,292 in PNS projects. PNS priorities included extending the successful Partnerships in Employment (PIE) cycle of grants to further improve state employment policies and employment outcomes for people with DD (\$6,017,926). Project Living Well addressed improvements to the quality of HCBS (\$4,570,000 over two years). Additionally, \$4,644,366 funded short-term PNS projects like advancing the self-advocacy movement, collecting data on family support and service outcomes, and providing technical assistance and training for disability network entities. Finally, \$1,500,000 continued funding on three longitudinal studies of trends in services and supports.

National projects

National Longitudinal Studies

For over 30 years, three longitudinal studies have collected data from each state to help DD networks, policymakers, service providers, and people with DD and their families make the most informed policy and individual decisions. These studies provide an overarching, higher-level evaluation of the conditions of people with DD in the United States.

The State of the States in Developmental Disabilities (SOS), The National Residential Information System Project (RISP), and the National Data Collection on Day and Employment Services for Citizens with DD are essential for many stakeholders. Data derived from these projects combined with local surveys help Councils, UCEDDs, and P&As identify needs in their state and guide planning for future goals and outcomes. People with DD and family members use the information to compare their states with other peer states regarding services. The information is used to prepare testimony and reports for the U.S. Congress and state legislatures, and policymakers use the information as background to make policy improvements. Journalists use it to write in-depth stories.

Users can access these data in several ways. Each project publishes an annual report, has a website with useful graphics and features for building special-use and custom reports.

The State of the States in Intellectual and Developmental Disabilities

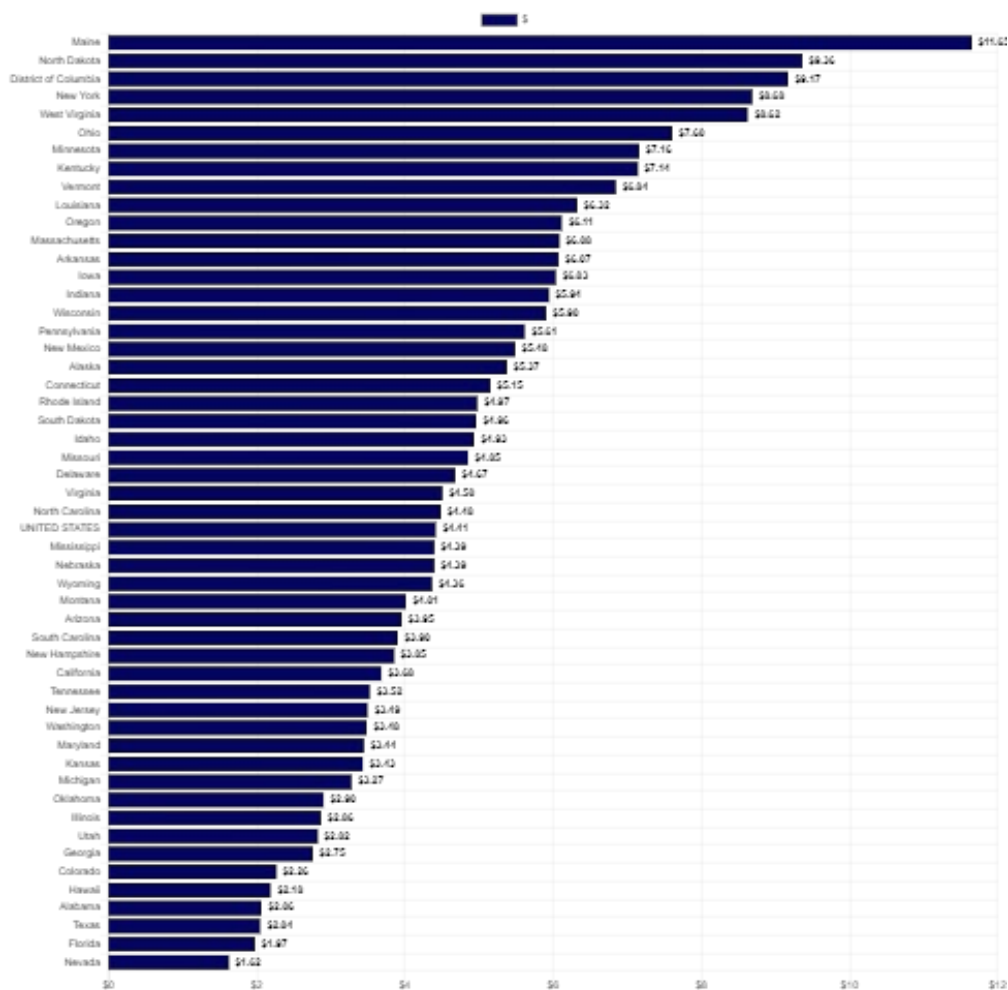
SOS is a longitudinal study of public spending and programmatic trends in DD supports and services that started in 1982. The project has collected data to create a 40-year record of revenue, spending, and programmatic trends in the 50 states, the District of Columbia, and the United States as a whole. Analysis of the data show the impact over time of federal, state, and local government fiscal policy. The data reveal important service delivery trends in the states for community living, public and private residential institutions, family supports, supported employment, supported living, technology solutions, and Medicaid Waivers (e.g., 1115 waivers and HCBS waivers). Demographic data include general population, personal income, and total state budget.

The study published its 11th edition in July of 2017. Statistical profiles for the 50 states, the District of Columbia, and the country as a whole are included in each edition. The project's 11th edition includes information about:

- Out-of-home placements in 2015;
- Federal, state, and local Medicaid spending in FY 2013-2015;
- Fiscal effort (a state's spending for DD services from federal, state, and local sources per \$1,000 aggregate statewide personal income) (See figure 2);
- The annual cost of care across years for residents in five settings, followed by a look to the future in terms of demographic and legal forces, implications of changes to Medicaid, and key challenges foreseen for the future;
- Trends and innovations in the financing of family support, supported living, and supported employment in the states;
- Results from Special studies, such as Medicaid spending for special education; and
- Targeted current-year and longitudinal data on the project website from collaboration with the National Data Collection on Day and Employment Services for Citizens with DD and t RISP.

As in previous editions, the 11th edition provides statistical profiles for the 50 states and the District of Columbia, the country as a whole, and a create-a-chart option allowing reports to be customized.

Figure 2: Fiscal Effort by State, 2017



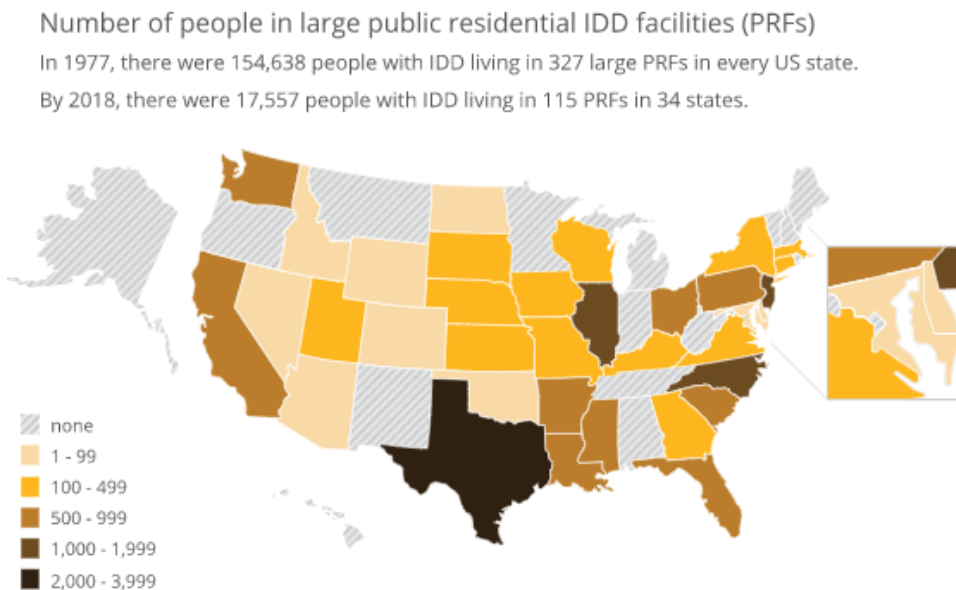
The total community and institutional spending for DD services, per \$1,000 of personal income in 2017, known as Fiscal Effort (2018 data is not available yet).

The National Residential Information Systems Project

RISP is the principal national source of annual statistics on residential and Medicaid services for people with DD. It also tracks data on family supports. The RISP project uses longitudinal survey research, literature reviews, state-level policy analyses, case studies, and secondary analysis to report national and state-by-state statistics on institutional and community-based supports for people with DD. It is widely used in policy development, evaluation, and advocacy. The project analyzes data on a variety of sources of funding for residential and supportive services, including public, non-public, and Medicaid funding. The longitudinal study utilizes a large multi-state database on people with DD to examine the associations between personal characteristics, housing, financing and support models, state systems on inclusion, self-determination, satisfaction, and outcomes. Annually, the project conducts state policy and

program surveys on key topics in residential and other community services. The project website includes a clearinghouse of information and resources on consumer-controlled housing, the direct support workforce, and community living outcomes. Research findings are disseminated through annual reports, the IMPACT publication, (a magazine published three times per year containing strategies, research, and success stories in specific focus areas related to persons with I/DD and other disabilities), and the project website.

Figure 3: Number of People in Large Public Residential Facilities by State, 2018⁸



The number of large state-run IDD facilities declined from 327 in 1977 to 115 in 2018. The number of people living in those settings declined from 154,638 to 17,557. By 2018, 17 states had closed all their large state-run IDD facilities. Nine states had only 1 large state-run IDD facility remaining, most serving 100 or fewer people. However, four states (Illinois, New Jersey, North Carolina, and Texas) had 5 or more large state-run IDD facilities. Those states served totals of between 1,000 and 3,000 people in large state-run IDD facilities.

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 DD describes day and employment services nationwide for people with DD. The project collects data from multiple sources and provides access through published editions and its website <https://www.statedata.info/>.

⁸ Residential Information Systems Project (2020). Infographics. Minneapolis: University of Minnesota, RISP, Research and Training Center on Community Living, Institute on Community Integration. Retrieved from: <https://risp.umn.edu>.

Additionally, the project promotes Employment First, and systems change efforts through supporting outcome-based practices and includes studies monitoring the effectiveness of inclusive employment and services for people with DD in vocational rehabilitation agencies and state developmental disability agencies. The project tracks and describes employment and economic trends on a state and national level; develops guidelines for non-work, community-based activities; and highlights best practices and outcomes in the transition from school to employment.

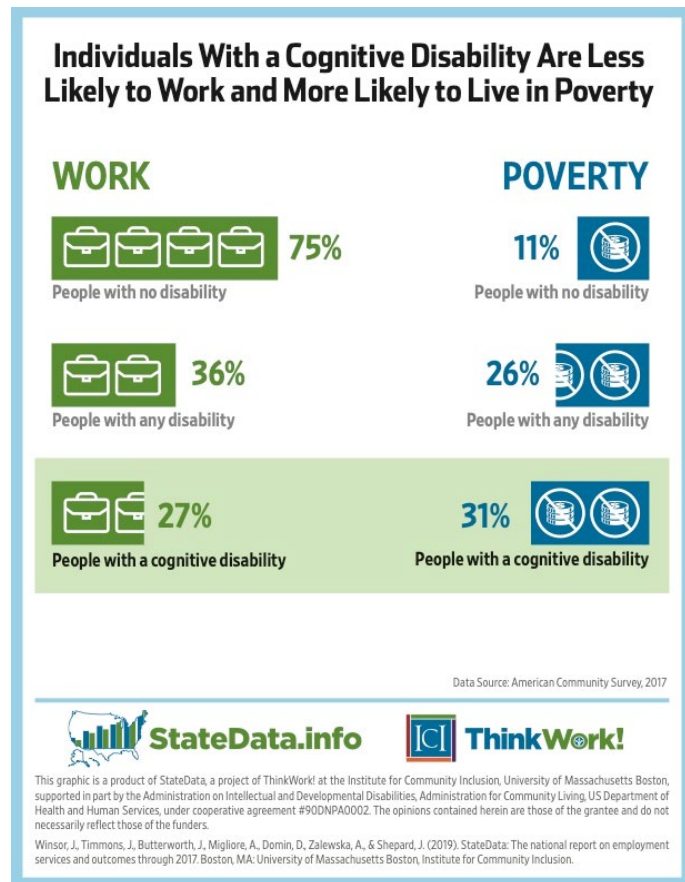
On the StateData.info site data and information is available from federal and state agencies. It includes state DD agencies and vocational rehabilitation outcomes and services from the Rehabilitation Services Administration. It also features data from the Social Security Administration, state mental health agencies, the U.S. Census Bureau's American Community Survey, the National Core Indicators Project, and the U.S. Department of Labor.⁹ Additionally, publications that analyze issues related to employment of people with DD are also available.

Major Themes in PNS Investments

While improvements in employment, self-advocacy, and community inclusion have been made, they continue to be leading PNS themes. In addition to these focus areas, PNS program activities also addressed diversity, the quality of community living, and supporting families.

Employment

Starting in 2011, ACL began funding the PIE Systems Change grants. The fiscal year 2017 and 2018 PNS PIE grants were an expansion of the original PIE grants, extending the work into new states. The five-year PIE grants aimed to increase competitive employment outcomes for youth



On the statedata.info website, users can find, sort, and analyze data to generate charts, like the one included here.

⁹ Winsor, Jean, PhD. "About StateData." StateData, <https://www.statedata.info/about>. Accessed May 2021.

and young adults with DD by enhancing collaboration across existing state systems, including programs administered by state DD agencies, state vocational rehabilitation agencies, state educational agencies, and other entities to prioritize employment as the first and preferred option for youth and young adults with DD. These grants worked on developing the right supports and accommodations for people of all abilities to participate fully in integrated employment and community life. States worked to align policies, service delivery practices, and reimbursement structures to ensure that youth and young adults with DD are supported to access integrated and competitive employment.

Select activities and accomplishments during FY 2017 and 2018 include:

- Establishment and support for project work teams;
- Establishment of self-advocacy peer support groups;
- Development of training modules for professional development on high school transitions, family engagement, and benefits;
- Employer trainings that reached hundreds of employees
- Implementation of Pre-Employment Transition Services (Pre-ETS) in multiple school districts
- Signing of a high school credential alternative diploma into law;
- Passage of and participation in a state Employment First Study Committee;
- Creation and leadership of a Business Coalition for Employment of People with Disabilities;
- Convenings of community conversations; and
- Development of websites and communication tools (blogs, newsletters) distributes through list serves and consortia.

Kentucky works Employment Partnerships for Youth with Significant Disabilities

The Human Development Institute at the University of Kentucky (HDI) was awarded a PIE grant to lead KentuckyWorks. Over the lifespan of the grant, the program aimed to establish a state-level employment workgroup with consortium members, self-advocates, and family members; utilize the Kentucky Community Work Transition Program to pilot additional enhanced transition practices for students with DD; develop and distribute resources to families and students with DD, employers, and service providers; and track and evaluate post-school outcomes for students with DD annually.

The South Carolina Employment First Initiative

ABLE South Carolina was awarded a PIE grant to lead the South Carolina Employment First Initiative (SCEFI). The grant aimed to equip high school students and recent graduates with DD with the skills, awareness, and confidence needed to enter competitive employment; unified and empowered South Carolina education professionals, employment service providers,

families, and community members towards the support of Employment First principles; developed and expanded supports for South Carolina-based employers who hired persons with disabilities in competitive community-based positions.

DC Learners and Earners

DC Department on Disability Service's grant for the DC Learners and Earners (DCL&E) initiative aimed to improve employment outcomes for youth and young adults with DD. DCL&E worked with people with disabilities and families to build high expectations for employment. Tips for success were shared with neighborhoods throughout the District of Columbia to build community-based networks of support for young people and examined where the government policies and practices must change. The grant was guided by person-centered thinking and the LifeCourse principles. DCL&E partnered with people with DD, including self-advocacy leaders in the district, and families that informed and influenced the planning and creation of many materials and resources found on their website.

The Massachusetts Department of Developmental Services (DDS): Massachusetts Partnership for Transition to Employment

The Massachusetts Partnership for Transition to Employment (MPTE) was a systems-change project of the Massachusetts Department of Developmental Services. The project was designed to improve employment outcomes for people with DD transitioning from school to adult life. The broad-based MPTE Consortium guided and supported the goals and objectives of MPTE across MPTE's 4 focus areas, which research has shown are critical to the transition process:

1. *Cross Systems Collaboration;*
2. *Work Experiences;*
3. *Family Engagement;* and
4. *Self-Determination and Self-Advocacy.*

Hawaii Jobs Now Partnership

The University of Hawaii's Jobs Now Partnership (JNP) aimed to develop policies and practices that removed barriers, reduced funding redundancies, and improved the transition to competitive employment for youth and young adults with DD. Over the course of the grant, JNP identified and implemented effective policies and practices locally and nationally, using a Community of Practice (COP) approach to involve stakeholders in shaping a new framework. The project also piloted multi-agency, career-pathway services, developed training materials on person-centered planning, and provided staff training across agencies. The approach was refined based on feedback and outcomes, and a sustainable plan was developed to address structural, financial, and functional barriers to employment for this population.

Utah School to Work Interagency Transition Initiative

Utah's grant implemented the Utah School to Work Initiative, which aimed to ensure transition-age youth (ages 14-22) with DD (including those with the most significant disabilities) are engaged in competitive, integrated employment across the entire state. The project worked with school districts and directly with schools on implementing necessary changes in service delivery to improve employment outcomes for youth with disabilities.

Yes! Center

The YES! Center is a national training and technical assistance center that serves as a central source of information, expertise, and comprehensive support for the PIE state projects. The YES! Center works closely with PIE states to develop customized plans for each state to ensure improved employment outcomes, working toward the goal to improve competitive, integrated employment outcomes for transition-aged youth and young adults with DD.

Quality Community Living - Project Living Well

Project Living Well began in fiscal year 2017 in Georgia, New Hampshire, and Virginia. The following year, the project expanded across the nation through grants to Alaska, Idaho, Indiana, Missouri, and Wisconsin. Project Living Well tested model approaches for enhancing the quality, effectiveness, and monitoring of HCBS for people with DD. Successful models will be replicated and distributed throughout the country. Across the projects, programs prioritized support and development of self-advocates through a train-the-trainer model for capacity building, the incorporation of evidence-based practices, data collection and review, and career enhancement for direct support workers.

The grants sought to strengthen HCBS systems and promote the health, safety, independence, and participation of people with disabilities. Grantees worked with a broad coalition of state stakeholders to:

- Support professionals working directly with people with disabilities;
- Promote the leadership of self-advocates and families;
- Promote the use of evidence-based and promising practices such as supportive decision making, person-centered planning, and competitive integrated employment;
- Address abuse and rights violations in the HCBS delivery system; and
- Increase the capacity of states to provide HCBS in integrated settings.

Resources Centers

National Resource Center for Supported Decision-Making

A PNS grant created the National Resource Center for Supported Decision-Making, a training, technical assistance, and resource center that documents and disseminates successful supported decision-making practices while researching to fill data and information gaps. The center develops training materials and provides technical assistance to networks and is developing strategies that measure and demonstrate the impact of supported decision-making

on the lives of people with DD. The National Resource Center for Supported Decision-Making also funded small-grants demonstration programs with community organizations. The resource center launched a website as a “one-stop” location for diverse stakeholders, including older adults, people with DD, families, guardians, advocates, researchers, practitioners, members of the legal community, and policymakers.

Several state organizations were awarded grants through the resource center to review guardianship policy and procedures. These grantees developed innovative methods to increase knowledge of, access to, and implementation of, supported decision-making. Recipients included: Delaware Developmental Disabilities Council, The Arc of Indiana, Disability Rights Maine, First in Families of North Carolina, Wisconsin Board for People with Developmental Disabilities, the Northern Florida Office of Public Guardian, the University of Georgia, Disability Rights Maine, the Second Judicial District Court in Nevada, the Brookdale Center for Healthy Aging of Hunter College, and The Arc of Tennessee.

Through their website, <http://www.supporteddecisionmaking.org/>, the center houses resource and research libraries. Their collection of webinars and presentations to support education include examples from each state and connections to local resources for more information.

Business Acumen Center

The Home and Community-Based Services Business Acumen Center (BAC) was funded to equip community-based organizations with business resources and information and training to promote sustainability in a changing environment. These tools supported the development of business relationships between community-based organizations and health plans, integrated health care entities, and other payers to produce positive outcomes for people with disabilities.

BAC and its partners developed a toolkit to prepare community-based organizations to contract with integrated health care entities to help expand the ways they do business. Other grant highlights include:

- Hosting 25 webinars attended by nearly 4,000 participants. Each presentation, audio recording, and transcript from the webinars can be found in a webinar archive.
- Maintaining the HCBS Business Acumen Center website that stores all the resources and information from the Business Acumen for Disability Organizations grant.
- Issuing two reports that connect disability-focused CBOs and integrated care entities: *“What Health Plans Need to Know About You”* and *“The Essential Roles of Disability Community-Based Organizations in an Integrated Care Program”* and publishing five spotlight reports on promising practices.
- Conducting 35 conference presentations; and

- Managing two separate learning collaboratives, one focused on state-specific issues related to the development of disability-focused CBOs and one focused specifically on business development activities in CBOs were facilitated.

Self-Advocacy Resource and Technical Assistance Center (SARTAC)

SARTAC is part of an ongoing effort to amplify voices of self-advocates that are often missing from key conversations. The mission of SARTAC is to strengthen the self-advocacy movement by supporting self-advocacy organizations to grow in diversity and leadership. Grant activities during the reporting period include:

- Compiling resources, best practices, training curriculum, and success stories for an online clearinghouse accessible to the public.
- Researching the history of the self-advocacy and other civil rights movements to understand their evolution, leadership, and best practices to produce a report and webinar on the findings.
- Providing training and technical assistance to new entities in addition to the more than 1,000 self-advocacy organizations established across the nation for advising, building consensus, recruiting youth, supporting grant writing, developing leaders, and more.
- Providing mini grants to disability organizations for disability fellowships that offer leadership development and employment opportunities for fellows.

Diversity

Community of Practice on Cultural and Linguistic Competence in Developmental Disabilities

The goal of the COP on Cultural and Linguistic Competence in DD was to increase the number, diversity, and capacity of formal and informal leaders to transform their state/territorial DD systems by: (1) advancing and sustaining cultural and linguistic competence (CLC) systemically through changes in values, policy, structures, and practices; and (2) responding effectively to the growing cultural and linguistic diversity among people with DD and their families who reside in states, territories, and tribal nations.

Under a five-year (2014–19) grant, the Diversity Leadership Institute was established. The Institute included underserved people from racial and ethnic minority groups, people with disabilities, and people from other socially, culturally, economically, or educationally disadvantaged backgrounds. It promoted the training and development of selected candidates who were in leadership positions or who demonstrated an interest in leadership roles within the DD Network or programs concerned with people with DD.

The Institute conducted an annual Leadership Academy with at least 30 participants who were engaged in an intensive course of study comprised of two-and-a-half months of preparatory activities and a three-and-a-half-day learning experience. Participants were guided through an array of learning opportunities designed for multiple learning styles. Upon successful

completion of the Academy, participants continued learning in their home environment supplemented by coaching for up to one year by the Leadership Institute staff.

Technical Assistance for DD Network Programs

Councils, UCEDDs, and P&As each have dedicated technical assistance programs to support them in maintaining standards of operation, meeting outcomes, and adapting to network wide updates and changes. A combination of funded programs and existing resource centers aid grantees in:

- Building capacity through increased training and supports aimed toward increased productivity and efficacy.
- Facilitating overcoming obstacles that cross state lines in scope and responsibility.
- Updating grantees in cultural and procedural changes in real-time within the work schedule available to them.
- Ensuring the adoption of administrative processes, data collection, optimal use of technological tools.
- Promoting promising practices and providing expertise on emerging matters.

By supporting grantees to operate at optimal levels, ACL ensures that people with DD have the greatest opportunities for success and the pursuit of full lives in the community.

DD Network Technical Assistance Resources

Councils

Through a contract with ACL, the Information and Technical Assistance Center for Councils on Developmental Disabilities (ITACC) provided technical assistance to the national network of Councils. ITACC provided targeted technical assistance to meet the specific need of each Council request and may include on-site assistance or training if requested. High-quality training on broader topics was provided through webinars and teleconferences.

ITACC held several in-person events including an annual two-day Technical Assistance Institute (TAI) designed to increase and enhance the skills and knowledge of Council members and staff. Webinars and resource materials from this event were made available on the ITACC website. An Executive Director Orientation was held to support Directors new to their role and a Council Chairperson Leadership Meeting held biennially to support Council members serving in the leadership role of Chair.

Along with TAI and other conference material, ITACC provided information to Councils about topics that improve Council operations, performance, and outcomes. ITACC hosted a listserv for people to post questions, share information and network.

The ITACC implemented a rapid response system designed to provide Council members, staff, and Executive Directors access to information, technical assistance, and training resources quickly. ITACC staff responded within 48 hours of receiving the request. All rapid response requests were tracked to determine emerging trends. ITACC staff provided teleconference opportunities on issues that were of importance to Council members, staff, and Executive Directors.

A sample of resource materials and webinars that were featured in fiscal years 2017 and 2018 include:

- Enhancing Council Program Opportunities and Improving Fiscal Accountability;
- Reporting, Advocacy, Diversity (resource);
- Frameworks for Achieving Cultural & Linguistic Competence in Councils (resource);
- Tools for the Trade: Resources for Engaging Diverse Members and Communities;
- CLC Starts with ME! Getting Started and Moving Onward with Cultural & Linguistic Competence (resource);
- Advancing Cultural & Linguistic Competence: Where is your Council on the Journey;
- Developing a Language Assistance and Implementation Plan What Councils Should Know (webinar);
- What is Linguistic Cultural Competence and What does it Mean for Developmental Disabilities Councils (webinar);
- Cultural and Linguistic Competence: Definitions, Frameworks, and Implications for Councils (webinar); and
- Culturally and Linguistically Competent Strategies to Engage Diverse Communities (webinar).

P&As

Through an interagency agreement, ACL; the Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, HHS; and the Rehabilitation Services Administration, Office of Special Education and Rehabilitation Services, U.S. Department of Education funded training and technical assistance to P&As through the Training and Advocacy Support Center (TASC).

TASC designed training and technical assistance that provided fundamental skills and knowledge proven to effectively address the specialized and highly complex legal advocacy activities and cases undertaken by the P&As. Complementing training and technical assistance, annual conferences were held to learn new skills and strategies and continuing education lectures. In addition, an annual meeting for fiscal managers was held to address fiscal management issues by providing training and information on cost allocation, budgeting, audits, reporting, and managing the fiscal office.

TASC provides targeted, on-site training and technical assistance based on needs assessments, requests from P&As, and themes uncovered by TASC. For instance, when a governing board was out of compliance, targeted technical assistance was provided to the board chair, members, and executive director to assist with building capacity to meet the statutory requirements. Regular webinars on various topics, such as abuse and neglect, were provided by TASC that offered an opportunity for P&As to share their experiences on such topics.

TASC staff provides rapid response on legal and operational matters to P&As. P&As have noted the responsiveness of the TASC staff to meet those needs. A sample of resource materials and webinars that were featured in fiscal years 2017 and 2018 include:

- Medicaid and Health Services in Schools;
- State and Local Fire, Safety, and Zoning Requirements that may be Barriers to Creating Community-based Residential Settings;
- Update on Private Enforcement of the Medicaid Act: The Supremacy Clause and 42 U.S.C. § 1983;
- Using Achieving a Better Life Experience (ABLE) Accounts to Save Money to Support Independence, Employment and Pay for Assistive Technology;
- Designing an Informed Choice Process in Olmstead Litigation;
- Every Student Succeeds Act: Advocacy Opportunities for Students with Disabilities;
- Freedom of Choice in Section 1915(c) Waivers;
- Is this a Protection and Advocacy for Assistive Technology (PAAT) Case? Becoming Familiar with the Definitions of AT Devices and AT Services;
- Status of Implementation of the Lane v. Brown Settlement Agreement to Increase Integrated Employment; and
- A series of webinars titled *Using Communication to Support P&A Litigation*, *Clarifying P&A Access*, *Expanding your PAAT Practice*, and *Diversity, Equity, and Inclusion in Your Hiring Process*.

UCEDDs

Technical assistance to UCEDDs is provided by the UCEDD Resource Center (URC). In 2017 and 2018 URC responded to 357 requests for information and assistance; developed 12 unique products in response to emerging TA needs as well as disseminated seven recurring products on a weekly, semi-weekly, and monthly basis; supported 49 collaborations; and hosted 15 TA events.

The annual Directors' Retreat and TA Institute sustained and facilitated the growth of the network and worked to enhance and build upon ongoing work within the UCEDDs. The 2018 event was held at Gallaudet University and a high percentage of attendees were satisfied with the TA received.

Throughout 2018, every UCEDD received some form of Technical Assistance. Requests for information had an average turnaround time of one business day. Critical or urgent issues were responded to within hours with information and resources. In evaluating the effectiveness of TA services, the global TA survey showed that 97 percent of respondents felt the TA received helped them perform their roles better. And, that 94 percent were satisfied with the technical assistance received.

A sample of resource materials and webinars that were featured in fiscal years 2017 and 2018 include:

- Tip Sheet: UCEDD Grants Management: Negotiating UCEDD-University Agreements;
- Tip Sheet: Carryover Requests and No-Cost Extensions;
- UCEDD Messaging Tool and UCEDD Elevator Speech;
- Tip Sheet: Continuing Education for UCEDDs;
- Tip Sheet: Interdisciplinary Pre-Service Preparation for UCEDDs without a LEND or Training Grant;
- Equity, Diversity & Inclusion Action Plan
- URC TA Evaluation Design Report;
- Screening and Linkage to Services for Autism (SaLSA): Study of Patient Navigation for Low Income Families (webinar);
- Emerging Populations: Challenges for the Early Childhood System (webinar);
- Early Intervention and Preschool Child Outcomes Evaluation: A Closer Look (webinar);
- Best Practices in Accessibility for Training and Dissemination (webinar);
- Interdisciplinary Pre-Service Preparation for UCEDDs without a LEND or Training Grant (webinar);
- An Introduction to Embedding Cultural Diversity and Cultural and Linguistic Competence: A Guide for UCEDD Curricula and Training Activities (webinar);
- Considerations for Cultural and Linguistic Differences in Community Education and Information Dissemination; and
- Early Childhood Inclusion: Peer Competence as a Core Element.

Data Tables

Biennial Report to the President, Congress, and the National Council on Disability
on the Developmental Disabilities Assistance and Bill of Rights Act
Fiscal Years 2017 and 2018

Administration on Disabilities
Administration for Community Living

Protection of Rights for People with Disabilities – Data Tables¹⁰

The following tables provide details on the individual and group activities P&As undertook during FY 2017 and 2018.

Table 6: Investigations of Abuse and Neglect	2017	2018	Total
Investigations (not death related)	1,492	1,546	3,038
Investigations of abuse and neglect completed with a finding or determination (not including death investigation)	931	1,073	2,004
Death investigations	327	501	828
Death investigations completed with a finding or determination	187	297	484
People with disabilities who benefitted from the findings of investigations abuse and neglect	252,149 ¹¹	50,954	303,103
Provisions in policy added or prevented	104	102	206

Table 7: Types of Facilities Monitored	2017		2018		Total	
	n	%	n	%	n	%
Community Residential Home for Adults	132	20.0	226	25.1	358	22.9
Community Residential Home for Children and Youth (0-18 Years)	79	12.0	15	1.7	94	6.0
Foster Care	1	0.2	1	0.1	2	0.1
Homeless	1	0.2	4	0.4	5	0.3
Independent	4	0.6	15	1.7	19	1.2
Intermediate Care Facilities	167	25.3	160	17.8	327	20.9
Jail	8	1.2	20	2.2	28	1.8
Non-Medical Community Base Residential Facility for Children and Youth	26	3.9	32	3.6	58	3.7
Not Applicable - Intervention not focused on a particular living facility	44	6.7	144	16.0	188	12.0
Nursing Homes, Including Skilled Nursing Facilities (SNF)	35	5.3	70	7.8	105	6.7
Other Federal Facility	-	0.0	9	1.0	9	0.6
Parental or Other Family Home	-	0.0	8	0.9	8	0.5
Private Institutional Living Arrangement	39	5.9	48	5.3	87	5.6
Psychiatric Wards (Public or Private)	24	3.6	39	4.3	63	4.0
Public And Private General Hospitals including Emergency Rooms	2	0.3	6	0.7	8	0.5
Public Institutional Living Arrangement	59	8.9	60	6.7	119	7.6
State Prison	40	6.1	44	4.9	84	5.4
Total	661	100.0	901	100.0	1,562	100.0

¹⁰ Due to rounding, all percentages in tables do not sum to 100 percent.

¹¹2017 was the first year this data was being collected. Therefore, the number reported was high. After receiving TA, the grantees were more accurate with the data.

Table 8: Rights-Based Individual Advocacy Services	2017	2018	Total
People with disabilities who had their rights enforced and/or restored	7,020	6,838	13,858
People with disabilities who were assisted in obtaining access to administration or judicial processes	701	638	1,339
Closed cases in which client objective was met or partially met	7,485	7,354	14,839

Table 9: Intervention Strategies Used in Serving Individuals	2017		2018		Total	
	n	%	n	%	n	%
Self-Advocacy Assistance	10,696	55.6	5,380	55.2	16,076	55.5
Limited Advocacy	3,984	20.7	2,037	20.9	6,021	20.8
Administrative Remedies	1,134	5.9	580	6.0	1,714	5.9
Negotiation	2,338	12.1	1,178	12.1	3,516	12.1
Mediation/Alternative Dispute Resolution	326	1.7	165	1.7	491	1.7
Litigation	792	4.1	407	4.2	1,199	4.1
Total Individual Advocacy	19,253		9,738		28,991	
Individual Investigation	2,464		1,246		3,710	
Total	21,717	100.1	10,984	100.1	32,701	100.1

Table 10: Reasons for Closing Individual's Case Files - Individual Advocacy Case Files	2017		2018		Total	
	n	%	n	%	n	%
Number of Closed Cases in which Client's Objective Was Partially or Fully Met	8,068	78.0	7790	79.3	15858	78.6
Other Representation Found	318	3.1	189	1.9	507	2.5
Individual Withdrew Complaint	632	6.1	594	6.0	1226	6.1
Services Were Not Needed Due to Client's Death or Relocation	107	1.0	106	1.1	213	1.1
P&A Withdrew Because Individual or Client Would Not Cooperate	399	3.9	367	3.7	766	3.8
Individual's Case Lacked Merit	526	5.1	456	4.6	982	4.9
Individual's Issue Not Favorably Resolved	217	2.1	239	2.4	456	2.3
Appeal(s) Unsuccessful	76	0.7	82	0.8	158	0.8
Total	10,343	100.0	9823	100.0	20166	100.0

Table 11: Reasons for Closing Individual's Case Files - Individual Investigation Files	2017		2018		Total	
	n	%	n	%	n	%
Complaint was withdrawn	25	2.0	33	3.1	58	2.5
Other appropriate entity investigating	48	3.8	21	2.0	69	3.0
P&A withdrew because individual or client would not cooperate	18	1.4	28	2.7	46	2.0

Investigation completed	1,166	92.8	968	92.2	2134	92.5
Total	1,257	100.0	1,050	100.0	2307	100.0

Table 12: Analysis of Group Advocacy Efforts	2017	2018	Total
Group advocacy case	1,623	1,774	3,397
Number of people potentially impacted by group cases	13,345,949	14,368,797	27,714,746
Group Advocacy Cases Targeting Racial/Ethnic Minority	335	330	665

Table 13: Intervention Strategies Used in Group Cases/Projects	2017		2018		Total	
	n	%	n	%	n	%
Abuse and Neglect Investigation	334	20.8	418.0	23.9	752.0	22.4
Systemic Litigation	124	7.7	141.0	8.1	265.0	7.9
Educating Policymakers	420	26.2	396.0	22.6	816.0	24.3
Other systemic Advocacy	727	45.3	795.0	45.4	1522.0	45.4
Total	1,605	100.0	1750.0	100.0	3355.0	100.0

UCEDD Services Provided - Tables

Table14: Information Dissemination Products	2017		2018		Total	
	n	%	n	%	n	%
Audio Visuals	261	3.4	177	2.2	438	2.8
Books	42	0.5	44	0.5	86	0.5
Book Chapters	191	2.5	185	2.3	376	2.4
Doctoral Dissertations	31	0.4	39	0.5	70	0.4
Distance Learning Module	174	2.3	134	1.6	308	1.9
Electronic Media	162	2.1	186	2.3	348	2.2
News Release	339	4.4	405	4.9	744	4.7
Public Announcement	711	9.2	903	11.0	1,614	10.1
Press communication	262	3.4	248	3.0	510	3.2
Posters	2,349	30.5	2,500	30.4	4,849	30.5
Peer Reviewed Publications	428	5.6	470	5.7	898	5.6
Review Journals	1,038	13.5	921	11.2	1,959	12.3
Review Journals-Scientific	335	4.3	334	4.1	669	4.2
Web Based Products	1,074	13.9	1,207	14.7	2,281	14.3
Other	308	4.0	463	5.6	771	4.8
Total	7,705	100.0	8,216	100.0	15,921	100.0

Table 15: UCEDD Participants in Continuing Education Programs by Area of Emphasis	2017		2018		Total	
	n	%	n	%	n	%

Childcare	2,131	1.1	7,986	3.6	10,117	2.4
Education	80,075	40.8	60,165	27.4	140,240	33.7
Employment	24,879	12.7	32,635	14.8	57,514	13.8
Health	47,745	24.3	55,836	25.4	103,581	24.9
Housing	39	0.0	80	0.0	119	0.0
Quality Assurance	11,417	5.8	12,826	5.8	24,243	5.8
Quality of Life	6,925	3.5	11,006	5.0	17,931	4.3
Recreation	683	0.3	50	0.0	733	0.2
Transportation	30	0.0	130	0.1	160	0.0
Other	11,545	5.9	24,439	11.1	35,984	8.6
Other - Assistive Technology	8,862	4.5	6,894	3.1	15,756	3.8
Other - Cultural Diversity	1,196	0.6	6,508	3.0	7,704	1.9
Other – Leadership	689	0.4	1,400	0.6	2,089	0.5
Total	196,216	100.0	219,955	100.0	416,171	100.0

Table 16: Continuing Education Events	2017	2018	Totals
Number of continuing education events	2,628	2,119	4,747
Total Duration (hours)	54,242	43,873	98,115
Reporting on Increase in Knowledge Gained			
Strongly Agree	25,604	20,249	45,853
	58%	65%	61%
Agree	15,851	9,381	25,232
	36%	30%	33%
Disagree	707	368	1,075
	2%	1%	1%
Strongly Disagree	439	269	708
	1%	1%	1%
Total Responses	44,410	31,240	75,650
	91%	83%	88%
Total Surveys Sent	48,536	37,559	86,095

Table 17: Participants in Community Training Programs by Areas of Emphasis	2017		2018		Total	
	n	%	n	%	n	%
Childcare	46,777	11.1	13,130	1.7	59,907	4.9
Education	100,034	23.7	88,216	11.1	188,250	15.5
Employment	33,153	7.9	25,528	3.2	58,681	4.8
Health	91,660	21.7	106,590	13.4	198,250	16.3
Housing	1,479	0.4	1,329	0.2	2,808	0.2
Quality Assurance	16,356	3.9	28,162	3.5	44,518	3.7
Quality of Life	29,891	7.1	29,424	3.7	59,315	4.9

Recreation	1,751	0.4	2,924	0.4	4,675	0.4
Transportation	298	0.1	332	0.0	630	0.1
Other	48,011	11.4	449,013	56.5	497,024	40.8
Other - Assistive Technology	29,471	7.0	21,690	2.7	51,161	4.2
Other - Cultural Diversity	13,868	3.3	19,993	2.5	33,861	2.8
Other – Leadership	9,308	2.2	8,360	1.1	17,668	1.5
Total	422,057	100.0	794,691	100.0	1,216,748	100.0

Table 18: Continuing Training Events	2017	2018	Total
Number of continuing training events	5,986	4,199	10,185
Total Duration (hours)	63,214	48,103	111,317
Training Participants Reporting on Increase in Knowledge Gained			
Strongly Agree	39,071	19,881	58,952
	65%	67%	66%
Agree	15,459	8,189	23,648
	26%	28%	26%
Disagree	1,188	596	1,784
	2%	2%	2%
Strongly Disagree	455	138	593
	1%	0%	1%
Total Responses	60,077	29,503	89,580
	57%	77%	62%
Total Surveys	106,290	38,339	144,629

Table 19: Participants in Demonstration Services Provided by Areas of Emphasis	2017		2018		Total	
	n	%	n	%	n	%
Childcare	27	0.2	27	0.1	54	0.1
Education	792	5.9	11,165	44.4	11,957	31.1
Employment	1,679	12.6	790	3.1	2,469	6.4
Health	2,996	22.5	7,025	28.0	10,021	26.1
Housing	0	0.0	1	0.0	1	0.0
QA	2,674	20.1	1,561	6.2	4,235	11.0
Quality of Life	1,119	8.4	2,603	10.4	3,722	9.7
Recreation	47	0.4	313	1.2	360	0.9
Other	72	0.5	117	0.5	189	0.5
Other - Assistive Technology	3,899	29.2	1,505	6.0	5,404	14.1
Other – Leadership	29	0.2	12	0.0	41	0.1
Total	13,334	100.0	25,119	100.0	38,453	100.0

Table 20: Participants in Model Services - Specialized Direct Services Offered by Areas of Emphasis (direct Clinical Services/Model Services)	2017		2018		Total	
	n	%	n	%	n	%
Childcare	598	0.5	27	0.0	625	0.3
Education	6,575	5.2	6,871	6.7	13,446	5.9
Employment	359	0.3	229	0.2	588	0.3
Health	107,799	85.2	85,820	83.3	193,619	84.4
Housing	1,068	0.8	150	0.1	1,218	0.5
QA	3,835	3.0	869	0.8	4,704	2.0
Quality of Life	319	0.3	3,623	3.5	3,942	1.7
Recreation	212	0.2	948	0.9	1,160	0.5
Other	2,206	1.7	2,214	2.1	4,420	1.9
Other - Assistive Technology	3,461	2.7	2,048	2.0	5,509	2.4
Other - Cultural Diversity	10	0.0	0	0.0	10	0.0
Other – Leadership	19	0.0	10	0.0	29	0.0
Total	126,461	100.0	103,055	99.8	229,516	99.9

Table 21: Participants in Interdisciplinary Preservice Trainings Program by Areas of Emphasis	2017		2018		Total	
	n	%	n	%	n	%
Childcare	59	0.1	0	0.0	59	0.0
Education	19,367	28.1	11,696	22.5	31,063	25.7
Employment	800	1.2	387	0.7	1,187	1.0
Health	27,957	40.6	25,809	49.5	53,766	44.5
Housing	274	0.4	66	0.1	340	0.3
QA	2,308	3.4	951	1.8	3,259	2.7
Quality of Life	3,070	4.5	3,261	6.3	6,331	5.2
Recreation	143	0.2	111	0.2	254	0.2
Other	1,548	2.2	1,528	2.9	3,076	2.5
Other - Assistive Technology	1,531	2.2	1,091	2.1	2,622	2.2
Other - Cultural Diversity	1,604	2.3	1,414	2.7	3,018	2.5
Other – Leadership	10,190	14.8	5,783	11.1	15,973	13.2
Total	68,851	100.0	52,097	100.0	120,948	100.0

Table 22: Participants in Other Model Services - Specialized Direct Services Offered by Areas of Emphasis	2017		2018		Total	
	n	%	n	%	n	%
Childcare	833	0.7	620	0.5	1,453	0.6
Education	17,231	15.3	11,309	10.0	28,540	12.7

Employment	5,862	5.2	6,945	6.2	12,807	5.7
Health	14,916	13.3	7,606	6.7	22,522	10.0
Housing	2,209	2.0	1,005	0.9	3,214	1.4
QA	5,202	4.6	5,370	4.8	10,572	4.7
Quality of Life	20,516	18.3	25,895	23.0	46,411	20.6
Recreation	9,467	8.4	6,051	5.4	15,518	6.9
Transportation	472	0.4	4,066	3.6	4,538	2.0
Other	8,026	7.1	12,835	11.4	20,861	9.3
Other - Assistive Technology	23,991	21.4	30,253	26.8	54,244	24.1
Other - Cultural Diversity	3,087	2.7	326	0.3	3,413	1.5
Other – Leadership	497	0.4	491	0.4	988	0.4
Total	112,309	100.0	112,772	100.0	225,081	100.0

Table 23: Participants in Research and Evaluation Activities by Areas of Emphasis	2017		2018		Total	
	n	%	n	%	n	%
Childcare	1,860	1.4	543	0.3	2,403	0.8
Education	37,867	29.2	107,694	66.2	145,561	49.8
Employment	38,322	29.6	9,929	6.1	48,251	16.5
Health	19,881	15.4	24,553	15.1	44,434	15.2
Housing	46	0.0	237	0.1	283	0.1
QA	19,709	15.2	8,257	5.1	27,966	9.6
Quality of Life	3,663	2.8	5,347	3.3	9,010	3.1
Recreation	107	0.1	23	0.0	130	0.0
Transportation	0	0.0	17	0.0	17	0.0
Other	6,310	4.9	4,737	2.9	11,047	3.8
Other - Assistive Technology	158	0.1	195	0.1	353	0.1
Other - Cultural Diversity	386	0.3	752	0.5	1,138	0.4
Other – Leadership	1,205	0.9	412	0.3	1,617	0.6
Total	129,514	100.0	162,696	100.0	292,210	100.0

Table 24: Participates in TA Programs by Areas of Emphasis	2017		2018		Total	
	n	%	n	%	n	%
Childcare	23,729	5.9	8,642	1.8	32,371	3.6
Education	125,795	31.5	170,542	34.7	296,337	33.3
Employment	24,269	6.1	27,515	5.6	51,784	5.8
Health	77,945	19.5	50,080	10.2	128,025	14.4
Housing	4,523	1.1	2,769	0.6	7,292	0.8
QA	41,084	10.3	30,125	6.1	71,209	8.0
Quality of Life	24,401	6.1	49,698	10.1	74,099	8.3
Recreation	1,081	0.3	2,601	0.5	3,682	0.4

Transportation	0	0.0	750	0.2	750	0.1
Other	20,938	5.2	27,392	5.6	48,330	5.4
Other - Assistive Technology	42,216	10.6	107,681	21.9	149,897	16.8
Other - Cultural Diversity	3,629	0.9	4,077	0.8	7,706	0.9
Other – Leadership	8,237	2.1	9,761	2.0	17,998	2.0
Total	399,501	99.6	491,633	100.0	891,134	99.8

Grant Allocations

Table 25: State Developmental Disabilities Councils Annual Allocations			
State/Territory	2017	2018	Total
Alabama	\$1,291,034	\$1,291,034	\$2,582,068
Alaska	\$486,307	\$507,546	\$993,853
Arizona	\$1,411,676	\$1,446,620	\$2,858,296
Arkansas	\$770,894	\$770,894	\$1,541,788
California	\$6,527,210	\$7,499,029	\$14,026,239
Colorado	\$880,804	\$972,924	\$1,853,728
Connecticut	\$687,124	\$713,800	\$1,400,924
Delaware	\$486,307	\$507,546	\$993,853
District of Columbia	\$486,307	\$507,546	\$993,853
Florida	\$3,655,639	\$3,787,345	\$7,442,984
Georgia	\$2,065,602	\$2,096,590	\$4,162,192
Hawaii	\$486,307	\$507,546	\$993,853
Idaho	\$486,307	\$507,546	\$993,853
Illinois	\$2,618,348	\$2,624,830	\$5,243,178
Indiana	\$1,484,870	\$1,488,546	\$2,973,416
Iowa	\$772,264	\$774,176	\$1,546,440
Kansas	\$613,072	\$614,590	\$1,227,662
Kentucky	\$1,198,210	\$1,198,210	\$2,396,420
Louisiana	\$1,372,326	\$1,375,724	\$2,748,050
Maine	\$486,307	\$507,546	\$993,853
Maryland	\$1,005,670	\$1,095,178	\$2,100,848
Massachusetts	\$1,362,510	\$1,363,306	\$2,725,816
Michigan	\$2,537,470	\$2,537,470	\$5,074,940
Minnesota	\$1,022,764	\$1,028,414	\$2,051,178
Mississippi	\$911,980	\$914,238	\$1,826,218
Missouri	\$1,364,596	\$1,364,596	\$2,729,192
Montana	\$486,307	\$507,546	\$993,853
Nebraska	\$486,307	\$507,546	\$993,853
Nevada	\$540,162	\$555,197	\$1,095,359
New Hampshire	\$486,307	\$507,546	\$993,853
New Jersey	\$1,549,484	\$1,635,456	\$3,184,940
New Mexico	\$489,030	\$508,351	\$997,381
New York	\$4,090,946	\$4,090,946	\$8,181,892
North Carolina	\$2,015,964	\$2,015,964	\$4,031,928
North Dakota	\$486,307	\$507,546	\$993,853

Table 25: State Developmental Disabilities Councils Annual Allocations			
State/Territory	2017	2018	Total
Ohio	\$2,839,690	\$2,846,720	\$5,686,410
Oklahoma	\$895,034	\$897,250	\$1,792,284
Oregon	\$779,362	\$779,362	\$1,558,724
Pennsylvania	\$3,019,046	\$3,026,520	\$6,045,566
Rhode Island	\$486,307	\$507,546	\$993,853
South Carolina	\$1,094,290	\$1,097,000	\$2,191,290
South Dakota	\$486,307	\$507,546	\$993,853
Tennessee	\$1,457,786	\$1,461,396	\$2,919,182
Texas	\$4,802,026	\$5,169,382	\$9,971,408
Utah	\$633,704	\$633,704	\$1,267,408
Vermont	\$486,307	\$507,546	\$993,853
Virginia	\$1,498,220	\$1,542,988	\$3,041,208
Washington	\$1,167,690	\$1,334,454	\$2,502,144
West Virginia	\$737,516	\$739,342	\$1,476,858
Wisconsin	\$1,308,704	\$1,308,704	\$2,617,408
Wyoming	\$486,307	\$507,546	\$993,853
American Samoa	\$253,256	\$264,316	\$517,572
Guam	\$253,256	\$264,316	\$517,572
Northern Mariana Islands	\$253,256	\$264,316	\$517,572
Puerto Rico	\$2,500,740	\$2,506,930	\$5,007,670
Virgin Islands	\$253,256	\$264,316	\$517,572
TOTAL	\$72,794,779	\$75,270,088	\$148,064,867

Table 26: Protection and Advocacy Agencies Annual Allocations			
State/Territory	2017	2018	Total
Alabama	\$581,326	\$578,212	1,159,538
Alaska	\$384,693	\$404,556	789,249
Arizona	\$693,630	\$746,747	1,440,377
Arkansas	\$393,051	\$410,767	803,818
California	\$3,368,311	\$3,730,779	7,099,090
Colorado	\$463,243	\$492,364	955,607
Connecticut	\$387,054	\$409,502	796,556
Delaware	\$384,693	\$404,556	789,249
District of Columbia	\$384,693	\$404,556	789,249
Florida	\$1,954,664	\$2,066,218	4,020,882
Georgia	\$1,054,137	\$1,110,944	2,165,081
Hawaii	\$384,693	\$404,556	789,249
Idaho	\$384,693	\$404,556	789,249
Illinois	\$1,226,808	\$1,292,508	2,519,316
Indiana	\$713,146	\$699,654	1,412,800
Iowa	\$384,693	\$404,556	789,249
Kansas	\$384,693	\$404,556	789,249
Kentucky	\$535,195	\$536,407	1,071,602
Louisiana	\$537,239	\$558,966	1,096,205
Maine	\$384,693	\$404,556	789,249
Maryland	\$487,463	\$534,545	1,022,008
Massachusetts	\$602,938	\$647,433	1,250,371
Michigan	\$1,121,176	\$1,093,387	2,214,563
Minnesota	\$502,368	\$529,282	1,031,650
Mississippi	\$409,051	\$429,754	838,805
Missouri	\$643,191	\$656,217	1,299,408
Montana	\$384,693	\$404,556	789,249
Nebraska	\$384,693	\$404,556	789,249
Nevada	\$384,693	\$404,556	789,249
New Hampshire	\$384,693	\$404,556	789,249
New Jersey	\$758,684	\$808,962	1,567,646
New Mexico	\$384,693	\$404,556	789,249
New York	\$1,801,964	\$1,923,114	3,725,078
North Carolina	\$1,062,747	\$1,091,960	2,154,707
North Dakota	\$384,693	\$404,556	789,249
Ohio	\$1,236,193	\$1,290,170	2,526,363

Table 26: Protection and Advocacy Agencies Annual Allocations			
State/Territory	2017	2018	Total
Oklahoma	\$395,264	\$417,604	812,868
Oregon	\$409,773	\$425,209	834,982
Pennsylvania	\$1,292,853	\$1,337,666	2,630,519
Rhode Island	\$384,693	\$404,556	789,249
South Carolina	\$550,926	\$554,239	1,105,165
South Dakota	\$384,693	\$404,556	789,249
Tennessee	\$705,805	\$719,167	1,424,972
Texas	\$2,463,437	\$2,703,555	5,166,992
Utah	\$384,693	\$404,556	789,249
Vermont	\$384,693	\$404,556	789,249
Virginia	\$728,405	\$788,673	1,517,078
Washington	\$640,525	\$694,618	1,335,143
West Virginia	\$384,693	\$404,556	789,249
Wisconsin	\$596,587	\$598,542	1,195,129
Wyoming	\$384,693	\$404,556	789,249
American Samoa	\$205,808	\$216,435	422,243
Guam	\$205,808	\$216,435	422,243
Northern Mariana Islands	\$205,808	\$216,435	422,243
Puerto Rico	\$805,132	\$825,982	1,631,114
Virgin Islands	\$205,808	\$216,435	422,243
Native American P&A	\$205,808	\$216,435	422,243
TOTAL	\$37,845,186	\$39,876,442	\$75,772,841

Table 27: University Centers for Excellence in Developmental Disabilities Annual Allocations			
	2017	2018	Total
Core Funding Award Amount ¹²	\$547,000 per UCEDD	\$547,000 per UCEDD	\$1,094,000 per UCEDD

¹² Core funds are distributed equally across all UCEDDs.

APPENDIX

The Protection and Advocacy for Individuals with Mental Illness (PAIMI) Program Activities Report For Fiscal Years 2017 And 2018

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INTRODUCTION

This report summarizes the annual activities for Fiscal Years (FY) 2017 and 2018 of the Protection and Advocacy for Individuals with Mental Illness (PAIMI) grantees, funded and administered by the Substance Abuse and Mental Health Services Administration (SAMHSA), Center for Mental Health Services (CMHS). 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.¹³ SAMHSA summarizes the grantee activity information and prepares a report, which includes aggregate data for the Secretary.¹⁴

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 DD.¹⁵ These entities, the state Protection & Advocacy (P&A) systems, were governor-designated and approved by the Administration on Disabilities¹⁶ (AoD), within the Administration for Community Living (ACL). The DD Act authorized formula grants to each eligible state P&A system to support activities on behalf of individuals with I/DD through the Protection and Advocacy for Developmental Disabilities (PADD) Program, administered by ACL/AoD. ACL/AoD, which oversees the first P&A program, is the lead federal agency on matters pertaining to designation or re-designation of a P&A system.

The PAIMI Act of 1986¹⁷ 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 care and treatment facilities. The same AoD-approved, governor-designated state P&A systems that received PADD Program funding were authorized to administer the PAIMI Program.

The PAIMI Act¹⁸ mandated state P&A systems to:

- 1) Protect and advocate for the rights of residents with significant mental illness (adults) and significant emotional impairments (children and youth),¹⁹ 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, or other appropriate

¹³ 42 U.S.C. 10805(a)(7)

¹⁴ PAIMI Act at 42 U.S.C. 10824

¹⁵ 42 U.S.C. 6041

¹⁶ Formerly named the Administration on Intellectual and Developmental Disabilities (AIDD)

¹⁷ 42 U.S.C. 10801 et seq.

¹⁸ 42 U.S.C. 10801(b)

¹⁹ Adults with *significant* mental illness denotes adults with *serious* mental illness. Children with *significant* emotional impairments denotes children with *severe* emotional impairments.

remedies on their behalf;

- 2) Investigate reports of abuse, particularly incidents involving serious injuries and deaths, related to the inappropriate use of seclusion and restraint; and
- 3) 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). The remaining 11 P&A systems were state or territory operated (Alabama, American Samoa, Connecticut, Indiana, Kentucky, New York, North Carolina, North Dakota, Ohio, the Commonwealths of Puerto Rico, and Virginia) and independent of any state agency that provided treatment or services, other than advocacy services, to individuals with mental illness.²⁰ However, as of September 30, 2018, there remained five state-operated P&A systems (Alabama, American Samoa, Kentucky, North Dakota, and the Commonwealth of Puerto Rico). In 2000, the PAIMI Act was amended by the Children's Health Act (CHA) of 2000.²¹ The CHA established a 57th P&A system for Native Americans, the American Indian Consortium (AIC). The AIC is composed of the Navajo Nation and Hopi tribal councils in the Four Corners region of the Southwest (Colorado, Utah, Arizona, and New Mexico).

The CHA²² requires "a 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, including 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."²³ Per CHA, "each facility 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 not later than seven days after the date of the death of the individual involved."²⁴ The CHA clarified that the state P&A systems had the authority to investigate incidents of restraint and seclusion in these types of facilities. The CHA also allowed state P&A systems to serve PAIMI-

²⁰ 42 U.S.C. 10801(b)

²¹ 42 U.S.C. 290 *et seq.*

²² 42 U.S.C. 290ii

²³ 42 U.S.C. 290ii (a)

²⁴ *op. cit.* at 42 U.S.C. 290ii - 1

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.

FUNDING

Each P&A system must submit an annual application or update its annual program priorities, proposed budget/expenditures, the PAIMI Program assurances, and any other information requested by SAMHSA.²⁵ The annual PAIMI Program awards, subject to availability of appropriations, are based on a formula prescribed by the statute.²⁶ The PAIMI 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 per capita income.²⁷ Relative per capita income is the quotient of the per capita income of the United States and the per capita income of the state. Relative per capita income is not used for American Samoa, Guam, the Commonwealth of the Northern Mariana Islands, and the U.S. Virgin Islands. Their quotient shall be considered as one.²⁸ The Secretary shall use no more than two percent of the amount appropriated, commonly known as the set-aside under the PAIMI Act, to provide technical assistance to eligible systems.²⁹

The following table reflects the total annual PAIMI Program grant appropriations, the technical assistance set-aside, and the minimum and maximum grant allotments awarded to the states and territories in FY 2017 and 2018. Based on the final allocations, California, the largest state P&A system, received the maximum state award of \$3,140,635 for FY 2017 and \$3,101,059 for FY 2018. The minimum state allotment for P&A system grants were \$428,000 for both fiscal years. Four of the five territories (American Samoa, Guam, the Commonwealth of the Northern Mariana Islands, and the U.S. Virgin Islands) and the American Indian Consortium each received \$229,300 for both fiscal years.

	FY 2017	FY 2018
To State P&A Systems	\$35,319,775	\$35,329,908
Technical Assistance Set-aside	\$706,396	\$706,598
Total Annual PAIMI Grant Funding	\$36,026,171	\$36,036,506
	FY 2017	FY 2018
Minimum State Award	\$428,000	\$428,000
Maximum State Award	\$3,140,635	\$3,101,059
Minimum Territory Award	\$229,300	\$229,300

[See Appendix - Table 1]

²⁵ 42 U.S.C. 10821

²⁶ 42 U.S.C. 10822

²⁷ 42 U.S.C. 10822 (a) (1) (A) (i) and (ii)

²⁸ 42 U.S.C. 10822 (a) (1) (B)

²⁹ 42 U.S.C. 10825

PAIMI PROGRAM ACTIVITIES

A. Demographic Information

1. Age and Sex

The following tables summarize the number of PAIMI-eligible individuals or clients served in each FY by age and sex.

Age in Years	FY 2017	FY 2018
0-4	9	7
5-12	660	520
13-18	1,420	1,367
19-25	934	744
26-64	6,738	6,206
65 and over	689	684
Total Served	10,450	9,528
Sex	FY 2017	FY 2018
Male	5,508	5,254
Female	3,833	4,243
Unknown	1,109	31
Total Served	10,450	9,528

[See Appendix - Table 2]

2. Ethnicity and Race

PAIMI clients served by the P&A systems self-identified their ethnicity and race³⁰. The following tables provide the ethnicity and racial identities reported by individuals served by the P&A systems. The information was self-reported by clients and individuals/clients served were permitted to select one or more races.

Ethnicity	FY 2017	FY 2018
Hispanic/Latino	1,021	913
Non-Hispanic/Latino	8,328	7,962
Unknown	778	473

³⁰ The total number of PAIMI eligible individuals reported by the P&A programs for the Age and Sex tables and for the Ethnicity and Race tables are not identical. There was no category to indicate an “unknown” value for the data element “race” and no “unknown” value for either “sex” or “age”, only the combination of these values. Hence any individual with an unknown “race” or an unknown “sex” or “age” would not be counted in the totals for “race”, “age” or “sex”. This lapse has been corrected for future data collection.

Race	FY 2017	FY 2018
American Indian/Alaskan Native	247	203
Asian	147	129
Black/African American	2,112	1,898
Native Hawaiian/Other Pacific Islander	108	122
White/Caucasian	6,128	6,099
Multiple Race	603	437

[See Appendix - Table 3]

3. **Living Arrangements**

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

Living Arrangement Type	FY 2017	FY 2018
Independently in the community	2,163	2,182
Adult community residential home	354	365
Psychiatric hospitals	1,546	1,802
Public and private institutional living	1,197	866
Legal detention/jail	1,613	1,256
Homeless/shelter	217	205
Total	7,090	6,676

[See Appendix - Table 4]

B. Services for 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.³¹ 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 individual abuse complaints investigated and closed per FY included:

Abuse Complaints	FY 2017	FY 2018
Cases Investigated & Closed	1,733	1,390
Inappropriate/excessive use of restraints	347	277
Inappropriate/excessive medication	143	126
Involuntary electroconvulsive therapy	2	3
Failure to provide mental health treatment	907	697
Physical assaults resulting in serious injuries	155	153

³¹ 42 U.S.C. 10805(a)(1)

Sexual assaults	77	59
Staff threats/retaliation/assaults	102	75

[See Appendix - Tables 5]

Case Examples from FY 2017

Alaska

The P&A received an anonymous complaint regarding an incarcerated 31-year-old man with schizophrenia who had been placed in an open population module in the prison, where he was physically and sexually assaulted. The P&A staff contacted the Deputy Director of Health and Rehabilitation at the Department of Corrections (DOC) and found that the inmate was already working with the Prison Rape Eliminator Act Coordinator and the Alaska State Troopers. The inmate was transferred to a different facility and was placed in a sub-acute mental health unit for his protection.

Guam

While detained in prison, a mental health client diagnosed with schizophrenia and bipolar disorder was not receiving appropriate mental health care and treatment, which included seeing a psychiatrist when needed and appropriate medication management. The P&A advocated for the client to be moved to the mental health adult inpatient unit until the client case was transferred to the mental health court system. Upon release from the court system, the client was able to receive the mental health care and treatment needed under the residential recovery program.

Hawaii

The P&A received a call from a 57-year-old client with mental illness living in Maui, who requested help with financial abuse committed against him by his daughter. The P&A advocated and investigated the complaint and found that the client's daughter used his money, but since she had financial power of attorney (POA) at the time, there was no legal recourse. As a result of the client's complaint and the P&A's advocacy efforts with his case manager, the POA was terminated, and the client secured a guardian through the Office of Public Guardian.

Case Examples from FY 2018

Arkansas

The P&A advocated and investigated an incident of reported abuse at a juvenile assessment and treatment facility, involving a 16-year old PAIMI-eligible male diagnosed with emotional disturbance; attention deficit hyperactivity disorder; bipolar disorder; and oppositional defiant disorder. The client alleged that a staff member of the facility entered the room, where he was lying on the top bunk of a bed, to transfer him to an isolation area. The client stated he refused

to move off of the top bunk, whereupon the staff member pulled him off the bunk, causing him to hit his brow on the opposite bunk. The P&A investigated the incident, which included watching videos of the event and interviewing staff. The P&A determined that the technique used to remove the client from the top bunk caused his injury. The staff member was subsequently terminated, and remaining staff members in the unit underwent retraining on de-escalation techniques.

Wyoming

The Wyoming State Hospital (WSH) strapped a pregnant PAIMI-eligible individual to a transport board that the WSH started using as a long-term mechanical supine floor restraint. The patient contacted the P&A and authorized an investigation. The P&A's investigation revealed that the patient was placed on the transport board at one time for one and a half hours. On another occasion when the client was placed on the transport board, it resulted in her not attending a scheduled ultrasound appointment. The P&A obtained and reviewed a video from WSH, which clearly showed that the patient was strapped to a transport board without prenatal medical assessments. WSH's medical records admitted that mechanical chest and abdominal restraints were medically contraindicated during pregnancy. The P&A substantiated neglect for failure to have and follow an appropriate treatment plan and abuse for improper use of a temporary transport device as a long-term mechanical restraint; and abuse for the improper supine floor restraint without medical attention. The P&A reported the findings to appropriate agencies. As a direct result of the P&A's investigation, the use of dangerous restraints ceased for this patient during the rest of her pregnancy.

2. Neglect

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

Neglect Complaints	FY 2017	FY 2018
Cases Investigated & Closed	1,626	1,277
Discharge planning	945	686
Personal care	289	242
Mental health diagnoses	153	110
Environmental safety	48	52
Personal safety	191	187

[See Appendix - Table 6]

Case Examples from FY 2017

Delaware

The P&A received numerous complaints from a 38 year-old resident at the Delaware Psychiatric Center (DPC). The complaints, rising to the level of potential abuse and neglect, included: poor maintenance and cleaning of bathroom facilities; denial of access to telephones; lack of privacy

(no shower curtain in communal bathroom); and retaliatory transfer to an inappropriate unit with elderly patients. The P&A investigated and reported neglect concerns to the facility. Regarding the telephones, the facility initiated a plan to install additional phones and to revise its policy. The P&A reported the cleanliness and shower curtain issues to the Delaware Office of Facilities Licensing, which inspected and cited the facility. As a result of the P&A's investigation, the facility developed a correction plan.

Illinois

The P&A was contacted by an elderly resident of a state-operated mental health hospital. The client alleged that the facility was failing to respond to his complaints regarding his health needs, including care for his ears, which was adversely affecting his hearing. The P&A contacted the medical director at the facility, and he agreed to have a doctor address the client's complaints right away. The client met with a doctor the next day and reported that the doctor addressed all of his medical needs.

Maine

The P&A was contacted by a 61 year-old woman with mental illness, living in a group home. She informed the P&A that she had reported being assaulted by another resident of the group home, but the staff ignored her reports. The P&A went to the group home unannounced and met with the client and reviewed records. The P&A made a determination that the group home, as a mandatory reporter of abuse, had failed in its obligation by not reporting the client's incident to state licensing. The P&A contacted state licensing. The state licensing did an immediate investigation and issued sanctions against the group home for its failure to report. The group home now has a system in place to always report resident allegations of abuse, including allegations concerning another resident. The client also wanted to move from this group home. The P&A assisted the client with finding another place, and the client successfully moved from the group home.

Case Examples from FY 2018

Alaska

The P&A was contacted by the parent of a child with Post Traumatic Stress Disorder (PTSD). The child had been denied admittance to all residential treatment facilities enrolled in the Alaska Medicaid Program. The parents were concerned that they could not cover the financial cost associated with the child's residential treatment, nor could they bring home their child due to the safety risk he posed to other children in their home. The family requested that the P&A assist them with appealing the Medicaid denial to pay for their child's treatment. The P&A advised the parents to request a meeting with the Division of Behavioral Health out-of-state placement team for a clinical review of the child's medical records and residential facilities that were capable of providing the appropriate intensive behavioral supports the child needed. This meeting resulted in the child's acceptance to a residential treatment facility in the State of

Utah. The P&A was able to contest a Medicaid denial of benefits and ultimately get the child into appropriate treatment.

District of Columbia

The P&A represented a 36 year-old man with serious mental illness who was born in Sierra Leone and has lived in the United States since childhood. The client's immigration attorney contacted the P&A because he was connected to a mental health core service agency (CSA) but was not receiving any services. The P&A was initially told by CSA that the client was not receiving services because he did not have active health insurance. When the P&A complained that he was not receiving services, the CSA agreed to assign a case worker and to provide some services. When the client ran out of medication, the P&A worked with a free-standing mental health clinic to provide the medications, with no assistance from his CSA. The P&A also provided information to his CSA about his eligibility for benefits. Since the client was granted asylum status, he was eligible for health insurance, but his CSA was not aware of it. The P&A worked with the client and his immigration attorney to apply for the Assertive Community Treatment (ACT) services from a different agency, one which uses a housing first model. The client was accepted by the ACT team, which assisted him with medication management and housing search.

Illinois

The P&A represented a man with anxiety disorder, residing at a high security mental health center, who was placed in the facility after being found not guilty by reason of insanity. He was concerned that he missed getting his medications every time he had to go to court. The P&A viewed this issue as neglect and wrote a demand letter. The facility administrator quickly responded and agreed that there were failures in care relating to medication for court trips. In response, the administrator ensured that the facility made policy revisions and also trained staff on these policies. Subsequently, the client reported that he was getting his medications on the days that he was going to court.

Maryland

The P&A investigated a complaint on behalf of a youth with mental illness and Asperger's disorder, who was a resident at a Residential Treatment Center (RTC). The youth was 17 years old and had completed high school. Because he had completed his schooling, the RTC would not permit him to attend school classes during the day. Consequently, while other residents were at school, the client sat in his unit for hours at a time, with virtually no activities or structured programming. He felt that his rights were being violated, due to a lack of meaningful programming and activities that he could access. The P&A advocated for the youth (and future students who may find themselves similarly situated) by bringing this issue to the attention of RTC's leadership and advocating for changes and increased programming. The P&A was able to substantiate that the youth was, in fact, spending much of his day without anything to do. Prior to the resolution of this case, the youth was discharged and is now doing well at a therapeutic

group home. The P&A continued to advocate for changes surrounding this issue. As a result, RTC's leadership informed the P&A that they would be implementing a new, more robust vocational program to offer to future students who find themselves similarly situated.

3. **Rights Violations**

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

Rights Violations	FY 2017	FY 2018
Cases Investigated & Closed	537	589
No written treatment plan	185	233
Guardianship/conservator problems	247	234
Problems with advanced directives	78	86
Failure to provide confidentiality	27	36

[See Appendix - Table 7]

Case Examples from FY 2017

Illinois

The P&A assisted a female nursing home resident with major depressive disorder, who was experiencing rights violations regarding privacy rights and right to community passes. The woman had an upcoming care plan meeting and wanted the P&A's advice on how to advocate for herself with respect to those rights violations. First, with respect to the privacy concern, the nursing home was only allowing her to meet with visitors in the lobby. The P&A advised her of her right to meet with visitors in private. At the care plan meeting, the woman provided the information about her privacy rights, and the nursing home has now allowed her to meet with visitors in her room. In addition, her community pass privileges were revoked after the nursing home claimed that she tested positive for alcohol when she returned from a weekend visit. The woman advised the P&A that this couldn't be true because she had not consumed any alcohol for over a year. The P&A advised her that she had a right to see the test results. The woman made a request for the test results at the care plan meeting. Upon making that request, the facility restored her community pass privileges.

Kansas

The P&A received a call from a young woman with severe mental illness, including anxiety, depression, and bipolar disorder. She contacted the P&A because she was unhappy with her guardian and felt that she no longer needed one. In the past, the young woman had been institutionalized and was periodically unstable. The P&A worked with the young woman to show that she was able to take care of herself for several months and had been compliant with medications and therapy. After an evaluation, her therapist was able to report how well the young woman was doing and that she no longer needed a guardian. The P&A filed a petition to

terminate the young woman's guardianship with the court. The court granted the motion, and the guardianship was ended.

Rhode Island

The P&A represented a woman regarding a Petition for Guardianship that had been filed by a family member, based upon a Decision-Making Assessment Tool (DMAT) prepared by her former physician at the facility where she resides. The P&A prepared a Motion to Dismiss, but were able to successfully negotiate with the petitioner's counsel that the matter be dismissed, as the client had executed a Durable Power of Attorney for Healthcare, which is an alternative to guardianship. Rhode Island law requires that alternatives to guardianship be ruled out before a Petition for Guardianship is filed. In addition, due to the DMAT being prepared by her former physician at the facility, the P&A offered to provide training for patients and their families and staff regarding alternatives to guardianship. The offer was accepted, and the P&A provided two trainings on alternatives to guardianship at the facility during FY 2017.

Case Examples from FY 2018

Arizona

The P&A provided rights violation assistance in the case of a 17-year-old individual who was diagnosed with severe depression at the age of 12 years. The individual's mother contacted the P&A for assistance after the individual had been inpatient at a behavioral health treatment facility for approximately four weeks. The individual's mother alleged that the inpatient behavioral health facility denied the individual's right to appropriate discharge planning, when the facility disregarded the family's request for what they thought was a more appropriate placement. The individual's mother also alleged that the inpatient behavioral health facility had violated the individual's privacy rights. The P&A provided the individual's mother with rights information regarding the individual's right to appeal the failure of the inpatient behavioral health facility to provide adequate discharge planning. The P&A also provided the individual's mother with information on how to file a Health Insurance Portability and Accountability Act (HIPAA) of 1996 privacy complaint. The individual's mother was able to advocate for the individual after receiving this information from the P&A.

Iowa

The P&A was contacted by a 33-year-old transgender female diagnosed with bipolar disorder. The client's mother was her guardian and conservator, and she contacted the P&A alleging that her guardian was being overly restrictive and intended to prevent her from transitioning. The client requested assistance terminating the guardianship and conservatorship. The P&A met with the client, obtained, and reviewed records, and interviewed the guardian. Following discussion with the P&A, the guardian conceded that the guardianship and conservatorship were no longer necessary, and asked the court to terminate them both, which it did. As a result, the client's rights were restored.

Minnesota

The P&A was contacted by a 61-year-old PAIMI-eligible man, indeterminately committed to the state's forensic mental hospital for individuals with severe mental illness who are considered dangerous. The client stated that he was unable to have legal telephone calls with his court appointed civil commitment attorney in a private area away from hospital staff and other patients. The P&A contacted the hospital administration and outlined the practical necessity and legal rights of the patient to have private phone calls. As a result of the P&A's advocacy, the hospital program director reviewed the complaint, and agreed with the P&A's analysis. The client was provided a confidential area to make calls and confirmed that he is now able to complete his telephone calls in private. Although the individual's rights violations have been resolved, during the current federal fiscal year, the P&A staff is following up with the hospital to ensure that this protocol is consistently available to other patients as well.

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.³² Most states had no mandatory reporting statutes, central registries, or other statewide systems to capture incidents of restraint, seclusion, serious injuries, 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 review the information to determine incidents requiring investigation. Deaths reported by states and CMS, and investigated by state P&A systems and other sources were as follows:

Death Reported by	FY 2017	FY 2018
States	1,087	786
CMS	1	1
Other	164	187
Deaths Reported Total	1,252	974

Deaths Investigated, by incident type	FY 2017	FY 2018
Seclusion (S)	6	14
Restraints (R)	8	9
Non S or R related	261	250
Deaths Investigated Total	275	273

[See Appendix - Table 8]

³² at 42 U.S.C. 10802 (1), (3), (4), and (5)

Case Examples from FY 2017

Alaska

The P&A received a media report alleging an inmate attempted suicide while incarcerated, and subsequently died. Based on the complaint, the P&A initiated a secondary investigation and found that the inmate's suicide was due to DOC's negligent inaction in response to the inmate's suicidality. The P&A requested an expert consultant to review the records and provide recommendations on what should have been done in response to the inmate's suicidality, and recommended changes to the current DOC Suicide Prevention policy and procedure.

Florida

The P&A investigated the death of an adult male with psychiatric disabilities, at a state prison. The deceased had a history of major depressive disorder and had a long history of self-injurious behavior. He was being treated in the prison system's equivalent of a crisis stabilization unit. Prior to his death, the deceased had several incidents of suicidal ideation and attempts. Although he made these attempts and wrote a suicide letter, staff at the facility were skeptical regarding the threat, believing that he was exaggerating and seeking attention. On the day of the deceased's death, he attempted to hang himself. Staff intervened approximately forty minutes later. Staff applied handcuffs, leg irons, and a spit guard and placed the client in an observation cell. Unfortunately, he was found to be unresponsive 20 minutes later and was pronounced dead at the hospital. The P&A discovered this death during routine monitoring of the conditions at the various state prison mental health treatment facilities. The deceased was one of several deaths that were determined to be suspicious and warranted further investigation. The P&A's investigation consisted of a review of all mental health, medical, and classification files, in addition to interviewing prison staff, other inmates, and reviewing the autopsy findings. This death, in addition to others, prompted the P&A to hire three prison mental health experts to review the findings and participate in monitoring visits to the prisons. Ultimately, the P&A presented these findings to DOC and are now in mediation to develop an agreement that will improve care and conditions throughout the prison systems in the State of Florida.

Montana

The P&A was contacted about a 15-year-old male with bipolar disorder, who was placed by his family at a Montana adolescent rehabilitation program, essentially an "outdoor wilderness school," where he was left unsupervised long enough for him to commit suicide by hanging. The P&A is now establishing communication with the state regulatory board governing these facilities, to ensure that they are enforcing regulatory compliance, to protect youth with mental illness from abuse and neglect in "wilderness schools."

Case Examples from FY 2018

District of Columbia

The P&A investigated an unexpected, sudden death of a woman in her thirties, due to an intracranial bleed while she was a patient at St. Elizabeth's Hospital. The P&A's extensive review of the medical records and the facility's own investigation report exposed multiple instances of serious nursing and medical neglect. The P&A produced a report entitled "A Patient's Suffering and Death at St. Elizabeth's Hospital." Among the recommendations in the report, the P&A requested that the Department of Behavioral Health (DBH) and the Department of Health develop a plan to ensure that medical and nursing personnel at St. Elizabeth's Hospital are adequately trained and have the requisite skills to address the patients' needs.

New Jersey

The P&A reviewed the death of a 49-year-old patient at a private general hospital, who was admitted for abdominal pain and received surgery for an abdominal hernia. While in the hospital, the patient was transferred to the psychiatric unit for psychiatric stabilization. While on the psychiatric unit, the patient became aggressive toward other patients. The patient was medicated by injection and appeared to be calming down. When staff attempted to place the patient in a seclusion room, she threw chairs across the room. The patient fought staff who were attempting to physically restrain her until mechanical restraints arrived. A towel was placed over her face to prevent the patient from spitting on hospital staff. The patient's legs and one arm were placed in the restraints, when it was noted that she was unresponsive. Emergency life support procedures were initiated, but she did not respond, and was pronounced dead. As a result of the patient's death, the hospital completed an intensive root cause analysis (RCA). The P&A communicated with the hospital's attorneys, to ensure that the RCA's many recommendations were implemented. The P&A reviewed the documentation, to ensure that all recommendations were appropriately implemented. The family hired a private attorney to file a wrongful death complaint. The P&A closed the file after receiving assurances that the hospital had implemented the new procedures.

North Carolina

The P&A, as a result of a detailed complaint filed with surveyors, investigated the death of a young woman with mental illness. The P&A took the case for investigation after it received a death report about the young woman, who died in seclusion in the hospital's emergency room, following involuntary commitment. The findings were significant, because surveyors looked at the death during a "recertification" survey of the hospital and did not find any deficiencies. After conducting a three-day investigation, based on the P&A's complaint, surveyors determined that the hospital had violated CMS regulations related to the use of seclusion. The hospital's Plan of Correction included rewriting hospital policy and retraining staff about the circumstances under which seclusion may be used and must be discontinued and the monitoring procedures during and following the seclusion that must occur.

5. Complaints Favorably Resolved for Clients

The case examples in section (1) Abuse, (2) Neglect, and (3) Rights violations provide information on the types of favorable outcomes achieved on behalf of individual P&A system clients. The following table shows the total number of individual PAIMI complaints investigated, closed, and resolved.

Complaints Investigated and Closed, by type	FY 2017	FY 2018
Abuse	2,397	1,902
Neglect	2,021	1,654
Rights violations	4,597	3,976
Total	9,015	7,532

[See Appendix - Table 9, 10, & 11]

6. Intervention Strategies

The P&A systems are authorized by the PAIMI Act³³ 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.

Intervention Strategies, by Type	FY 2017	FY 2018
Short-term assistance	4,841	4,041
Abuse & neglect investigations	1,294	1,028
Technical assistance	1,222	1,030
Administrative remedies	288	329
Negotiation/mediation	1,146	877
Legal remedies	288	284
Total Intervention Strategies	9,079	7,589

[See Appendix - Table 12]

Case Examples from FY 2017

Arizona

The P&A provided short-term assistance in the case of a 17-year-old male with mental illness. The individual's mother contacted the P&A for assistance because Mercy Maricopa Integrated Care (MMIC), the Regional Behavioral Health Authority for Maricopa County, neglected the individual, as a result of its failure to provide for appropriate discharge planning from the

³³ at 42 U.S.C. 10805 (a) (1) (C)

inpatient behavioral health facility in which the individual was residing. The individual was discharged from his inpatient behavioral health facility to a group home too early, which resulted in the individual becoming violent and ultimately incarcerated. The P&A provided the individual's mother with verbal and written information on the right to file a grievance with MMIC. The P&A also provided the individual's mother with referrals to additional legal resources. With the information the P&A provided her, the individual's mother was able to advocate on the individual's behalf.

Colorado

The P&A received a complaint from a 48-year-old client with mental illness, who was residing in public housing. The client had recently received a notice denying his request for an assistance animal from the local housing authority, stating that the animal barked and was a nuisance. The housing authority received this information from the client's neighbors. The client was adamant that the neighbors were lying, and his dog was not causing any additional noise. The client has difficulty regulating his emotions, due to his disability, and his dog allows him to stay calm and conflict free in his home. The client had paperwork to support his need for the animal. The P&A reviewed documents provided by the client, met with him multiple times at his home, and assisted him in gathering evidence to support his claims. The P&A also assisted the client in following the housing authority appeal process. The P&A organized an informal grievance meeting with the local housing authority, to advocate for the client. Ultimately, the housing authority allowed the client's dog as an assistance animal, as long as the client filled out some additional paperwork. The client was facing possible eviction due to this issue, and the P&A provided a reasonable solution for him to keep his housing.

Maryland

The P&A investigated the cases of three patients at a state psychiatric hospital, who were secluded in their bedrooms for nearly 24 hours a day, in a new hospital policy called "zoning," where patients with difficult behaviors were made to stay in their room continuously. The P&A's investigation found that at least two of the patients had been required to stay in their rooms for over two years. The P&A also noted that the patients' behavior management plans were inadequate, and not aimed at preventing violent behavior or understanding the causes of the behavior. Further, the P&A's investigation revealed that at least one of the patients was diagnosed with an intellectual disability that made it difficult to conform to hospital rules. The P&A contacted the hospital administration, to request that zoning of clients be ended. When this request was unsuccessful, the P&A filed a complaint with the Office of Health Care Quality, who filed a Deficiency Report. The hospital was required to file a plan of correction, and the P&A's clients reported that they have enjoyed being out of their rooms and participating in hospital groups and activities.

North Dakota

A 49-year-old woman, with a diagnosis of major depression and history of overmedicating on prescription drugs, lived alone in an apartment in Bismarck, ND. The client worked in an administrative position and had an established history of good performance. The client was terminated from her job while taking an approved leave of absence for mental health treatment. As a result of this action, the client suffered financially, had to move, and ended up reaching out to nonprofit agencies for financial assistance. She eventually worked two jobs to make up for what she was paid at her former employment. The P&A assisted the client to file a complaint with the North Dakota Department of Labor (NDDOL). An investigation was done and a “no cause” determination was made by the NDDOL investigator, despite strong evidence that disability-related discrimination had occurred. The P&A filed an employment discrimination complaint in court on the client’s behalf. The employer ultimately entered into negotiations and a very healthy settlement was reached on behalf of the client.

Case Examples from FY 2018

Connecticut

The P&A received a call from an individual who was residing in a public mental health facility. The individual was experiencing gynecological issues and despite repeated requests, had not been taken to see a doctor. The P&A got involved, met with the client, reviewed the record, and approached the administration regarding lack of medical treatment. The P&A pursued the issue, and the individual was able to see a medical professional about her issues.

District of Columbia

The P&A represented a 51-year-old man with serious mental illness, who was discriminated against by his graduate program. When the university learned that he had mental illness they suspended his participation in the program and required him to get documentation from a psychiatrist that he was fit to be in the program. He was not then seeing a psychiatrist, so he was forced to pay \$1,000 for a psychiatrist to evaluate him. The psychiatrist found him fit to be in the program. Then, the university disclosed to a prospective employer that he had a mental illness. The P&A wrote a letter to the university, asking that the client be reimbursed for the evaluation and compensated for the time he was suspended and the delay in his employment, after the illegal disclosure of his mental illness. The P&A also recommended training for the university on their requirements under Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act. When the university failed to address his concerns the P&A assisted the client in filing a complaint with the Office of Human Rights, alleging the university violated ADA, Section 504 of the Rehabilitation Act and the District of Columbia Human Rights Act. The parties were sent to mediation and were able to negotiate a confidential settlement that addressed the client's concerns.

Idaho

The P&A filed a complaint with a state psychiatric hospital on behalf of a 32-year-old female diagnosed with chronic PTSD and anxiety, alleging rights violations regarding safety and mental health care. The client contacted the P&A because she felt that the facility doctor was not listening to her when she talked about emerging symptoms, to the point that an outside physician had to be called to order anxiety medication one night, when she had a panic attack. She also complained that the staff did not address safety concerns, in that a box knife was left on the unit floor by contractors replacing floor tile, within reach of the patients. Patients were concerned and upset, with some wanting to use the knife and others afraid for their safety, so the client told staff. Her concerns were ignored, until she threatened to go to the administration; staff then asked the contractors to pick up their tools, including the knife. The P&A reviewed policy and filed a grievance with the Patient Advocate at the facility. The Patient Advocate reviewed video of the incident and stated that he would provide further training to the contractors while they are working at the facility. The Patient Advocate also forwarded the complaint to medical staff. The client was satisfied with the remedy and was soon discharged.

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.³⁴ This type of litigation is a 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 affect 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:

Class Action Litigations	FY 2017	FY 2018
Number of Events	61	81
Individuals Impacted	2,444,669	1,612,221

[See Appendix – Table 13a]

Case Examples from FY 2017

Delaware

The P&A and Delaware Department of Corrections (DOC) resolved a class action regarding the utilization of solitary confinement for inmates with serious and persistent mental illness. Approximately 1,000 inmates were identified as having a serious mental illness, and 200 of them were isolated in restrictive housing. A Federal Judge approved the settlement, which created better treatment options for these inmates. A prison riot in early 2017 led to disruption in implementation of the agreement. However, the P&A have continued to work with DOC to

³⁴ 42 U.S.C. 10805 (a)(1)(B)

monitor the implementation and progress within DOC. The P&A randomly selects and reviews 20 inmate files on a monthly basis, to ascertain whether the inmates are receiving services as contemplated in the agreement.

District of Columbia

In *Brown v. District of Columbia*, the P&A continued to represent class members who are District of Columbia Medicaid enrollees in nursing facilities, seeking transition assistance from the District of Columbia government to help them move back to the community, with the services that they need. The class includes adults with serious mental illness, who also have a physical disability. Transition assistance included essential steps such as obtaining identification documents and income-benefit statements, helping class members complete housing applications, assessing their long-term care service needs in Medicaid, and linking them to provider agencies. The P&A provided extensive assistance in preparing the evidence presented to the Court. In September 2017, the Court issued its decision in favor of the District and dismissed plaintiffs' legal claims. The Court found that "[t]he District has little to be proud of regarding its historic inability to comply with *Olmstead's* integration mandate"³⁵ but, because the majority of class members need housing and subsidized housing is difficult to find, the Court found plaintiffs' claims for transition assistance were essentially futile. Despite the negative decision, the District reported that 38 nursing home residents transitioned to the community during FY 2017, which exceeded its goal of 33.

Illinois

In FY 2007, the P&A and its co-counsel filed a class action lawsuit against state officials for failing to provide community services for people living in nursing homes in Cook County, Illinois, primarily people with mental illness and people with physical disabilities. Suit was brought under ADA, and pursuant to the U.S. Supreme Court's *Olmstead* decision. It is estimated that over 16,000 people live in nursing homes in Cook County. In FY 2008, the case was certified as a class action. In FY 2012, the judge granted final approval of a Consent Decree, appointed an Independent Monitor, and the parties worked to develop the requisite Implementation Plan. At the end of FY 2017, over 1,800 class members had moved into the community from nursing homes.

Case Examples from FY 2018

California

The P&A filed a federal class action lawsuit on behalf of five prisoners in the Santa Barbara County Jail, claiming conditions at the jail do not meet minimum standards under the U.S. Constitution and federal law, including ADA. The lead plaintiff, a 67-yearold PAIMI-eligible U.S. Army veteran, requested but received no meaningful treatment to help him manage his PTSD.

³⁵ *Olmstead v. LC*: 1999 United States Supreme Court Decision

Another class member was denied prescribed psychiatric medications that he had been taking prior to his arrest. Despite jail staff documenting his reports of an exacerbation of his mental health disability, his condition worsened and, a few days later, the class member attempted suicide by cutting his wrist. The prisoners are seeking an order from the court requiring Santa Barbara County officials to improve jail conditions, to comply with constitutional and statutory standards. In June 2018, the U.S. District Court granted the P&A's motion for class certification. The P&A is meeting with the Sheriff's office and county officials to negotiate a remedial plan.

Colorado

The P&A entered a class action lawsuit against the Federal Bureau of Prisons (BOP) for their 8th Amendment violations by failing to exclude inmates with serious mental illness from the Administrative Maximum Facility (ADX), located in Florence, Colorado, and for failing to provide a constitutionally appropriate level of mental health screening and treatment to inmates at the ADX. A settlement agreement was reached after years of discovery, policy development and settlement discussions. In January 2017, the settlement agreement was approved, and found to be fair, reasonable, and adequate for the class and subclass. The case is currently in the monitoring phase, where two experienced corrections psychiatrists are checking BOP's compliance with a very detailed settlement agreement. The P&A is part of the monitoring process commenting on compliance/ noncompliance issues and receiving inmate complaints concerning implementation of the settlement agreement.

Louisiana

Early in 2017, the P&A found probable cause to believe that Defendants were exposing prisoners with mental illness and other disabilities at David Wade Correctional Center (DWCC) in Homer, Louisiana to neglect and abuse, by subjecting them to extended periods of solitary confinement and failing to provide adequate mental health services. As a result, the P&A initiated an investigation of the prison's use of isolation and restraints and whether mental health treatment at DWCC was adequate and appropriate. At DWCC, hundreds of prisoners, many of whom were known to have serious mental illness, including history of self-harm or suicidal tendencies, were routinely placed on extended lockdown. A lawsuit was brought on behalf of two individuals, both of whom are currently in custody of the DWCC, and all persons in a similar situation. One individual, having no history of mental illness, now complains of auditory and visual hallucinations, as a result of his stay in extended lockdown and lack of mental health resources. The other individual, despite having been diagnosed as bipolar and being on suicide watch at the time of his evaluation, was categorized as having no mental problems. He has attempted suicide twice and been on suicide watch five times. It is the P&A's contention that extended lockdown is a cruel, inhumane punishment, in which these men are deprived of human contact, the outdoors, speaking with their families or even a regular shower. By subjecting prisoners to such treatment, the plaintiffs contend that Defendants are violating the rights of prisoners under the First and Eighth Amendments, as well as ADA and Section 504 of the Rehabilitation Act.

Iowa

The P&A filed a class action lawsuit on behalf of boys with mental illness against a State-operated juvenile justice facility, to eliminate the use of fixed restraints and solitary confinement for punishment purposes and to ensure that the boys were receiving constitutionally required mental health treatment. Part of the remedies requested will require that the Iowa Department of Human Services change their regulations concerning the use of restraint and seclusion in this facility.

D. Interventions on Behalf of Groups of PAIMI-eligible Individuals

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 resolution of a range of systemic issues affecting 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. Activities reported under the Legislative and Regulatory Advocacy section are limited to providing technical assistance, education, and awareness about current statutes and regulations regarding the rights and protection of individuals with serious mental illness (SMI) or serious emotional disturbance (SED) and do not include strictly prohibited activities, such as the inappropriate use of federal dollars to influence legislation or any actions by federal or state governments described in Section 503 of Title V, in Division H of the Consolidated Appropriations Act and specific prohibitions against lobbying in the PAIMI regulations.³⁶

Non-Litigation Advocacy	FY 2017	FY 2018
Number of Events	2,977	1,983
Total number of individuals impacted	12,429,482	10,193,626

[See Appendix – Table 13b]

Legislative & Regulatory Advocacy	FY 2017	FY 2018
Number of Events	149	243
Total Number of Individuals Impacted	10,212,335	8,737,697

[See Appendix – Table 13c]

³⁶ 42 CFR Part 51. Subpart A

Case Example from FY 2017

District of Columbia

In February 2017, the Green Door, a non-profit mental health provider, closed with very little notice to the 1,200 mental health consumers who relied on them for support. The P&A attended a consumer forum at the Green Door before it closed, and conducted outreach immediately afterwards, interviewing consumers regarding whether their needs were being met during the transition period. The P&A raised concerns to the Department of Behavioral Health (DBH) and the District of Columbia City Council about the lack of notice to consumers regarding the closure and lack of an adequate transition period and advocated that the mental health provider that was acquiring Green Door's space and clients receive special training and supervision in providing the evidence-based practice of Assertive Community Treatment (ACT) services. As a result of the P&A's advocacy, the District of Columbia City Council requested that DBH provide a plan to follow each client.

Case Example for FY 2018

Kentucky

The P&A provided PAIMI services to a 17-year-old female who was diagnosed with several mental disorders. The P&A was notified because the client was bruised during a Safe Crisis Management (SCM) restraint at a Psychiatric Residential Treatment Facility. The allegations were investigated by the Child Protective Services (CPS) and reported to the Office of Inspector General (OIG). The P&A received and reviewed a copy of the final investigation report. The allegations were substantiated as "risk of harm," due to excessive use of force during SCM. The report also indicated that the staff member who administered the SCM was non-compliant with required training. CPS recommended the facility terminate the staff's employment. The OIG also issued a statement of deficiency to the facility. The P&A sent a letter to the guardian of the client, to let the guardian know the outcome of the investigation and continued monitoring the treatment of the client and other residents. Both CPS and OIG continue to be involved in the monitoring of the facility for regulatory compliance and the safety of residents.

Nevada

The P&A provided PAIMI services to a 55-year-old male with mental illness, whose sister was his guardian. The client was placed on a mental health hold and admitted to a psychiatric facility. Rather than filing a Petition for Involuntary Commitment, the hospital permitted the guardian to "voluntarily" admit the client over his objection. The P&A contacted the public defender and the client's attorney appointed in the guardianship case. The P&A discovered that the guardianship judge specifically found that the guardian did not have the authority to voluntarily admit the client and communicated this information to hospital staff. Rather than file Petition to hold, the client was released by the hospital. The client submitted a complaint with the Nevada's regulatory agency concerning the hospital's failure to timely file a petition as

required by state law. The complaint was joined by the client’s attorney in the guardianship case and the public defender’s office.

E. Public Education, Training, and Awareness 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 awareness, education, and training activities. Many state PAIMI Programs met with and provided civil rights informational training to 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. The P&A system provided information to the public by various means, including newspapers, radio/television public service announcements, agency newsletters, websites, publications, investigative reports, and listservs. 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. The PAIMI Program public education, training, and awareness activities conducted by the P&A systems included:

Educational or Training Activities	FY 2017	FY 2018
Information and Referral Requests	24,764	23,029
a. Number of Public Awareness Activities or Events	1,910	2,055
b. Number of Educational/Training Activities Undertaken	2,436	2,428
c. Number (approximate) of Persons Trained in b.	80,753	72,687

[See Appendix, Table 14]

Case Examples from FY 2017

Delaware

The P&A assisted a client, diagnosed with depression and substance use disorder, with multiple concerns, including lost mail, an alleged HIPAA violation, cleanliness of the unit, and poor staff interactions. The P&A assisted the client in filing grievances, provided information and referral, attended a treatment team meeting with the client, and arranged contact with the HIPAA Compliance Officer at DPC. In addition, the client had a pending family law matter in New Jersey. The P&A facilitated telephonic attendance at an arbitration and court hearing for this client.

Maine

The P&A assisted a 34-year-old woman with mental illness, who was transported by police to a hospital emergency department for a mental health evaluation. The woman was subjected to restraint and involuntary medications, due to the hospital claiming that she was being “disruptive” to other patients. The P&A investigated the client’s treatment and determined that

staff had not been properly trained regarding the rights of individuals with mental illness awaiting mental health evaluations in the emergency department. The hospital agreed to, and accepted training for, emergency room staff from the P&A in this area of patient rights.

Mississippi

The P&A collaborated with Southern Poverty Law Center's Youth Justice Project to monitor a juvenile detention facility in Hinds County. The P&A is working with the facility to ensure that eligible youths have access to advocates, receive appropriate mental health and medical treatment, are not subject to force and restraints, and are given educational services. The P&A has been able to collaborate with local mental health providers to initiate services to youth at the detention facility.

Case Examples from FY 2018

Delaware

A client with schizoaffective disorder bipolar type at DPC asked for P&A assistance with discharge planning, a housing voucher issue in New York State, and other patient advocacy concerns. The P&A investigated her complaints, provided information and referral about her mental health patient rights, and involuntary commitment rights. The P&A advocated for the client to get a belongings inventory list and referred her to a legal services program in New York, regarding the housing voucher issue. Because the client is now discharged from DPC and her legal problem resolved, her case has been closed.

Massachusetts

The P&A collaborated with the Western Massachusetts and Eastern Massachusetts Peer Networks to share information and trends on mental health issues throughout the Commonwealth. The P&A provided extensive legal advice about community-based living rights and responsibilities, involuntary medication, and human rights laws. Representatives from the Peer Networks shared concerns with the P&A about specific provider abuses and a social media campaign that they were planning. The P&A followed up with monitoring additional group homes and hospitals, based on this advocacy, as well as with providing legal guidance around social media campaigns, to raise awareness about mental health abuse/neglect.

Texas

The P&A conducted an education and training and focus group meeting at the Rio Grande State Center in February 2018. One of the issues raised by participants was their right to a safe environment and why they did not feel safe in the unit. The discussion led to issues regarding the lack of availability of the quiet room. The residents stated that the quiet room was not available. The P&A raised the issue of residents not being able to access the quiet room with the Director of Social Work, who confirmed it was not available due to construction in the unit.

The P&A requested that an alternative location be provided. Several follow up inquiries were made with the staff. Due to the persistence of the P&A, and the efforts in negotiating closure on this issue, the quiet room was restored for use by residents.

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

Examples from FY 2017

Maine

The P&A continues to provide contract advocacy services to both of Maine's state psychiatric hospitals and one of Maine's largest private psychiatric hospitals. The P&A continues to provide regular outreach and monitoring visits to other private psychiatric hospitals throughout the state. In FY 2017, the P&A conducted this type of monitoring and outreach on 16 separate occasions to 4 different hospitals, including another large private psychiatric hospital.

North Dakota

The P&A investigated and identified a number of systemic issues that resulted in denial of appropriate assessment and mental health services to a client. The P&A had meetings with personnel at the jail, the regional human service center, the States Attorney's Office, and other offices, to address the identified systemic problems that contributed to the client's situation.

Case Examples from FY 2018

American Samoa

During the transition of five clients from the correctional facility to the LBJ Behavioral Health Center for ongoing treatment and care their rehabilitation needs were initially not being met, due to limited resources, including mental health care professionals and programs available for the clients. At a Behavioral Health Planning Council meeting, the P&A suggested, and a rehabilitation subcommittee was formed. The goal was to collaborate and share resources amongst government and private agencies, to enable implementation of appropriate programs that could be attended by clients both housed long-term at the Behavioral Health Center and in the general community. Programs developed included Computer Skills training with the Department of Youth & Women, Workforce Innovation and Opportunity Act from the Department of Human Resources for employment on the job training skills, Check In group with

Department of Human and Social Services (focusing on communication and social skills), a Drop-in group (now on hold), which gave ukulele lessons, art and meditation sessions, and Self-advocacy and Rights for clients training for clients and their family members by the P&A and peer mentor staff. Several cases were able to be closed, due to collaboration among a collective group of agencies on the island willing to come together for rehabilitation goal setting and achievement. This collaboration was an accomplishment not only for the five clients in transition, but also for the mental health system in general.

Illinois

An individual with schizophrenia who was in the maximum-security mental health center, with a status of not guilty by reason of insanity, contacted the P&A seeking assistance to avoid being transported to court in shackles. After the P&A engaged in extensive negotiations, the facility relented and allowed the client to go to court accompanied by staff, but without shackles. This advocacy also had a systemic effect, by educating the facility and Division of Mental Health that the statewide policy does not require shackles where other security measures are sufficient, based on an individualized assessment of the person.

2. Impediments & Unmet Needs

Examples from FY 2017

Alabama

While the P&A's PAIMI Act access authority has been repeatedly reaffirmed in jurisdictions across the United States, facilities in Alabama continue to challenge the P&A's access to monitor and investigate any abuse, neglect, or rights violations. During FY 2017, the P&A was denied access by county jails, requiring the P&A to engage in protracted negotiations with the jails over its access authority. Even though the P&A has successfully met access challenges to date, it has done so with a considerable amount of expenditures, time, and resources, which could have been used to provide direct client services.

Alaska

For the P&A, the major impediment to the implementation of mandated PAIMI activities is the lack of a comprehensive, statewide plan to fill service delivery gaps for individuals with severe mental illness. The absence of community-based services for individuals exiting institutional environments, such as prisons or psychiatric facilities, results in unacceptable recidivism and readmission rates. This "revolving door" consequence places a tremendous strain on the system, making it difficult for other individuals to access needed stabilization services. The dearth of step-up or step-down services challenges the individual advocacy conducted by the P&A.

California

The P&A did not receive any notification from CMS regarding reports of behavioral restraint-related deaths in California hospitals. The P&A renewed its data use agreement to receive notification of restraint-related hospital deaths, as required by CMS; to facilitate the sharing of information.

Vermont

The P&A's impediment is the lack of a requirement in Vermont that Emergency Departments report to the State Department of Mental Health (DMH) episodes of seclusion and restraint of psychiatric patients or of voluntary patients in the inpatient units. This lack of reporting represents an obstacle, unlike seclusions and restraints of involuntary patients in psychiatric units, which are all reported to the P&A in one, easy to review and analyze dataset by the DMH, the other reports above are fragmented and hard to obtain, thus not allowing for a systematic review for systemic concerns.

Examples from FY 2018

Delaware

The P&A's greatest external impediment to progress is a staffing shortage that the state seems unable to address. The understaffing has led directly to deficiencies in a number of categories, including lack of peer oversight, inconsistent programming, a non-functioning investigations unit, and other issues. The lack of an effective and efficient investigations system at the Delaware Psychiatric Center has negatively impacted the P&A's ability to obtain timely investigative reports and other materials. There are unacceptably long delays between incidents and investigations and investigations and production of documents.

Louisiana

The P&A did not regularly receive reports of seclusion, restraint, death, or serious injury from licensed facilities, the State Medicaid agency, or the CMS regional office. The P&A regularly visited many of the facilities outlined in the Children's Health Act of 2000, as well as other facilities on monitoring visits, and spoke with residents regarding conditions and incidents. In addition, the P&A monitored the media for reports of death or serious injury.

Maryland

The P&A received complaints of alleged sexual abuse or harassment from patients at state psychiatric hospitals, yet they failed to comply with the mandatory reporting requirements. Moreover, the reports of sexual abuse that P&A does receive are delayed, impeding its ability to investigate and address the allegations in a timely manner. Furthermore, some state hospitals fail to use the proper reporting forms, which upon investigation, the P&A noted, is

often because the hospital staff were not aware of the reporting procedures. The P&A works with the Assistant Attorney General for the Maryland Department of Health to ensure that staff receive appropriate training on their obligations for responding to sexual assault reports and implementing the proper reporting forms and procedures required by the Doe v. Department of Health and Mental Hygiene settlement agreement. The P&A continues to provide “Know Your Rights” presentations to both patients and staff on their rights related to sexual abuse allegations.

Tennessee

For the P&A, the external impediments remain unchanged. In Tennessee, there continues to be a shortage of resources for mental health services, especially for clients with the most serious behaviors related to their mental illness and those with secondary disabilities, such as deafness or other physical disabilities. In addition, there continues to be a move toward shorter duration inpatient treatment, with limited community support options. The most significantly impacted are some of the most vulnerable Tennesseans, those with limited access to medical insurance, as well as those with secondary disabilities and the aging population. This move limits the advocacy options, culturally and linguistically appropriate service options, and the safe community living resources.

GOVERNANCE

1. *The Governing Authority*

The DD Act of 1975,³⁷ which created the state P&A systems, and the PAIMI Act³⁸ mandated that private, non-profit entities have a multimember governing authority (the Board) to oversee the system.³⁹ Each Board is responsible for the planning, design, implementation, and functioning of the system.⁴⁰ The Board must work jointly with its PAIMI Advisory Council (PAC)⁴¹ and establish policies and procedures for the selection of its members.⁴² The DD Act included provisions for Board terms of appointment, size, and composition. The DD Act required that:

- Board members be selected according to policies and procedures of the system;
- The Board include individuals who broadly represent or are knowledgeable about the needs of the clients served by the system;
- The Board must make continuing efforts to ensure that its members represent racial and ethnic minorities.⁴³
- The majority of Board members include individuals with disabilities who are current or

³⁷ 42 U.S.C. 15043 (a), amended in 2000.

³⁸ 42 U.S.C. 10805(c)

³⁹ 42 U.S.C. 15044

⁴⁰ 42 U.S.C. 10805(c) (2) (A)

⁴¹ 42 U.S.C. 10805(c) (2) (B)

⁴² 42 U.S.C. 10805(c) (1) (B)

⁴³ respectively at, 42 U.S.C. 10805(a) (6) (C) and 42 CFR 51.22(b) and (c)

former recipients of disability services, their family members, guardians, authorized representatives, and advocates;

- The system set term limits to ensure rotating membership on the board; and
- Board vacancies be filled within 60-days.⁴⁴

As of September 30, 2018, there were 52 private, non-profit P&A systems. Unlike private, non-profit P&A systems, state-operated P&A systems may have a governing authority but are not required to do so.

The PAIMI Act and Rules also require the PAC Chair, who must be a current or former recipient of mental health services or a family member of such an individual, sit on the governing Board of private, non-profit P&A systems.

2. The PAIMI Advisory Council

Each state P&A system is mandated to establish a PAC⁴⁵ to advise the system on policies and priorities to be carried out in protecting and advocating for the rights of individuals with mental illness.⁴⁶ The composition of the PAC is also mandated.⁴⁷ The PAC Chair must be a current or former mental health recipient or a family member of such an individual.⁴⁸

Each PAC 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 submit a section of the system's annual report.⁴⁹ Council terms of appointment must be staggered and of reasonable duration. The size of the PAC varies by state, but at least 60 percent of Council members must be current or former recipients of mental health services or their family members. The Council must meet at least three times each calendar year, include ethnic and racial minorities, and receive information related to its corresponding P&A system's budget, staff, current program policies, priorities, and performance outcomes.⁵⁰

The PAC 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 PAIMI Act requires that the PAC Chair sit on the governing board of private, non-profit state P&A systems;⁵¹ however, any PAC member may serve on the governing board.⁵²

⁴⁴ respectively, at 42 U.S.C. 15044 (a) (1) (A), (B) (i), (ii) and (C) (3) and (4)

⁴⁵ PAIMI Act at 42 U.S.C. 10805(a) (6) (C)

⁴⁶ at 42 U.S.C. 10805 (a) (6) (A)

⁴⁷ PAIMI Act at 42 U.S.C. 10805(a) (6) (B)

⁴⁸ 42 U.S.C. 10805(a) (6) (C) and the PAIMI Rules at 42 CFR at 51.23(b) (2)

⁴⁹ PAIMI Rules at 42 CFR 51.23 (a) (1) - (3)

⁵⁰ PAIMI Rules at 42 CFR 51.23(b) (2), (3) and (c)

⁵¹ 42 U.S.C. 10805 (a) (6) (A), 42 CFR at 51.22 (b) (3)

⁵² 42 CFR at 51.22(d)

By January 1 of each year, each P&A system is required to submit an annual Program Performance Report (PPR) to the HHS Secretary.⁵³ The PAC is also required to submit a section of that annual PPR, as mandated by the PAIMI Act⁵⁴ and the PAIMI Rules.⁵⁵

The Council's report must:

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

In addition to attending meetings, PAC members participated in numerous activities sponsored or endorsed by the PAIMI Program (e.g., attending in- and out-of-state trainings, serving on P&A governing board committees, engaging in systemic advocacy; and participating 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 AoD. AoD, which oversees the PADD Program, is the first federal protection and advocacy program, and is the lead on the federal P&A system for issues pertaining to designation, re-designation, and regulations. SAMHSA supports the IAA with funds specifically set-aside for T/TA but 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 the Individual Rights Program, the Client Assistance Program, and the Protection and Advocacy for Assistive Technology Program. RSA has a separate IAA with AoD. This consolidation of federal P&A program set-aside funds maximizes each agency's 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 was the contractor selected by the AoD to serve the P&A systems. Under the contract, TASC is responsible for various T/TA tasks including both general and agency-specific tasks (for example, the annual PAC training). TASC activities under FYs 2017 and 2018 contract included the following:

- Investigation protocols for incidents of abuse and neglect cases involving deaths;

⁵³ 42 U.S.C. 10805 (a) (7)

⁵⁴ 42 U.S.C. 10824

⁵⁵ 42 CFR 51.8

- Seclusion and restraint;
- Community integration (Olmstead);
- Medicaid funding;
- Consumer self-advocacy;
- Role of PACs;
- Access to jails, prisons, and juvenile detention facilities;
- Housing; and
- Outreach strategies for unserved and underserved populations, including members of ethnic and racial minorities and individuals in urban or rural settings, prisons, jails, and detention centers.

TASC also assisted P&A systems prepare legal briefs when their PAIMI Act investigative and access authority was challenged.

Under the IAA, TASC prepared three publications: the *TASC Update* (monthly), *LegalEase* (monthly), and the *P&A News* (quarterly). Each publication was reviewed and edited by the federal P&A TA partners (SAMHSA, AoD, and RSA) before AoD approved their distribution 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 state P&A systems;
- Developed model guidelines, training manuals, and legal advocacy materials, including *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, including 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 and 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, including the Annual Conference, training the P&A executive director, and fiscal management training.

Through the IAA, SAMHSA assists P&As to improve performance (for example, legal advocacy services to include individual and systems advocacy), operations, and outcomes; maintain

statutory compliance; support P&A's as leaders and catalysts of systems change, capacity building, and advocacy at the national, state/territory, and local levels.

CONCLUSION

This report offers examples of successful implementation of statutorily mandated activities related to the PAIMI program. PAIMI grantees worked tirelessly to protect and advocate for the rights of individuals 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, or other appropriate remedies on their behalf. PAIMI grantees successfully investigated reports of abuse, particularly incidents involving serious injuries and deaths related to the inappropriate use of seclusion and restraint, and ensured enforcement of the United States Constitution, federal laws and regulations, and state statutes.

Through the PAIMI program systemic changes were implemented in a variety of settings, which ultimately improved treatment, support, and services for those with SMI and SED. The PAIMI grantees assisted states/territories make systemic changes, change or improve practices, and implement best practices. Through these and other efforts, the PAIMI program assisted individuals and families obtain better treatment, decreased abuse or neglect, protected rights of individuals, expanded employment and educational opportunities, and promoted access to community living.

Appendix A

DATA TABLES FOR FISCAL YEARS 2017 & 2018

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Table 1 – State PAIMI Appropriations

State/Jurisdiction	FY 2017 Final Appropriations	FY 2018 Final Appropriations
Alabama	\$453,952	\$458,554
Alaska	\$428,000	\$428,000
Arizona	\$626,682	\$634,205
Arkansas	\$428,000	\$428,000
California	\$3,140,635	\$3,101,059
Colorado	\$438,159	\$443,445
Connecticut	\$428,000	\$428,000
Delaware	\$428,000	\$428,000
District of Columbia (DC)	\$428,000	\$428,000
Florida	\$1,738,714	\$1,761,727
Georgia	\$925,906	\$934,106
Hawaii	\$428,000	\$428,000
Idaho	\$428,000	\$428,000
Illinois	\$1,066,670	\$1,051,088
Indiana	\$600,047	\$592,729
Iowa	\$428,000	\$428,000
Kansas	\$428,000	\$428,000
Kentucky	\$428,000	\$428,000
Louisiana	\$428,000	\$428,000
Maine	\$428,000	\$428,000
Maryland	\$466,105	\$467,047
Massachusetts	\$507,663	\$502,978
Michigan	\$887,795	\$878,974
Minnesota	\$445,887	\$446,246
Mississippi	\$428,000	\$428,000
Missouri	\$537,097	\$542,302
Montana	\$428,000	\$428,000
Nebraska	\$428,000	\$428,000
Nevada	\$428,000	\$428,000
New Hampshire	\$428,000	\$428,000
New Jersey	\$678,311	\$675,631
New Mexico	\$428,000	\$428,000
New York	\$1,522,109	\$1,507,227
North Carolina	\$909,472	\$912,914
North Dakota	\$428,000	\$428,000
Ohio	\$1,019,483	\$1,019,501
Oklahoma	\$428,000	\$428,000
Oregon	\$428,000	\$428,000

Pennsylvania	\$1,058,552	\$1,051,937
Rhode Island	\$428,000	\$428,000
South Carolina	\$457,957	\$460,260
South Dakota	\$428,000	\$428,000
Tennessee	\$588,878	\$589,859
Texas	\$2,278,953	\$2,321,910
Utah	\$428,000	\$428,000
Vermont	\$428,000	\$428,000
Virginia	\$671,652	\$674,079
Washington	\$573,587	\$577,376
West Virginia	\$428,000	\$428,000
Wisconsin	\$494,807	\$493,292
Wyoming	\$428,000	\$428,000
American Indian Consortium (AIC)	\$229,300	\$229,300
American Samoa (Am. Samoa)	\$229,300	\$229,300
Guam	\$229,300	\$229,300
Northern Marianas (N. Marianas)	\$229,300	\$229,300
Puerto Rico	\$528,202	\$528,962
Virgin Islands	\$229,300	\$229,300
Total State P&A Systems	\$35,319,775	\$35,329,908
Technical Assistance Set-aside (2%)	\$706,396	\$706,598
Total Annual PAIMI Appropriations	\$36,026,171	\$36,036,506

Table 2a – PAIMI Eligible Individuals Served by Age Group and Sex – FY2017

State/Jurisdiction	HHS	Age							Sex			
	Region	0-4	5-12	13-18	19-25	26-64	65+	Total	Male	Female	Unk.	Total
Alabama	4	0	25	46	13	110	21	215	169	46	0	215
Alaska	10	0	1	4	8	47	1	61	30	31	0	61
AIC	11	0	4	14	1	9	0	28	21	7	0	28
Am. Samoa	9	0	1	3	33	17	0	54	49	5	0	54
Arizona	9	0	2	10	25	277	22	336	141	195	0	336
Arkansas	6	0	31	38	4	45	6	124	83	41	0	124
California	9	0	35	58	69	614	71	847	0	0	847	847
Colorado	8	0	3	9	13	65	2	92	77	15	0	92
Connecticut	1	0	0	0	0	7	2	9	3	6	0	9
Delaware	3	0	2	8	21	148	8	187	92	95	0	187
DC	3	0	0	11	16	94	19	140	77	63	0	140
Florida	4	0	6	6	14	195	13	234	172	62	0	234
Georgia	4	0	1	9	11	99	3	123	62	61	0	123
Guam	9	0	2	4	2	20	0	28	15	13	0	28
Hawaii	9	0	49	50	6	96	11	212	125	87	0	212
Idaho	10	0	7	5	8	69	11	100	38	61	1	100
Illinois	5	1	53	96	32	278	31	491	259	232	0	491
Indiana	5	0	14	18	13	50	5	100	64	36	0	100
Iowa	7	0	8	10	7	16	0	41	26	14	1	41
Kansas	7	0	20	18	25	334	31	428	214	214	0	428
Kentucky	4	0	12	17	20	84	12	145	106	39	0	145
Louisiana	6	0	20	26	16	57	5	124	92	32	0	124
Maine	1	0	28	86	16	81	8	219	128	91	0	219
Maryland	3	0	0	12	13	113	5	143	99	44	0	143
Massachusetts	1	0	2	8	21	113	10	154	76	78	0	154
Michigan	5	0	23	18	12	49	17	119	76	43	0	119
Minnesota	5	0	14	24	7	144	6	195	90	105	0	195
Mississippi	4	0	13	41	4	11	0	69	46	23	0	69
Missouri	7	0	1	7	10	171	21	210	139	71	0	210
Montana	8	0	7	50	24	131	13	225	0	0	225	225
Nebraska	7	0	0	0	2	19	1	22	10	12	0	22
Nevada	9	0	0	2	2	39	6	49	22	27	0	49

New Hampshire	1	1	5	13	36	167	12	234	106	128	0	234
New Jersey	2	0	15	32	25	194	27	293	108	154	31	293
New Mexico	6	0	7	10	4	123	14	158	105	53	0	158
New York	2	0	3	19	12	164	13	211	118	93	0	211
North Carolina	4	0	6	15	23	87	7	138	97	41	0	138
North Dakota	8	0	46	86	20	89	12	253	176	77	0	253
N. Marianas	9	0	0	0	1	11	0	12	8	4	0	12
Ohio	5	3	57	59	49	413	29	610	351	258	1	610
Oklahoma	6	0	15	11	7	45	1	79	57	22	0	79
Oregon	10	0	0	3	9	38	5	55	40	15	0	55
Pennsylvania	3	1	25	46	26	139	8	245	155	90	0	245
Puerto Rico	2	0	7	8	8	94	6	123	58	65	0	123
Rhode Island	1	1	14	21	34	115	27	212	82	130	0	212
South Carolina	4	0	7	161	5	28	7	208	129	79	0	208
South Dakota	8	0	13	21	4	21	0	59	34	25	0	59
Tennessee	4	0	8	18	7	54	2	89	56	33	0	89
Texas	6	1	27	104	92	444	35	703	423	280	0	703
Utah	8	0	5	14	21	97	4	141	79	62	0	141
Vermont	1	0	0	2	11	76	8	97	51	46	0	97
Virgin Islands	2	0	1	3	0	13	0	17	12	5	0	17
Virginia	3	0	1	11	21	77	22	132	67	64	1	132
Washington	10	1	2	10	31	481	76	601	438	161	2	601
West Virginia	3	0	5	9	7	62	7	90	55	35	0	90
Wisconsin	5	0	7	36	11	71	3	128	83	45	0	128
Wyoming	8	0	0	0	2	33	3	38	19	19	0	38
Totals		9	660	1,420	934	6,738	689	10,450	5,508	3,833	1,109	10,450
Percentages		0.09	6.32	13.59	8.94	64.48	6.59	100.00	52.71	36.68	10.61	100.00

Table 2b – PAIMI Eligible Individuals Served by Age Group and Sex – FY2018

State/Jurisdiction	HHS	Age							Sex			
	Region	0-4	5-12	13-18	19-25	26-64	65+	Total	Male	Female	Unk.	Total
Alabama	4	0	27	66	15	73	14	195	145	50	0	195
Alaska	10	0	2	3	3	41	0	49	27	22	0	49
AIC	11	0	4	13	2	2	0	21	14	7	0	21
Am. Samoa	9	0	0	0	9	57	0	66	52	14	0	66
Arizona	9	0	4	13	31	292	18	358	147	211	0	358
Arkansas	6	0	21	30	2	37	3	93	59	34	0	93
California	9	2	28	53	48	576	73	780	367	407	6	780
Colorado	8	0	1	6	25	89	2	123	97	24	2	123
Connecticut	1	0	1	2	2	10	3	18	8	10	0	18
Delaware	3	0	4	11	16	145	7	183	86	97	0	183
DC	3	0	0	12	8	75	18	113	71	42	0	113
Florida	4	0	0	6	14	166	16	202	140	62	0	202
Georgia	4	0	2	5	13	74	2	96	53	43	0	96
Guam	9	0	0	7	2	5	2	16	8	8	0	16
Hawaii	9	0	23	34	1	61	7	126	77	49	0	126
Idaho	10	0	7	7	9	76	3	102	51	51	0	102
Illinois	5	1	52	98	35	259	27	472	273	199	0	472
Indiana	5	0	14	9	3	67	3	96	65	30	1	96
Iowa	7	0	7	15	1	14	3	40	20	19	1	40
Kansas	7	1	10	20	23	343	34	431	182	249	0	431
Kentucky	4	0	5	20	10	70	6	111	78	33	0	111
Louisiana	6	0	9	16	5	28	4	62	49	13	0	62
Maine	1	0	20	54	12	93	10	189	107	82	0	189
Maryland	3	0	2	28	9	112	9	160	76	84	0	160
Massachusetts	1	0	2	1	4	23	3	33	16	16	1	33
Michigan	5	0	21	26	17	67	28	159	98	61	0	159
Minnesota	5	0	11	26	11	159	12	219	105	114	0	219
Mississippi	4	0	2	19	3	6	0	30	14	16	0	30
Missouri	7	0	0	3	9	143	11	166	114	52	0	166
Montana	8	0	6	73	12	109	2	202	65	137	0	202
Nebraska	7	0	0	0	1	11	2	14	5	9	0	14
Nevada	9	0	0	1	6	25	5	37	17	20	0	37

New Hampshire	1	0	15	40	29	197	15	296	119	177	0	296
New Jersey	2	0	5	33	33	179	33	283	151	132	0	283
New Mexico	6	0	4	15	3	75	22	119	71	48	0	119
New York	2	0	3	6	12	112	9	142	65	76	1	142
North Carolina	4	0	4	16	13	67	4	104	60	44	0	104
North Dakota	8	0	64	88	20	81	15	268	176	92	0	268
N. Marianas	9	0	0	1	3	15	1	20	16	4	0	20
Ohio	5	2	36	66	46	320	27	497	259	237	1	497
Oklahoma	6	0	1	0	4	54	7	66	44	22	0	66
Oregon	10	0	0	1	3	28	4	36	19	17	0	36
Pennsylvania	3	1	20	43	25	172	16	277	126	135	16	277
Puerto Rico	2	0	1	1	4	63	9	78	34	44	0	78
Rhode Island	1	0	8	21	18	155	27	229	113	116	0	229
South Carolina	4	0	7	166	11	23	4	211	131	80	0	211
South Dakota	8	0	5	6	4	13	2	30	17	13	0	30
Tennessee	4	0	9	17	4	48	2	80	54	26	0	80
Texas	6	0	32	89	72	511	37	741	461	280	0	741
Utah	8	0	7	11	24	121	5	168	71	97	0	168
Vermont	1	0	0	9	6	71	10	96	48	48	0	96
Virgin Islands	2	0	1	3	0	5	0	9	4	5	0	9
Virginia	3	0	2	17	13	85	25	142	78	64	0	142
Washington	10	0	0	5	20	330	73	428	303	123	2	428
West Virginia	3	0	4	7	3	53	7	74	47	27	0	74
Wisconsin	5	0	7	29	13	92	2	143	89	54	0	143
Wyoming	8	0	0	0	0	28	1	29	12	17	0	29
Totals		7	520	1,367	744	6,206	684	9,528	5,254	4,243	31	9,528
Percentages		0.07	5.46	14.35	7.81	65.13	7.18	100.00	55.14	44.53	0.33	100.00

Table 3a – PAIMI Eligible Individuals Served by Race and Ethnicity – FY2017

State/ Jurisdiction	HHS Region	Race							Ethnicity			
		American Indian / Alaska Native	Asian	Black or African American	Multiple Races	Native Hawaiian / Other Pacific Islander	White	Total	Hispanic or Latino	Not Hispanic or Latino	Unk.	Total
Alabama	4	0	1	97	1	0	116	215	2	213	0	215
Alaska	10	11	0	4	3	0	39	57	3	0	1	4
AIC	11	28	0	0	0	0	0	28	0	28	0	28
Am. Samoa	9	0	0	0	5	49	0	54	0	54	0	54
Arizona	9	13	1	27	11	0	233	285	51	285	0	336
Arkansas	6	0	2	41	4	1	73	121	3	121	0	124
California	9	13	40	104	47	5	392	601	161	601	85	847
Colorado	8	1	1	25	1	0	64	92	10	82	0	92
Connecticut	1	0	0	1	0	0	8	9	2	7	0	9
Delaware	3	0	2	54	3	0	115	174	12	174	1	187
DC	3	1	1	116	3	0	17	138	2	138	0	140
Florida	4	2	0	88	5	0	117	212	14	167	53	234
Georgia	4	0	1	65	1	0	51	118	5	87	31	123
Guam	9	0	5	2	0	17	4	28	0	28	0	28
Hawaii	9	1	35	7	93	17	59	212	11	201	0	212
Idaho	10	3	0	2	6	1	88	100	6	91	3	100
Illinois	5	4	3	143	29	1	277	457	74	403	14	491
Indiana	5	0	0	21	0	0	79	100	0	100	0	100
Iowa	7	0	0	8	2	0	31	41	1	36	4	41
Kansas	7	9	2	50	21	1	318	401	24	377	27	428
Kentucky	4	0	0	25	13	0	107	145	3	142	0	145
Louisiana	6	0	0	62	4	0	51	117	7	117	0	124
Maine	1	5	0	5	5	0	204	219	0	93	126	219
Maryland	3	2	3	87	1	0	50	143	4	139	0	143
Massachusetts	1	1	4	15	1	0	132	153	10	144	0	154
Michigan	5	2	2	30	5	0	73	112	2	112	5	119
Minnesota	5	6	5	41	11	3	129	195	2	163	30	195
Mississippi	4	0	0	33	1	0	35	69	0	69	0	69
Missouri	7	1	1	62	0	0	146	210	3	207	0	210
Montana	8	16	0	2	1	0	201	220	3	220	2	225

Nebraska	7	1	0	2	1	0	16	20	1	20	1	22
Nevada	9	1	2	15	2	0	20	40	8	40	1	49
New Hampshire	1	1	1	3	4	0	217	226	2	226	6	234
New Jersey	2	0	4	75	12	1	201	293	30	245	18	293
New Mexico	6	7	1	7	0	0	143	158	67	91	0	158
New York	2	0	3	53	12	2	107	177	28	177	6	211
North Carolina	4	2	1	42	4	0	71	120	4	134	0	138
North Dakota	8	44	3	10	8	1	187	253	13	233	7	253
N. Marianas	9	0	1	0	2	5	4	12	0	12	0	12
Ohio	5	5	1	75	8	0	183	272	9	75	259	343
Oklahoma	6	10	0	17	1	0	51	79	8	71	0	79
Oregon	10	0	0	4	0	0	51	55	2	0	53	55
Pennsylvania	3	0	1	61	4	0	148	214	12	213	20	245
Puerto Rico	2	0	0	0	123	0	0	123	123	0	0	123
Rhode Island	1	1	2	15	9	0	185	212	17	195	0	212
South Carolina	4	0	0	97	7	1	103	208	7	194	7	208
South Dakota	8	11	0	0	4	1	43	59	3	56	0	59
Tennessee	4	0	1	27	3	0	57	88	1	88	0	89
Texas	6	5	5	166	11	0	318	505	185	518	0	703
Utah	8	1	0	4	1	0	107	113	27	98	17	142
Vermont	1	1	0	5	4	0	87	97	0	97	0	97
Virgin Islands	2	0	0	15	1	0	1	17	0	16	1	17
Virginia	3	1	3	41	3	0	84	132	2	130	0	132
Washington	10	24	8	113	91	2	363	601	40	561	0	601
West Virginia	3	4	0	14	2	0	68	88	2	88	0	90
Wisconsin	5	3	1	34	9	0	72	119	9	119	0	128
Wyoming	8	6	0	0	0	0	32	38	6	32	0	38
Totals		247	147	2,112	603	108	6,128	9,345	1,021	8,328	778	10,127
Percentages		2.64	1.57	22.60	6.45	1.16	65.58	100	10.08	82.24	7.68	100.00

Table 3b – PAIMI Eligible Individuals Served by Race and Ethnicity – FY2018

State/ Jurisdiction	HHS Region	Race							Ethnicity			
		American Indian / Alaska Native	Asian	Black or African American	Multiple Races	Native Hawaiian / Other Pacific Islander	White	Total	Hispanic or Latino	Not Hispanic or Latino	Unk.	Total
Alabama	4	0	1	88	1	0	105	195	6	189	0	195
Alaska	10	10	0	6	2	0	28	46	3	46	0	49
AIC	11	21	0	0	0	0	0	21	0	21	0	21
Am. Samoa	9	0	0	0	5	61	0	66	0	0	0	0
Arizona	9	9	4	33	9	1	254	310	48	310	0	358
Arkansas	6	0	0	25	5	1	61	92	1	91	1	93
California	9	8	30	104	28	4	537	711	174	539	67	780
Colorado	8	0	3	30	4	2	43	82	14	68	37	119
Connecticut	1	0	0	1	1	0	10	12	4	12	2	18
Delaware	3	0	2	52	5	0	108	167	12	167	4	183
DC	3	0	2	94	2	0	12	110	3	110	0	113
Florida	4	1	0	64	4	0	101	170	15	169	18	202
Georgia	4	1	0	45	3	0	46	95	3	92	1	96
Guam	9	0	1	1	0	12	2	16	0	16	0	16
Hawaii	9	0	21	2	48	11	44	126	8	70	0	78
Idaho	10	1	0	0	5	1	81	88	8	88	6	102
Illinois	5	6	7	148	30	0	255	446	53	393	26	472
Indiana	5	0	0	25	1	0	67	93	1	94	1	96
Iowa	7	0	0	7	0	0	33	40	0	39	1	40
Kansas	7	11	4	43	10	3	321	392	18	392	21	431
Kentucky	4	0	1	11	7	0	88	107	4	101	6	111
Louisiana	6	0	0	30	1	0	26	57	5	57	0	62
Maine	1	1	0	9	6	0	173	189	1	89	99	189
Maryland	3	2	4	88	3	1	55	153	4	150	1	155
Massachusetts	1	0	2	7	1	2	18	30	3	30	0	33
Michigan	5	1	1	48	7	0	95	152	2	157	5	164
Minnesota	5	4	4	50	15	0	146	219	9	210	0	219
Mississippi	4	0	0	13	0	0	16	29	1	29	0	30
Missouri	7	1	1	65	0	0	97	164	2	164	0	166
Montana	8	25	1	0	4	1	171	202	4	198	0	202

Nebraska	7	0	0	0	0	0	13	13	1	13	0	14
Nevada	9	0	2	10	2	0	21	35	2	35	0	37
New Hampshire	1	3	4	4	8	0	267	286	9	286	1	296
New Jersey	2	0	9	61	10	0	203	283	30	251	2	283
New Mexico	6	5	0	4	2	0	108	119	36	83	0	119
New York	2	1	0	36	7	0	86	130	17	113	12	142
North Carolina	4	1	0	24	3	1	51	80	3	80	21	104
North Dakota	8	45	1	8	14	0	200	268	16	251	1	268
N. Marianas	9	1	3	0	4	9	3	20	0	20	0	20
Ohio	5	2	1	105	8	0	300	416	6	410	81	497
Oklahoma	6	6	0	17	2	0	41	66	1	65	0	66
Oregon	10	0	0	1	0	0	35	36	2	27	7	36
Pennsylvania	3	0	4	58	15	0	164	241	15	263	0	278
Puerto Rico	2	0	0	0	78	0	0	78	78	0	0	78
Rhode Island	1	1	1	14	6	0	191	213	16	213	0	229
South Carolina	4	3	0	105	8	3	92	211	6	197	8	211
South Dakota	8	3	0	1	1	0	22	27	1	29	0	30
Tennessee	4	0	1	19	6	0	53	79	1	79	0	80
Texas	6	3	4	173	18	1	542	741	198	541	2	741
Utah	8	3	0	6	1	0	142	152	16	152	0	168
Vermont	1	2	2	7	3	2	79	95	1	95	0	96
Virgin Islands	2	0	0	8	0	0	1	9	0	9	0	9
Virginia	3	0	2	34	4	1	88	129	5	124	13	142
Washington	10	16	5	65	16	4	230	336	29	336	0	365
West Virginia	3	2	0	5	1	0	65	73	1	73	0	74
Wisconsin	5	2	1	44	8	1	87	143	12	102	29	143
Wyoming	8	2	0	0	5	0	22	29	5	24	0	29
Totals		203	129	1,898	437	122	6,099	8,888	913	7,962	473	9,348
Percentages		2.28	1.45	21.35	4.92	1.37	68.62	100	9.77	85.17	5.06	100.00

Table 4a - Living Arrangements of PAIMI Eligible Individuals – FY2017

State/ Jurisdiction	HHS Region	Community Residential Home for Children/ Youth up to age 18 Yrs.	Community Residential Home for Adults	Non-Medical Community -Based Residential Facility for Children/ Youth	Foster Care	Nursing Homes, Including Skilled Nursing Facilities (SNF)	Intermediate Care Facilities (ICF)	Public and Private General Hospital	Public and Private Institutions	Psychiatric Hospitals (Public or Private)	Legal/Jail/ Detention	Veterans Administration Hospital	Other Federal Facility	Homeless	Independent (in the community & PAIMI-eligible)	Parental or Other Family Home	Unk.	Total
Alabama	4	0	11	0	9	4	0	0	112	3	43	0	0	0	0	0	75	257
Alaska	10	0	7	1	0	0	0	0	1	0	7	0	0	3	28	11	3	61
AIC	11	1	0	0	3	0	0	0	1	0	4	0	0	0	5	14	0	28
Am. Samoa	9	0	0	0	0	0	0	0	0	12	18	0	0	0	11	13	0	54
Arizona	9	2	16	0	0	0	0	0	1	27	2	1	0	18	0	0	269	336
Arkansas	6	1	6	0	1	2	0	0	2	15	17	0	0	0	22	58	0	124
California	9	5	14	0	2	7	1	4	92	10	111	0	0	30	446	124	1	847
Colorado	8	0	2	0	0	2	0	4	1	2	69	0	0	1	8	3	0	92
Connecticut	1	0	1	0	0	5	0	0	0	0	1	0	0	0	1	0	1	9
Delaware	3	0	15	0	0	2	0	0	0	70	5	0	0	3	63	29	0	187
DC	3	0	9	0	0	3	0	2	38	15	5	0	0	22	9	13	24	140
Florida	4	1	11	0	0	1	0	1	120	15	72	0	0	3	8	9	0	241
Georgia	4	1	7	0	0	0	0	1	3	78	2	0	0	2	14	12	3	123
Guam	9	3	3	0	1	1	0	0	0	0	0	0	0	1	3	16	0	28
Hawaii	9	0	11	0	1	0	0	0	0	36	2	0	0	4	0	158	0	212
Idaho	10	1	9	0	2	5	0	0	47	6	5	0	0	1	13	11	0	100
Illinois	5	4	5	0	1	52	1	5	54	35	5	0	0	12	161	155	1	491
Indiana	5	2	0	0	0	3	0	0	0	22	24	0	0	4	14	26	5	100
Iowa	7	0	2	0	0	1	0	0	1	2	8	0	0	1	7	4	15	41
Kansas	7	0	13	0	0	58	1	1	32	29	0	0	0	10	227	57	0	428
Kentucky	4	14	0	0	4	5	0	0	45	3	36	0	0	0	14	22	2	145
Louisiana	6	0	1	1	0	4	0	1	34	5	15	0	0	1	5	9	48	124
Maine	1	23	20	0	1	2	0	20	0	37	35	0	0	3	4	4	70	219
Maryland	3	1	4	0	0	1	2	2	0	57	18	0	0	3	53	4	0	145
Massachusetts	1	0	7	0	1	3	0	11	57	0	2	0	0	3	43	27	0	154
Michigan	5	1	13	0	0	17	0	0	2	21	7	0	0	1	14	43	0	119

Minnesota	5	5	24	0	10	9	0	0	11	15	15	0	1	4	66	35	0	195
Mississippi	4	1	1	0	0	0	0	0	20	0	7	0	0	0	2	38	0	69
Missouri	7	0	15	0	1	37	2	0	64	0	32	0	0	0	41	18	0	210
Montana	8	0	4	50	0	2	0	3	43	0	56	1	0	4	47	11	4	225
Nebraska	7	0	1	0	0	1	0	0	15	0	0	0	0	0	2	0	3	22
Nevada	9	0	3	0	0	0	0	1	11	1	11	0	0	2	20	0	0	49
New Hampshire	1	3	12	0	1	2	0	7	0	45	22	0	0	6	0	0	142	240
New Jersey	2	0	2	0	0	2	0	13	0	181	3	0	0	0	36	56	0	293
New Mexico	6	1	7	0	1	1	0	3	0	113	6	0	0	0	14	12	0	158
New York	2	3	4	0	0	10	0	0	0	0	30	0	0	4	0	0	0	51
North Carolina	4	1	7	0	0	1	0	0	37	3	48	0	0	2	19	20	0	138
North Dakota	8	0	6	3	0	1	0	0	0	43	8	0	0	9	47	136	0	253
N. Marianas	9	0	0	0	0	0	0	0	0	1	4	0	0	1	6	0	0	12
Ohio	5	11	18	1	1	32	0	0	0	0	60	0	0	9	162	0	13	307
Oklahoma	6	0	2	0	0	0	0	1	0	30	31	0	0	0	8	7	0	79
Oregon	10	2	0	2	0	0	0	6	3	20	15	0	0	0	3	1	3	55
Pennsylvania	3	4	3	9	1	3	0	4	4	47	49	0	0	1	54	64	2	245
Puerto Rico	2	1	5	0	0	0	0	0	43	7	3	0	0	1	35	28	0	123
Rhode Island	1	1	9	0	0	12	0	3	9	76	5	0	0	4	55	73	9	256
South Carolina	4	1	2	0	1	0	0	0	12	11	148	0	0	0	10	21	2	208
South Dakota	8	1	2	1	0	1	0	0	4	8	3	0	0	0	9	30	0	59
Tennessee	4	3	6	0	0	0	0	0	2	21	28	0	0	4	2	0	23	89
Texas	6	27	14	3	21	12	0	5	18	321	68	0	2	17	114	80	1	703
Utah	8	2	0	0	1	0	0	0	8	1	23	0	0	1	85	21	0	142
Vermont	1	0	7	0	0	0	2	3	22	16	21	0	0	2	23	1	0	97
Virgin Islands	2	1	0	0	0	0	0	0	3	1	0	0	0	2	7	3	0	17
Virginia	3	0	1	0	0	1	0	0	115	3	9	0	0	0	0	3	0	132
Washington	10	0	3	0	0	0	0	0	102	1	351	0	0	11	81	12	40	601

West Virginia	3	0	3	0	1	2	0	0	0	39	6	0	0	7	18	14	0	90
Wisconsin	5	0	5	0	0	2	0	0	7	17	38	0	0	0	17	42	0	128
Wyoming	8	0	1	0	0	1	0	0	1	25	0	0	0	0	7	3	0	38
Totals		128	354	71	65	310	9	101	1,197	1,546	1,613	2	3	217	2,163	1,551	759	10,089
Percentages		1.27	3.51	0.70	0.64	3.07	0.09	1.00	11.86	15.32	15.99	0.02	0.03	2.15	21.44	15.37	7.52	100.00

Table 4b - Living Arrangements of PAIMI Eligible Individuals – FY2018

State / Jurisdiction	HHS Region	Community Residential Home for	Community Residential Home for Adults	Non-Medical Community -Based Residential Facility for Children/ Youth	Foster Care	Nursing Homes, Including Skilled Nursing Facilities (SNF)	Intermediate Care Facilities (ICF)	Public and Private General Hospital	Public and Private Institutions	Psychiatric Hospitals (Public or Private)	Legal/Jail/ Detention	Veterans Administration Hospital	Other Federal Facility	Homeless	Independent (in the community & PAIMI-eligible)	Parental or Other Family Home	Unk.	Total
Alabama	4	3	6	0	28	2	0	0	50	1	29	0	0	0	5	6	65	195
Alaska	10	0	5	0	0	0	0	0	0	1	0	0	0	7	26	10	0	49
AIC	11	1	0	0	2	0	0	0	2	0	1	0	0	0	1	14	0	21
Am. Samoa	9	0	0	0	0	0	0	0	0	42	4	0	0	0	20	0	0	66
Arizona	9	3	16	0	1	2	0	3	11	14	2	0	0	15	9	3	279	358
Arkansas	6	0	5	5	0	2	0	0	3	3	11	0	0	1	5	5	53	93
California	9	2	17	0	3	9	1	5	67	38	80	0	0	31	400	127	0	780
Colorado	8	0	0	0	0	1	0	16	2	12	68	0	0	1	21	1	10	132
Connecticut	1	0	0	0	0	6	0	1	1	3	1	0	0	0	4	2	0	18
Delaware	3	0	16	0	0	1	0	0	0	80	8	0	0	4	47	27	0	183
DC	3	0	6	0	0	1	0	0	43	9	6	0	0	17	10	8	13	113
Florida	4	0	5	0	0	3	4	0	101	24	49	0	0	0	8	5	3	202
Georgia	4	1	9	0	0	0	0	0	0	72	1	0	0	2	7	4	0	96
Guam	9	1	3	1	0	0	2	0	0	1	0	0	0	1	1	6	0	16
Hawaii	9	0	11	0	5	0	0	19	0	0	3	0	0	0	0	3	85	126
Idaho	10	0	10	2	0	1	2	1	3	57	2	0	0	4	8	12	0	102
Illinois	5	0	6	2	1	34	1	6	39	70	10	0	0	10	133	160	0	472
Indiana	5	0	2	1	0	0	0	0	14	1	30	0	0	0	21	17	10	96
Iowa	7	1	2	0	0	3	0	0	0	0	7	0	0	0	5	7	15	40
Kansas	7	0	14	0	0	63	0	2	22	21	8	0	0	6	248	47	0	431
Kentucky	4	11	0	0	2	4	1	0	34	5	22	0	0	2	12	17	1	111
Louisiana	6	1	4	1	1	2	1	0	4	12	3	0	0	0	10	23	0	62
Maine	1	14	21	7	2	1	0	25	0	47	21	1	0	4	22	11	13	189
Maryland	3	1	3	0	0	0	0	0	16	45	18	0	0	1	60	8	0	152
Massachusetts	1	0	3	0	0	1	0	5	12	0	1	0	0	1	5	5	0	33
Michigan	5	1	12	0	0	27	0	5	6	41	6	0	0	1	15	45	0	159

Minnesota	5	3	20	0	8	0	7	1	14	13	21	0	0	5	89	38	0	219
Mississippi	4	0	0	0	0	0	0	0	0	16	4	0	0	0	5	5	0	30
Missouri	7	0	16	1	1	23	4	0	43	12	28	0	0	2	31	5	0	166
Montana	8	1	6	0	1	1	0	2	102	2	53	0	0	4	22	7	1	202
Nebraska	7	0	0	0	0	2	0	0	8	0	0	0	0	0	4	0	0	14
Nevada	9	0	4	0	0	0	0	1	4	5	5	0	0	1	16	1	0	37
New Hampshire	1	0	9	0	0	3	0	5	24	33	11	0	0	7	78	1	125	296
New Jersey	2	3	1	0	1	2	0	5	3	178	0	0	0	0	41	49	0	283
New York	2	0	7	0	0	6	0	1	3	4	24	0	0	6	26	2	63	142
North Carolina	4	2	6	0	0	1	0	0	37	4	29	0	0	2	8	15	0	104
North Dakota	8	0	7	1	5	1	0	1	7	41	4	0	0	7	40	154	0	268
N. Marianas	9	0	0	0	0	0	0	0	0	1	6	0	0	1	7	5	0	20
Ohio	5	6	31	1	0	23	2	5	20	91	51	0	0	12	166	105	1	514
Oklahoma	6	0	0	0	0	1	0	0	0	11	50	0	0	0	2	1	0	65
Oregon	10	0	3	0	0	1	0	1	3	15	6	0	0	0	3	2	2	36
Pennsylvania	3	3	6	3	0	3	0	2	10	59	25	0	0	5	99	63	0	278
Puerto Rico	2	0	1	0	0	0	0	0	42	12	3	0	0	0	14	6	0	78
Rhode Island	1	1	8	2	0	11	0	7	11	44	6	0	0	5	74	52	8	229
South Carolina	4	2	1	1	0	0	0	1	20	6	140	0	0	0	7	31	2	211
South Dakota	8	0	1	2	0	2	1	0	1	7	1	0	0	0	7	8	0	30
Tennessee	4	0	7	4	0	0	0	0	0	14	23	0	0	1	5	0	26	80
Texas	6	11	9	9	1	13	0	3	13	398	90	0	0	10	122	50	12	741
Utah	8	2	0	0	0	2	0	0	9	3	11	0	0	6	114	21	0	168
Vermont	1	1	5	0	0	2	0	1	12	15	15	0	0	2	38	5	0	96
Virgin Islands	2	1	0	0	0	0	0	0	2	0	0	0	0	0	3	3	0	9
Virginia	3	0	14	1	0	3	0	0	13	98	7	0	0	0	2	4	0	142
Washington	10	1	13	1	0	2	2	1	33	50	200	0	0	17	4	1	103	428
West Virginia	3	0	3	1	1	0	0	0	0	30	5	0	0	3	20	11	0	74
Wisconsin	5	0	11	1	1	3	0	0	2	18	47	0	0	1	26	33	0	143

Wyoming	8	0	0	0	0	0	0	0	0	23	0	0	0	0	6	0	0	29
Totals		77	365	47	64	268	28	125	866	1,802	1,256	1	0	205	2,182	1,251	890	9,427
Percentages		0.82	3.87	0.50	0.68	2.84	0.30	1.33	9.19	19.12	13.32	0.01	0.00	2.17	23.15	13.27	9.44	100.00

Table 5a – Complaints Involving Alleged Abuse of PAIMI Eligible Individuals – FY2017

State/ Jurisdiction	HHS Region	Number of Abuse Complaints Closed	Inappropriate/Excessive					Involuntary				Failure to provide appropriate	Complaints Concerning							
			Medication	Physical Restraint	Chemical Restraint	Mechanical Restraint	Seclusion	Medication	Electric Convulsive Therapy (ECT)	Aversive Behavioral Therapy	Sterilization		Failure to provide Medical Treatment	Physical Assault	Sexual Assault	Staff Threats /Retaliation/Assaults	Coercion	Financial Exploitation	Suspicious Death	Other
Alabama	4	33	1	10	1	0	0	0	0	0	0	13	2	1	0	2	0	2	1	0
Alaska	10	9	0	0	0	2	1	1	0	0	0	3	0	0	2	0	0	0	0	0
AIC	11	1	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0
Am. Samoa	9	19	5	0	0	0	3	2	0	0	0	3	3	0	0	0	2	1	0	0
Arizona	9	8	0	1	0	0	0	0	0	0	0	1	1	1	3	0	0	1	0	0
Arkansas	6	19	1	1	0	0	2	0	0	0	0	7	2	2	1	2	0	1	0	0
California	9	66	3	4	1	0	2	3	0	0	0	14	2	14	7	3	1	2	10	0
Colorado	8	35	0	2	0	3	14	0	0	0	0	15	0	1	0	0	0	0	0	0
Connecticut	1	1	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0
Delaware	3	4	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	1	2	0
DC	3	32	1	5	1	0	0	4	0	0	0	6	3	6	3	2	0	1	0	0
Florida	4	71	5	2	0	0	1	1	0	0	0	34	22	1	0	1	0	3	1	0
Georgia	4	38	0	0	0	0	1	16	0	0	0	3	3	0	0	3	0	0	12	0
Guam	9	3	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	2	0
Hawaii	9	15	3	2	1	0	0	0	0	0	0	3	0	2	1	3	0	0	0	0
Idaho	10	12	3	1	0	0	0	0	0	0	0	5	0	1	0	1	0	0	1	0
Illinois	5	47	4	3	4	1	2	6	0	0	0	9	7	2	2	3	0	4	0	0
Indiana	5	8	0	1	0	0	0	0	0	0	0	4	0	1	0	2	0	0	0	0
Iowa	7	47	2	9	1	5	8	0	0	0	0	9	3	2	1	1	1	1	4	0
Kansas	7	28	4	1	0	1	1	2	0	0	0	7	0	5	2	0	1	4	0	0
Kentucky	4	13	1	3	1	1	2	1	0	0	0	2	0	1	0	0	0	0	1	0
Louisiana	6	17	0	1	0	0	0	1	0	0	0	7	4	3	0	1	0	0	0	0
Maine	1	49	0	8	1	0	0	0	0	0	0	38	0	0	0	0	0	2	0	0
Maryland	3	44	0	2	1	0	13	4	0	0	0	5	3	8	4	2	0	1	1	0
Massachusetts	1	45	1	3	2	0	0	0	0	0	0	27	6	4	1	1	0	0	0	0
Michigan	5	21	0	4	1	0	1	0	0	0	0	6	1	3	0	2	0	0	0	3
Minnesota	5	25	0	1	0	0	0	1	0	1	0	13	7	1	0	1	0	0	0	0

Mississippi	4	8	1	0	1	0	0	0	0	0	0	3	2	0	0	1	0	0	0	0
Missouri	7	86	17	4	0	0	0	3	1	0	0	28	28	2	1	1	0	0	1	0
Montana	8	82	1	13	0	0	8	0	0	0	0	22	5	6	7	3	1	1	1	14
Nebraska	7	9	0	1	0	0	1	0	0	0	0	1	3	1	0	1	0	1	0	0
Nevada	9	7	0	0	0	0	0	1	0	0	0	5	1	0	0	0	0	0	0	0
New Hampshire	1	46	3	4	1	0	3	2	0	0	0	28	1	2	2	0	0	0	0	0
New Jersey	2	79	17	2	0	0	0	0	0	0	0	10	6	14	2	8	0	0	20	0
New Mexico	6	99	21	4	1	0	5	22	0	0	0	13	7	10	10	2	0	2	2	0
New York	2	46	0	0	1	0	1	1	0	0	0	30	2	3	2	6	0	0	0	0
North Carolina	4	8	1	1	0	0	2	0	0	0	0	2	0	1	1	0	0	0	0	0
North Dakota	8	36	0	5	5	0	2	2	0	0	0	5	2	2	2	3	0	7	0	1
N. Marianas	9	1	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Ohio	5	141	11	3	1	1	13	1	0	0	0	36	31	17	4	14	3	3	0	3
Oklahoma	6	15	2	0	0	0	2	0	0	0	0	6	0	3	0	1	1	0	0	0
Oregon	10	17	0	1	0	0	5	0	0	0	0	3	0	1	1	0	6	0	0	0
Pennsylvania	3	21	1	2	0	0	1	0	0	1	0	7	2	6	0	1	0	0	0	0
Puerto Rico	2	5	1	1	0	0	1	0	0	0	0	1	1	0	0	0	0	0	0	0
Rhode Island	1	3	2	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0
South Carolina	4	127	0	0	0	0	0	0	0	0	0	124	0	1	0	0	0	0	0	2
South Dakota	8	13	0	0	0	0	1	1	0	0	0	8	1	0	0	2	0	0	0	0
Tennessee	4	32	5	2	1	0	1	0	0	0	0	12	2	8	1	0	0	0	0	0
Texas	6	180	10	11	2	0	2	5	1	0	0	88	42	7	5	3	0	4	0	0
Utah	8	7	0	0	0	0	0	0	0	0	0	5	2	0	0	0	0	0	0	0
Vermont	1	47	2	7	2	4	4	0	0	0	0	17	2	3	2	1	2	0	0	1
Virgin Islands	2	4	1	0	0	0	0	0	0	0	0	2	0	0	1	0	0	0	0	0
Virginia	3	55	1	7	0	6	0	1	0	0	0	15	1	6	5	3	7	0	3	0
Washington	10	301	9	10	3	1	33	9	0	1	0	173	35	1	0	17	0	5	0	4
West Virginia	3	18	3	2	0	0	2	0	0	0	0	2	0	1	2	5	0	1	0	0
Wisconsin	5	16	0	0	0	2	1	0	0	0	0	12	1	0	0	0	0	0	0	0
Wyoming	8	26	0	1	0	2	0	0	0	0	0	13	7	0	2	0	0	0	1	0
Totals		2,245	143	145	34	29	139	90	2	3	0	907	254	155	77	102	25	49	63	28
Percentages		100.0	6.3	6.4	1.5	1.2	6.1	4.0	0.09	0.13	0.00	40.40	11.31	6.9	3.4	4.54	1.1	2.1	2.8	1.2
		0	7	6	1	9	9	1						0	3		1	8	1	5

Table 5b – Complaints Involving Alleged Abuse of PAIMI Eligible Individuals – FY2018

State/ Jurisdiction	HHS Region	Number of Abuse Complaints Closed	Inappropriate/Excessive					Involuntary				Failure to provide appropriate	Complaints Concerning							
			Medication	Physical Restraint	Chemical Restraint	Mechanical Restraint	Seclusion	Medication	Electric Convulsive Therapy (ECT)	Aversive Behavioral Therapy	Sterilization		Failure to provide Medical Treatment	Physical Assault	Sexual Assault	Staff Threats /Retaliation/Assaults	Coercion	Financial Exploitation	Suspicious Death	Other
Alabama	4	22	2	5	2	0	1	0	0	0	0	3	0	8	1	0	0	0	0	0
Alaska	10	2	0	1	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0
AIC	11	3	0	0	0	0	0	0	0	0	0	3	0	0	0	0	0	0	0	0
Am. Samoa	9	5	0	0	0	0	0	0	0	0	0	0	1	1	0	1	0	2	0	0
Arizona	9	28	8	3	0	0	2	1	1	1	0	5	2	2	2	1	0	0	0	0
Arkansas	6	16	0	1	0	0	0	0	0	0	0	9	3	3	0	0	0	0	0	0
California	9	57	5	7	0	0	4	0	0	0	0	6	0	5	4	3	0	3	20	0
Colorado	8	17	0	0	0	0	0	0	0	0	0	16	1	0	0	0	0	0	0	0
Connecticut	1	3	1	1	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0
Delaware	3	15	0	2	0	0	0	0	0	0	0	6	1	2	2	1	0	1	0	0
DC	3	37	0	3	2	1	3	2	0	0	0	16	2	1	3	0	0	2	2	0
Florida	4	98	4	1	0	0	2	0	0	0	0	33	17	27	2	2	0	2	7	1
Georgia	4	30	0	1	4	0	0	7	0	0	0	1	1	2	0	1	0	0	10	3
Guam	9	2	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	1	0
Hawaii	9	5	0	0	0	1	0	0	0	0	0	1	0	3	0	0	0	0	0	0
Idaho	10	31	3	9	2	0	3	3	0	0	0	6	2	1	0	1	0	1	0	0
Illinois	5	55	5	10	1	1	7	5	0	2	0	6	6	5	0	2	0	3	0	2
Indiana	5	16	1	2	0	0	0	0	0	0	0	7	3	0	0	3	0	0	0	0
Iowa	7	33	0	5	0	0	7	0	0	0	0	9	1	2	1	3	0	1	4	0
Kansas	7	21	2	2	1	0	0	0	0	0	0	2	5	2	1	1	4	0	1	0
Kentucky	4	4	0	3	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0
Louisiana	6	5	0	0	0	0	0	2	0	0	0	1	1	1	0	0	0	0	0	0
Maine	1	50	0	6	1	0	1	0	1	0	0	36	3	2	0	0	0	0	0	0
Maryland	3	36	1	5	0	1	2	3	0	0	0	3	5	0	10	1	0	1	1	3
Massachusetts	1	9	0	1	0	0	0	1	0	0	0	0	6	0	0	0	0	1	0	0
Michigan	5	14	1	5	0	0	3	1	0	0	0	1	0	0	0	0	0	2	0	1
Minnesota	5	33	1	1	0	0	0	0	0	0	0	18	3	3	0	0	0	1	0	6

Mississippi	4	8	0	1	0	0	0	0	0	0	0	3	1	0	0	3	0	0	0	0
Missouri	7	83	9	2	2	0	2	0	1	0	0	29	29	0	1	2	0	0	6	0
Montana	8	59	5	3	1	0	6	0	0	1	0	28	3	2	7	0	1	1	0	1
Nebraska	7	2	0	1	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0
Nevada	9	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
New Hampshire	1	51	4	4	1	4	3	2	0	0	0	27	2	2	0	1	1	0	0	0
New Jersey	2	103	24	0	0	1	0	1	0	0	0	8	10	37	1	7	0	1	13	0
New Mexico	6	63	10	4	0	1	5	1	0	0	0	13	12	1	7	9	0	0	0	0
New York	2	11	0	0	0	0	2	0	0	0	0	7	2	0	0	0	0	0	0	0
North Carolina	4	17	2	0	0	0	2	0	0	0	0	7	1	2	0	3	0	0	0	0
North Dakota	8	28	2	5	0	2	0	0	0	0	0	2	0	3	2	2	1	8	0	1
N. Marianas	9	1	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0
Ohio	5	57	7	3	1	0	2	1	0	0	0	16	7	5	0	6	5	2	2	0
Oklahoma	6	16	0	1	0	0	0	0	0	0	0	4	9	2	0	0	0	0	0	0
Oregon	10	11	0	1	0	0	0	0	0	0	0	3	0	0	0	0	6	1	0	0
Pennsylvania	3	17	1	0	0	1	0	3	0	0	0	3	2	4	0	0	0	3	0	0
Puerto Rico	2	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Rhode Island	1	1	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
South Carolina	4	129	0	0	0	0	0	0	0	0	0	125	0	1	1	1	0	0	0	1
South Dakota	8	11	2	1	0	0	1	0	0	0	0	4	2	0	0	1	0	0	0	0
Tennessee	4	30	2	6	0	0	1	0	0	0	0	15	1	2	2	1	0	0	0	0
Texas	6	99	8	5	0	2	1	2	0	0	0	57	9	8	1	4	1	1	0	0
Utah	8	8	1	0	1	0	0	0	0	0	0	5	1	0	0	0	0	0	0	0
Vermont	1	33	0	5	2	1	3	0	0	0	0	7	3	3	0	4	1	1	0	3
Virgin Islands	2	10	1	0	0	0	1	0	0	0	0	2	1	2	2	0	0	0	1	0
Virginia	3	30	1	5	0	3	1	0	0	0	0	7	0	3	2	0	0	0	8	0
Washington	10	193	11	4	1	3	26	9	0	0	0	109	12	2	2	8	0	3	0	3
West Virginia	3	14	0	2	0	0	1	0	0	0	0	3	2	0	1	2	0	3	0	0
Wisconsin	5	32	0	2	0	0	6	0	0	0	0	16	4	2	2	0	0	0	0	0
Wyoming	8	21	1	3	0	1	2	0	0	0	0	6	5	1	1	1	0	0	0	0
Totals		1,785	126	132	22	23	100	44	3	4	0	697	182	153	59	75	20	44	76	25
Percentages		100.0	7.0	7.3	1.2	1.2	5.6	2.4	0.17	0.22	0.0	39.0	10.20	8.5	3.3	4.20	1.1	2.4	4.2	1.40
		0	6	9	3	9	0	6			0	5		7	1		2	6	6	

Table 6a – Complaints Involving Alleged Neglect of PAIMI Eligible Individuals – FY2017

State/ Jurisdiction	HHS Region	Number of Neglect Complaints Closed	Failure to Provide for Appropriate								
			Admission to Residential Care or Treatment Facility	Transportation to/from Residential Care or Treatment Facility	Discharge Planning or Release from Residential Care or Treatment Facility	Mental Health Diagnostic or Other Evaluation (does not include treatment)	Medical (non-mental health related) diagnostic physical examination	Inadequate Care (e.g., personal hygiene, clothing, food, shelter)	Physical Plant or Environmental Safety	Personal Safety Issues (unsecured access to facility, resident rooms, patient to patient abuse)	Other
Alabama	4	74	8	0	29	1	5	3	1	26	1
Alaska	10	2	0	0	1	1	0	0	0	0	0
AIC	11	1	0	0	0	0	0	1	0	0	0
Am. Samoa	9	9	1	1	2	1	1	1	1	0	1
Arizona	9	8	2	0	3	1	0	0	0	2	0
Arkansas	6	18	1	0	12	0	0	3	0	2	0
California	9	21	2	0	4	11	1	2	0	1	0
Colorado	8	2	0	0	1	0	1	0	0	0	0
Connecticut	1	0	0	0	0	0	0	0	0	0	0
Delaware	3	12	0	0	9	0	0	2	0	1	0
DC	3	43	0	0	18	3	0	20	0	2	0
Florida	4	32	1	0	10	1	5	11	2	2	0
Georgia	4	92	0	0	56	1	5	4	0	0	26
Guam	9	3	2	0	1	0	0	0	0	0	0
Hawaii	9	10	0	0	5	1	0	2	0	2	0
Idaho	10	59	2	0	42	2	5	6	0	2	0
Illinois	5	151	29	2	66	23	6	10	10	5	0
Indiana	5	17	1	0	8	0	0	4	1	3	0
Iowa	7	13	2	0	0	0	0	2	5	4	0
Kansas	7	40	2	0	27	0	4	4	1	2	0
Kentucky	4	16	0	0	11	3	1	0	0	1	0
Louisiana	6	17	1	0	12	0	0	1	0	3	0
Maine	1	37	4	0	32	0	0	1	0	0	0
Maryland	3	20	1	0	8	3	1	5	0	1	1
Massachusetts	1	35	3	0	20	3	2	4	0	3	0
Michigan	5	29	0	0	5	2	1	0	0	20	1

Minnesota	5	19	2	0	6	1	0	10	0	0	0
Mississippi	4	9	0	0	3	0	0	3	0	2	1
Missouri	7	95	1	0	30	10	30	22	1	1	0
Montana	8	51	1	0	6	13	14	5	6	2	4
Nebraska	7	3	0	0	0	0	1	0	2	0	0
Nevada	9	11	0	0	4	0	1	1	0	0	5
New Hampshire	1	30	11	0	16	0	1	1	0	1	0
New Jersey	2	31	0	0	23	0	2	1	2	2	1
New Mexico	6	199	22	0	63	6	12	72	0	24	0
New York	2	32	2	0	22	3	2	1	0	2	0
North Carolina	4	28	4	0	10	6	3	1	1	3	0
North Dakota	8	30	0	0	10	6	4	5	0	5	0
N. Marianas	9	1	0	0	0	0	0	1	0	0	0
Ohio	5	130	5	4	52	11	17	15	2	21	3
Oklahoma	6	10	0	0	10	0	0	0	0	0	0
Oregon	10	14	1	0	9	1	2	1	0	0	0
Pennsylvania	3	47	9	0	32	2	2	0	1	0	1
Puerto Rico	2	22	13	0	0	2	0	4	3	0	0
Rhode Island	1	19	3	0	11	1	1	0	0	1	2
South Carolina	4	6	1	0	2	0	0	0	1	0	2
South Dakota	8	9	0	0	6	2	0	1	0	0	0
Tennessee	4	11	4	0	0	1	1	2	0	3	0
Texas	6	136	5	0	74	5	0	30	3	19	0
Utah	8	2	1	0	0	0	0	0	0	0	1
Vermont	1	27	7	1	13	0	2	1	0	0	3
Virgin Islands	2	1	1	0	0	0	0	0	0	0	0
Virginia	3	61	3	0	34	2	6	3	1	12	0
Washington	10	164	6	2	93	20	16	16	1	6	4
West Virginia	3	32	0	0	21	1	5	3	0	2	0
Wisconsin	5	18	0	2	10	3	0	1	1	1	0
Wyoming	8	12	1	0	3	0	1	3	2	2	0
Totals		2,021	165	12	945	153	161	289	48	191	57
Percentages		100.00	8.16	0.59	46.76	7.57	7.97	14.30	2.38	9.45	2.82

Table 6b – Complaints Involving Alleged Neglect of PAIMI Eligible Individuals – FY2018

State/ Jurisdiction	HHS Region	Number of Neglect Complaints Closed	Failure to Provide for Appropriate								
			Admission to Residential Care or Treatment Facility	Transportation to/from Residential Care or Treatment Facility	Discharge Planning or Release from Residential Care or Treatment Facility	Mental Health Diagnostic or Other Evaluation (does not include treatment)	Medical (non-mental health related) diagnostic physical examination	Inadequate Care (e.g., personal hygiene, clothing, food, shelter)	Physical Plant or Environmental Safety	Personal Safety Issues (unsecured access to facility, resident rooms, patient to patient abuse)	Other
Alabama	4	59	3	0	25	3	1	1	0	3	23
Alaska	10	2	1	0	1	0	0	0	0	0	0
AIC	11	1	0	0	0	0	0	1	0	0	0
Am. Samoa	9	31	5	4	7	3	3	4	4	1	0
Arizona	9	35	5	1	7	13	1	4	0	3	1
Arkansas	6	5	3	0	1	0	0	0	1	0	0
California	9	23	1	1	6	2	9	2	1	1	0
Colorado	8	20	0	0	0	17	3	0	0	0	0
Connecticut	1	1	0	0	0	0	1	0	0	0	0
Delaware	3	34	0	0	23	0	0	8	1	2	0
DC	3	26	1	0	14	0	0	11	0	0	0
Florida	4	39	1	0	15	1	3	15	1	3	0
Georgia	4	105	0	1	58	1	5	6	0	2	32
Guam	9	4	4	0	0	0	0	0	0	0	0
Hawaii	9	7	0	0	3	1	1	0	0	2	0
Idaho	10	33	1	0	25	1	1	0	1	4	0
Illinois	5	59	9	0	36	6	1	4	2	1	0
Indiana	5	12	0	0	4	0	1	3	3	1	0
Iowa	7	15	2	1	2	1	0	7	1	1	0
Kansas	7	31	0	0	12	7	6	6	0	0	0
Kentucky	4	7	0	0	2	0	1	1	1	2	0
Louisiana	6	5	3	0	1	0	1	0	0	0	0
Maine	1	43	8	0	34	0	1	0	0	0	0
Maryland	3	19	5	0	11	1	0	0	1	0	1
Massachusetts	1	19	4	0	5	0	0	0	0	10	0

Michigan	5	22	1	0	5	1	2	7	0	6	0
Minnesota	5	34	14	2	11	1	0	5	0	0	1
Mississippi	4	8	1	0	1	0	0	6	0	0	0
Missouri	7	52	1	0	9	1	19	14	3	5	0
Montana	8	91	0	0	6	2	2	0	9	70	2
Nebraska	7	0	0	0	0	0	0	0	0	0	0
Nevada	9	8	0	0	2	0	1	3	0	0	2
New Hampshire	1	47	16	1	17	3	5	5	0	0	0
New Jersey	2	25	1	0	16	0	2	3	2	1	0
New Mexico	6	139	5	0	51	7	8	47	0	21	0
New York	2	28	2	0	21	1	0	4	0	0	0
North Carolina	4	7	0	0	4	1	2	0	0	0	0
North Dakota	8	40	3	0	3	1	6	14	3	10	0
N. Marianas	9	5	2	0	0	1	0	1	1	0	0
Ohio	5	68	11	3	18	6	8	12	3	6	1
Oklahoma	6	7	3	0	1	0	1	1	1	0	0
Oregon	10	4	0	0	3	1	0	0	0	0	0
Pennsylvania	3	26	1	0	13	3	6	0	0	2	1
Puerto Rico	2	2	2	0	0	0	0	0	0	0	0
Rhode Island	1	6	0	0	5	1	0	0	0	0	0
South Carolina	4	12	2	0	7	0	1	0	0	0	2
South Dakota	8	5	0	0	4	0	0	0	1	0	0
Tennessee	4	20	0	0	6	1	6	6	0	1	0
Texas	6	135	7	1	50	8	21	24	1	19	4
Utah	8	0	0	0	0	0	0	0	0	0	0
Vermont	1	25	5	0	12	1	0	3	1	2	1
Virgin Islands	2	9	2	0	0	2	1	1	2	1	0
Virginia	3	70	0	0	57	0	4	2	2	5	0
Washington	10	72	1	0	41	6	9	6	4	2	3
West Virginia	3	23	1	0	16	0	2	3	1	0	0
Wisconsin	5	21	0	2	11	5	2	1	0	0	0
Wyoming	8	8	0	0	4	0	2	1	1	0	0
Totals		1,654	137	17	686	110	149	242	52	187	74
Percentages		100.00	8.28	1.03	41.48	6.65	9.01	14.63	3.14	11.31	4.47

Table 7a – Complaints Involving Alleged Rights Violations of PAIMI Eligible Individuals – FY2017

State/ Jurisdiction	HHS Region	Number of Rights Complaints Closed	Denial of							Failure to Provide					Problem with Advance Directives	Denial of Parental /Family Rights	Other
			Financial Benefits and Entitlements	Guardianship /Conservative Problems	Rights Protection/Legal Assistance	Privacy Rights	Recreational Opportunities	Visitors	Access to Records	Individual Treatment Plan	Written Discharge Plan	Mental Health Services Planning	Confidentiality	Informed Consent			
Alabama	4	65	3	4	6	1	3	0	1	1	0	0	0	1	2	0	43
Alaska	10	29	16	0	0	0	0	0	1	0	0	0	0	0	0	0	12
AIC	11	13	2	0	0	0	0	0	0	0	0	0	0	0	1	0	10
Am. Samoa	9	25	0	0	4	2	2	2	0	4	3	0	0	0	0	3	5
Arizona	9	8	1	0	5	1	0	0	0	0	0	0	0	0	0	1	0
Arkansas	6	69	2	2	3	0	0	0	0	0	0	0	0	0	1	0	61
California	9	668	67	2	68	4	0	1	10	0	0	151	4	6	0	4	351
Colorado	8	14	0	0	8	3	3	0	0	0	0	0	0	0	0	0	0
Connecticut	1	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1
Delaware	3	58	31	1	1	1	1	1	0	0	0	0	0	0	1	1	20
DC	3	32	1	5	2	0	1	0	0	9	1	3	1	2	6	0	1
Florida	4	47	2	1	25	2	6	0	1	0	0	0	1	1	0	0	8
Georgia	4	13	1	2	3	0	0	0	0	0	0	0	0	2	0	0	5
Guam	9	19	1	7	6	0	0	0	0	0	0	0	0	0	4	1	0
Hawaii	9	174	14	14	0	0	0	0	0	0	0	91	0	0	38	0	17
Idaho	10	46	2	6	18	3	2	0	1	2	1	0	4	1	0	0	6
Illinois	5	323	9	31	1	6	2	0	7	0	0	0	0	1	3	1	262
Indiana	5	37	1	3	0	0	1	0	0	0	0	0	0	0	0	0	32
Iowa	7	32	3	3	0	0	1	0	0	0	0	1	0	0	0	0	24
Kansas	7	325	5	15	13	2	1	0	2	0	0	0	2	2	0	6	277
Kentucky	4	45	2	3	20	0	1	0	1	0	0	10	0	0	0	0	8
Louisiana	6	48	0	1	5	0	1	0	1	0	0	0	0	2	1	0	37
Maine	1	85	8	8	2	2	7	1	0	0	0	4	0	0	0	0	53
Maryland	3	74	3	0	4	2	3	0	0	1	0	0	0	2	0	0	59
Massachusetts	1	76	1	0	16	1	2	0	1	0	0	0	0	0	0	1	54
Michigan	5	27	4	0	1	0	0	0	1	1	4	1	0	0	0	0	15
Minnesota	5	102	7	8	2	13	2	3	3	15	2	25	0	0	0	2	20

Mississippi	4	11	1	0	2	0	2	0	0	0	0	0	0	0	0	0	6
Missouri	7	130	30	33	2	22	8	2	3	21	0	0	3	0	1	0	5
Montana	8	59	4	0	1	2	1	0	0	0	0	0	0	1	0	2	48
Nebraska	7	3	0	1	0	1	0	0	0	0	0	0	0	1	0	0	0
Nevada	9	21	0	0	4	1	0	1	0	0	0	0	0	0	0	0	15
New Hampshire	1	119	12	8	4	0	5	1	0	2	1	0	0	0	0	3	83
New Jersey	2	70	0	0	1	2	4	1	0	0	0	0	0	0	0	0	62
New Mexico	6	44	1	5	20	7	0	0	0	0	0	0	0	2	1	5	3
New York	2	121	5	4	2	1	0	0	1	0	0	0	0	0	0	4	104
North Carolina	4	46	1	9	9	1	6	1	0	0	0	0	0	0	0	1	18
North Dakota	8	72	1	0	3	0	1	0	0	63	1	0	0	0	0	0	3
N. Marianas	9	2	0	0	0	0	0	0	0	0	0	0	0	0	0	0	2
Ohio	5	354	22	22	13	18	24	3	7	9	1	4	3	24	2	4	198
Oklahoma	6	11	0	0	2	0	0	0	0	0	0	0	0	1	0	0	8
Oregon	10	11	0	3	0	0	0	0	0	0	4	2	0	0	0	0	2
Pennsylvania	3	163	4	5	16	0	0	2	0	49	0	0	0	0	5	2	80
Puerto Rico	2	38	7	0	12	0	0	0	1	0	0	0	0	0	0	0	18
Rhode Island	1	62	2	4	0	0	0	0	0	0	0	0	0	0	0	0	56
South Carolina	4	15	0	1	0	0	0	0	1	0	0	0	0	0	0	0	13
South Dakota	8	29	4	0	1	2	0	0	0	0	0	0	0	0	0	0	22
Tennessee	4	24	0	0	1	0	0	2	0	0	0	0	0	0	0	0	21
Texas	6	213	10	23	28	27	26	2	5	0	0	0	4	7	2	7	72
Utah	8	111	2	1	47	0	3	0	1	0	0	0	0	0	0	2	55
Vermont	1	31	0	0	4	1	1	0	2	0	0	0	0	0	9	0	14
Virgin Islands	2	6	2	2	1	0	0	0	1	0	0	0	0	0	0	0	0
Virginia	3	12	3	3	1	0	2	0	1	0	0	0	0	1	1	0	0
Washington	10	289	43	3	30	14	7	0	4	8	20	36	5	0	0	14	105
West Virginia	3	29	2	2	5	3	2	0	0	0	0	0	0	0	0	0	15
Wisconsin	5	36	0	1	1	1	0	0	0	0	0	0	0	0	0	0	33
Wyoming	8	10	2	1	5	1	1	0	0	0	0	0	0	0	0	0	0
Totals		4,597	344	247	428	147	132	23	57	185	38	328	27	57	78	64	2,442
Percentages		100.0 0	7.48	5.37	9.31	3.2 0	2.8 7	0.5 0	1.2 4	4.0 2	0.8 3	7.14	0.59	1.24	1.70	1.39	53.12

Table 7b – Complaints Involving Alleged Rights Violations of PAIMI Eligible Individuals – FY2018

State/ Jurisdiction	HHS Region	Number of Rights Complaints Closed	Denial of							Failure to Provide					Problem with Advance Directives	Denial of Parental /Family Rights	Other
			Financial Benefits and Entitlements	Guardianship /Conservative Problems	Rights Protection/Legal Assistance	Privacy Rights	Recreational Opportunities	Visitors	Access to Records	Individual Treatment Plan	Written Discharge Plan	Mental Health Services Planning	Confidentiality	Informed Consent			
Alabama	4	42	1	2	4	0	1	0	1	1	1	1	0	0	0	0	30
Alaska	10	23	14	0	1	0	0	0	0	0	0	0	0	0	0	0	8
AIC	11	11	0	0	0	0	0	0	0	11	0	0	0	0	0	0	0
Am. Samoa	9	24	0	0	1	3	2	0	0	4	7	4	0	0	0	3	0
Arizona	9	27	1	0	4	0	0	3	0	15	1	0	1	0	1	1	0
Arkansas	6	57	0	5	0	0	0	0	1	0	0	0	0	2	0	0	49
California	9	570	76	8	31	2	1	0	8	5	4	5	1	4	2	3	420
Colorado	8	34	0	0	10	2	7	0	0	0	10	5	0	0	0	0	0
Connecticut	1	4	0	0	0	0	0	0	0	0	0	0	0	0	0	0	4
Delaware	3	49	29	3	0	0	0	0	1	0	0	0	1	0	0	2	13
DC	3	28	0	3	0	1	1	0	0	0	3	1	0	1	14	0	4
Florida	4	50	2	6	21	5	4	0	2	0	0	0	0	0	0	0	10
Georgia	4	5	0	0	1	0	0	0	0	0	0	0	0	0	0	0	4
Guam	9	10	0	2	0	0	0	0	0	1	1	0	0	0	5	1	0
Hawaii	9	99	5	5	0	0	0	0	0	53	0	3	0	0	33	0	0
Idaho	10	26	1	3	7	2	1	0	3	4	0	1	1	0	0	0	3
Illinois	5	234	5	24	2	5	6	1	5	2	0	3	1	0	0	5	175
Indiana	5	12	0	0	0	4	1	0	0	0	0	2	0	1	0	0	4
Iowa	7	21	2	2	0	0	1	0	0	0	0	2	0	0	0	0	14
Kansas	7	323	91	19	5	0	2	0	1	0	0	0	4	6	1	2	192
Kentucky	4	33	0	3	1	4	5	1	0	0	8	1	0	3	0	0	7
Louisiana	6	10	2	2	1	0	1	0	0	0	2	0	0	1	0	0	1
Maine	1	73	4	6	8	5	1	0	0	0	3	15	1	0	1	1	28
Maryland	3	19	1	0	5	2	0	0	0	0	0	1	1	0	0	1	8
Massachusetts	1	11	0	0	5	0	1	0	0	0	0	0	0	0	0	0	5
Michigan	5	51	0	3	5	1	1	1	0	6	10	23	0	1	0	0	0
Minnesota	5	51	4	4	0	2	2	1	1	3	2	0	1	1	1	0	29

Mississippi	4	4	0	0	1	1	0	0	0	0	0	0	0	0	0	1	1
Missouri	7	69	20	27	1	7	4	0	0	3	4	0	0	0	1	0	2
Montana	8	30	1	0	1	1	0	0	0	1	5	0	0	1	0	4	16
Nebraska	7	5	0	5	0	0	0	0	0	0	0	0	0	0	0	0	0
Nevada	9	22	1	0	5	0	0	0	0	0	0	0	0	0	0	0	16
New Hampshire	1	162	19	9	8	3	13	1	0	3	0	0	8	3	0	4	91
New Jersey	2	57	0	1	1	1	2	0	1	0	0	3	0	0	1	1	46
New Mexico	6	32	0	5	19	0	0	0	3	0	0	0	0	4	0	1	0
New York	2	81	0	4	2	0	0	0	0	0	1	8	2	0	1	3	60
North Carolina	4	40	1	7	1	4	0	0	0	0	15	2	0	0	0	1	9
North Dakota	8	113	2	5	0	0	0	0	0	84	13	5	0	0	0	0	4
N. Marianas	9	4	3	0	0	0	0	0	0	0	0	0	0	0	1	0	0
Ohio	5	351	9	33	32	12	12	2	6	1	20	0	2	10	2	3	207
Oklahoma	6	7	0	1	2	0	0	0	0	0	2	1	0	0	0	0	1
Oregon	10	8	0	6	0	0	0	0	0	1	0	1	0	0	0	0	0
Pennsylvania	3	229	22	1	35	3	3	0	2	14	8	0	1	2	4	9	125
Puerto Rico	2	3	1	0	2	0	0	0	0	0	0	0	0	0	0	0	0
Rhode Island	1	17	0	3	0	0	0	0	0	0	0	0	0	0	0	0	14
South Carolina	4	19	0	0	0	1	0	0	0	0	3	0	0	0	0	0	15
South Dakota	8	12	1	0	0	0	1	0	2	0	0	0	0	0	0	0	8
Tennessee	4	20	1	0	7	0	0	1	0	0	0	0	0	0	0	0	11
Texas	6	250	6	8	69	28	27	1	3	0	35	0	4	15	11	4	39
Utah	8	134	5	6	121	0	0	0	0	0	1	1	0	0	0	0	0
Vermont	1	26	4	1	1	2	0	1	2	0	0	0	1	0	6	0	8
Virgin Islands	2	8	0	1	2	0	0	0	0	1	2	2	0	0	0	0	0
Virginia	3	25	2	3	3	0	5	0	3	0	2	3	0	3	1	0	0
Washington	10	261	31	7	15	9	9	1	10	18	34	67	5	1	0	4	50
West Virginia	3	36	3	0	12	1	0	0	0	1	3	0	1	0	0	0	15
Wisconsin	5	49	1	1	0	4	3	0	0	1	0	0	0	2	0	0	37
Wyoming	8	5	0	0	2	1	2	0	0	0	0	0	0	0	0	0	0
Totals		3,976	371	234	454	116	119	14	55	233	200	160	36	61	86	54	1,783
Percentages		100.0 0	9.33	5.89	11.42	2.92	2.99	0.35	1.38	5.86	5.03	4.02	0.9 1	1.53	2.16	1.36	44.84

Table 8a – Death Investigations – FY2017

State/ Jurisdiction	HHS Region	The number of deaths of individuals reported to the P&A for investigation				All Death investigations conducted involving PAIMI- eligible individuals related			
		Total Number of Deaths Reported	State	The Centers for Medicare & Medicaid Services	Other Sources	Total Number of Death Investigations	Number of deaths investigated involving incidents of seclusion (S).	Number of deaths investigated involving incidents of restraint (R).	Number of deaths investigated NOT related to incidents of S&R, (e. g., suicides.)
Alabama	4	2	0	0	2	2	0	0	2
Alaska	10	8	0	0	8	8	0	0	8
AIC	11	0	0	0	0	0	0	0	0
Am. Samoa	9	0	0	0	0	0	0	0	0
Arizona	9	0	0	0	0	1	0	0	1
Arkansas	6	0	0	0	0	0	0	0	0
California	9	20	19	0	1	20	0	1	19
Colorado	8	1	0	0	1	1	0	0	1
Connecticut	1	0	0	0	0	0	0	0	0
Delaware	3	19	17	0	2	19	0	0	19
DC	3	4	4	0	0	1	0	0	1
Florida	4	12	1	0	11	12	0	3	9
Georgia	4	12	0	0	12	12	0	0	12
Guam	9	2	2	0	0	2	0	0	2
Hawaii	9	0	0	0	0	0	0	0	0
Idaho	10	1	0	0	1	1	0	0	1
Illinois	5	0	0	0	0	5	0	0	5
Indiana	5	1	1	0	0	0	0	0	0
Iowa	7	6	0	0	6	6	0	0	6
Kansas	7	1	0	0	1	1	0	0	1
Kentucky	4	10	8	0	2	10	0	0	10
Louisiana	6	0	0	0	0	0	0	0	0
Maine	1	0	0	0	0	0	0	0	0
Maryland	3	71	12	0	59	2	1	0	1
Massachusetts	1	255	254	0	1	2	1	0	1
Michigan	5	10	5	0	5	10	0	0	10
Minnesota	5	0	0	0	0	0	0	0	0

Mississippi	4	0	0	0	0	0	0	0	0
Missouri	7	595	595	0	0	4	0	0	4
Montana	8	2	0	0	2	1	0	0	1
Nebraska	7	0	0	0	0	0	0	0	0
Nevada	9	2	0	0	2	1	0	0	1
New Hampshire	1	0	0	0	0	0	0	0	0
New Jersey	2	39	36	0	3	39	0	1	38
New Mexico	6	1	1	0	0	1	0	0	1
New York	2	12	0	0	12	12	0	1	11
North Carolina	4	21	21	0	0	1	0	0	1
North Dakota	8	4	3	0	1	4	0	0	4
N. Marianas	9	0	0	0	0	0	0	0	0
Ohio	5	2	2	0	0	2	0	0	2
Oklahoma	6	1	0	1	0	0	0	0	0
Oregon	10	0	0	0	0	0	0	0	0
Pennsylvania	3	41	41	0	0	0	0	0	0
Puerto Rico	2	2	1	0	1	2	0	0	2
Rhode Island	1	1	0	0	1	0	0	0	0
South Carolina	4	1	0	0	1	1	0	0	1
South Dakota	8	0	0	0	0	0	0	0	0
Tennessee	4	0	0	0	0	0	0	0	0
Texas	6	4	0	0	4	4	0	0	4
Utah	8	5	0	0	5	5	2	0	3
Vermont	1	4	0	0	4	3	0	0	3
Virgin Islands	2	0	0	0	0	0	0	0	0
Virginia	3	65	55	0	10	65	0	2	63
Washington	10	6	0	0	6	6	2	0	4
West Virginia	3	0	0	0	0	0	0	0	0
Wisconsin	5	7	7	0	0	7	0	0	7
Wyoming	8	2	2	0	0	2	0	0	2
Totals		1,252	1,087	1	164	275	6	8	261

Table 8b – Death Investigations – FY2018

State/ Jurisdiction	HHS Region	The number of deaths of individuals reported to the P&A for investigation				All Death investigations conducted involving PAIMI- eligible individuals related			
		Total Number of Deaths Reported	State	The Centers for Medicare & Medicaid Services	Other Sources	Total Number of Death Investigations	Number of deaths investigated involving incidents of seclusion (S).	Number of deaths investigated involving incidents of restraint (R).	Number of deaths investigated NOT related to incidents of S&R, (e. g., suicides.)
Alabama	4	2	0	1	1	2	0	1	1
Alaska	10	4	1	0	3	4	0	0	4
AIC	11	0	0	0	0	0	0	0	0
Am. Samoa	9	0	0	0	0	0	0	0	0
Arizona	9	0	0	0	0	0	0	0	0
Arkansas	6	0	0	0	0	0	0	0	0
California	9	18	13	0	5	11	0	1	10
Colorado	8	3	0	0	3	3	0	0	3
Connecticut	1	1	0	0	1	1	0	1	0
Delaware	3	7	6	0	1	7	0	0	7
DC	3	3	3	0	0	3	0	0	3
Florida	4	5	1	0	4	5	0	0	5
Georgia	4	10	0	0	10	10	0	0	10
Guam	9	1	0	0	1	1	0	0	1
Hawaii	9	0	0	0	0	0	0	0	0
Idaho	10	0	0	0	0	0	0	0	0
Illinois	5	0	0	0	0	3	0	0	3
Indiana	5	1	1	0	0	0	0	0	0
Iowa	7	4	0	0	4	4	0	0	4
Kansas	7	0	0	0	0	2	0	0	2
Kentucky	4	6	2	0	4	2	0	0	2
Louisiana	6	1	0	0	1	1	1	0	0
Maine	1	1	0	0	1	1	0	0	1
Maryland	3	69	8	0	61	3	0	0	3
Massachusetts	1	33	33	0	0	4	0	1	3
Michigan	5	6	4	0	2	6	0	0	6
Minnesota	5	0	0	0	0	0	0	0	0

Mississippi	4	0	0	0	0	0	0	0	0
Missouri	7	568	568	0	0	7	0	0	7
Montana	8	1	0	0	1	1	0	0	1
Nebraska	7	1	0	0	1	2	0	0	2
Nevada	9	0	0	0	0	0	0	0	0
New Hampshire	1	1	0	0	1	1	0	1	0
New Jersey	2	16	16	0	0	16	0	0	16
New Mexico	6	1	0	0	1	1	1	0	0
New York	2	6	0	0	6	6	3	0	3
North Carolina	4	3	3	0	0	3	0	1	2
North Dakota	8	1	1	0	0	1	0	0	1
N. Marianas	9	0	0	0	0	0	0	0	0
Ohio	5	6	2	0	4	6	0	0	6
Oklahoma	6	0	0	0	0	0	0	0	0
Oregon	10	1	0	0	1	1	0	0	1
Pennsylvania	3	40	40	0	0	0	0	0	0
Puerto Rico	2	0	0	0	0	0	0	0	0
Rhode Island	1	3	2	0	1	3	0	0	3
South Carolina	4	3	0	0	3	3	0	0	3
South Dakota	8	3	0	0	3	3	0	0	3
Tennessee	4	0	0	0	0	0	0	0	0
Texas	6	6	0	0	6	6	0	0	6
Utah	8	48	0	0	48	48	8	0	40
Vermont	1	4	2	0	2	5	1	2	2
Virgin Islands	2	1	0	0	1	1	0	0	1
Virginia	3	73	71	0	2	73	0	1	72
Washington	10	2	0	0	2	2	0	0	2
West Virginia	3	1	0	0	1	1	0	0	1
Wisconsin	5	9	8	0	1	9	0	0	9
Wyoming	8	1	1	0	0	1	0	0	1
Totals		974	786	1	187	273	14	9	250

Table 9a – Analysis of Alleged Abuse – FY2017

State/ Jurisdiction	HHS Region	Total Complaints Closed	Complaints withdrawn, no merit	Complaints withdrawn by Client	Resolved in client's favor	Not resolved in the client's favor	Percentage Favorably Resolved
Alabama	4	37	10	2	4	21	10.81
Alaska	10	9	4	1	4	0	44.44
AIC	11	1	0	0	0	1	0.00
Am. Samoa	9	20	0	0	20	0	100.00
Arizona	9	8	1	1	5	1	62.50
Arkansas	6	19	7	1	11	0	57.89
California	9	66	0	0	66	0	100.00
Colorado	8	55	20	2	33	0	60.00
Connecticut	1	1	0	0	1	0	100.00
Delaware	3	4	2	1	1	0	25.00
DC	3	32	3	5	23	1	71.88
Florida	4	98	25	11	60	2	61.22
Georgia	4	44	10	2	32	0	72.73
Guam	9	3	2	0	1	0	33.33
Hawaii	9	15	9	1	5	0	33.33
Idaho	10	12	7	0	2	3	16.67
Illinois	5	47	8	3	19	17	40.43
Indiana	5	12	1	3	8	0	66.67
Iowa	7	47	12	5	30	0	63.83
Kansas	7	42	11	10	21	0	50.00
Kentucky	4	14	4	0	8	2	57.14
Louisiana	6	17	0	3	12	2	70.59
Maine	1	49	2	6	34	7	69.39
Maryland	3	44	2	4	33	5	75.00
Massachusetts	1	45	0	7	38	0	84.44
Michigan	5	21	5	2	4	10	19.05
Minnesota	5	25	5	2	17	1	68.00
Mississippi	4	8	0	0	8	0	100.00
Missouri	7	86	1	0	84	1	97.67
Montana	8	82	10	0	68	4	82.93
Nebraska	7	9	3	3	3	0	33.33
Nevada	9	8	7	1	0	0	0.00

New Hampshire	1	46	9	4	33	0	71.74
New Jersey	2	79	16	6	56	1	70.89
New Mexico	6	99	5	10	75	9	75.76
New York	2	46	2	3	40	1	86.96
North Carolina	4	8	1	0	7	0	87.50
North Dakota	8	37	0	4	33	0	89.19
N. Marianas	9	1	0	0	1	0	100.00
Ohio	5	182	3	28	150	1	82.42
Oklahoma	6	16	0	5	11	0	68.75
Oregon	10	17	2	4	10	1	58.82
Pennsylvania	3	28	0	0	28	0	100.00
Puerto Rico	2	5	1	0	2	2	40.00
Rhode Island	1	3	1	0	2	0	66.67
South Carolina	4	127	2	1	112	12	88.19
South Dakota	8	13	0	4	8	1	61.54
Tennessee	4	45	24	6	0	15	0.00
Texas	6	180	19	22	31	108	17.22
Utah	8	8	0	1	6	1	75.00
Vermont	1	47	8	15	17	7	36.17
Virgin Islands	2	4	0	0	4	0	100.00
Virginia	3	55	4	4	47	0	85.45
Washington	10	311	0	0	311	0	100.00
West Virginia	3	18	1	2	14	1	77.78
Wisconsin	5	16	4	2	10	0	62.50
Wyoming	8	26	4	0	22	0	84.62
Totals		2,397	277	197	1,685	238	63.43

Table 9b – Analysis of Alleged Abuse – FY2018

State/ Jurisdiction	HHS Region	Total Complaints Closed	Complaints withdrawn, no merit	Complaints withdrawn by Client	Resolved in client's favor	Not resolved in the client's favor	Percentage Favorably Resolved
Alabama	4	23	1	2	13	7	56.52
Alaska	10	2	2	0	0	0	0.00
AIC	11	3	1	0	2	0	66.67
Am. Samoa	9	6	0	0	6	0	100.00
Arizona	9	28	0	0	28	0	100.00
Arkansas	6	16	2	1	13	0	81.25
California	9	71	6	5	59	1	83.10
Colorado	8	20	2	0	10	8	50.00
Connecticut	1	3	0	0	2	1	66.67
Delaware	3	15	2	0	13	0	86.67
DC	3	37	8	3	26	0	70.27
Florida	4	154	33	15	105	1	68.18
Georgia	4	34	12	4	18	0	52.94
Guam	9	2	0	0	2	0	100.00
Hawaii	9	5	4	1	0	0	0.00
Idaho	10	31	4	5	21	1	67.74
Illinois	5	55	3	4	31	17	56.36
Indiana	5	17	3	2	12	0	70.59
Iowa	7	33	8	6	19	0	57.58
Kansas	7	21	6	6	4	5	19.05
Kentucky	4	9	0	0	9	0	100.00
Louisiana	6	5	0	1	3	1	60.00
Maine	1	50	1	8	37	4	74.00
Maryland	3	37	4	4	25	4	67.57
Massachusetts	1	9	0	1	7	1	77.78
Michigan	5	14	0	0	12	2	85.71
Minnesota	5	33	7	8	18	0	54.55
Mississippi	4	8	1	0	7	0	87.50
Missouri	7	83	0	0	83	0	100.00
Montana	8	59	32	0	17	10	28.81
Nebraska	7	2	0	0	2	0	100.00
Nevada	9	0	0	0	0	0	0.00

New Hampshire	1	53	10	4	38	1	71.70
New Jersey	2	103	22	11	68	2	66.02
New Mexico	6	63	30	5	21	7	33.33
New York	2	11	0	0	11	0	100.00
North Carolina	4	17	1	1	15	0	88.24
North Dakota	8	31	13	5	12	1	38.71
N. Marianas	9	1	0	0	1	0	100.00
Ohio	5	57	4	10	42	1	73.68
Oklahoma	6	16	4	0	10	2	62.50
Oregon	10	13	1	2	5	5	38.46
Pennsylvania	3	18	0	0	18	0	100.00
Puerto Rico	2	0	0	0	0	0	0.00
Rhode Island	1	1	0	0	1	0	100.00
South Carolina	4	129	0	0	122	7	94.57
South Dakota	8	11	2	2	7	0	63.64
Tennessee	4	30	9	4	13	4	43.33
Texas	6	99	24	23	41	11	41.41
Utah	8	8	0	1	5	2	62.50
Vermont	1	39	5	10	22	2	56.41
Virgin Islands	2	13	0	0	9	4	69.23
Virginia	3	30	13	2	11	4	36.67
Washington	10	207	0	0	207	0	100.00
West Virginia	3	14	1	1	12	0	85.71
Wisconsin	5	32	5	7	10	10	31.25
Wyoming	8	21	1	0	20	0	95.24
Totals		1,902	287	164	1,325	126	65.65

Table 10a – Analysis of Alleged Neglect – FY2017

State/ Jurisdiction	HHS Region	Total Complaints Closed	Complaints withdrawn, no merit	Complaints withdrawn by Client	Resolved in client's favor	Not resolved in the client's favor	Successful outcomes from P&A involvement	Percentage Favorably Resolved
Alabama	4	74	40	2	28	4	0	37.84
Alaska	10	2	1	1	0	0	0	0.00
AIC	11	1	0	0	1	0	0	100.00
Am. Samoa	9	9	0	1	6	0	2	66.67
Arizona	9	8	0	0	8	0	0	100.00
Arkansas	6	18	3	1	8	1	5	44.44
California	9	21	0	0	21	0	0	100.00
Colorado	8	2	2	0	0	0	0	0.00
Connecticut	1	0	0	0	0	0	0	0.00
Delaware	3	12	0	0	10	0	2	83.33
DC	3	43	2	8	29	4	0	67.44
Florida	4	32	8	2	22	0	0	68.75
Georgia	4	92	1	8	82	1	0	89.13
Guam	9	3	0	0	3	0	0	100.00
Hawaii	9	10	2	0	7	1	0	70.00
Idaho	10	59	5	1	31	19	3	52.54
Illinois	5	151	9	9	34	27	72	22.52
Indiana	5	17	0	2	15	0	0	88.24
Iowa	7	13	0	2	9	0	2	69.23
Kansas	7	40	12	6	21	1	0	52.50
Kentucky	4	16	0	0	11	0	5	68.75
Louisiana	6	17	5	3	7	2	0	41.18
Maine	1	37	1	4	29	3	0	78.38
Maryland	3	20	0	0	13	0	7	65.00
Massachusetts	1	35	2	9	22	2	0	62.86
Michigan	5	29	3	2	5	1	18	17.24
Minnesota	5	19	3	3	12	1	0	63.16
Mississippi	4	9	0	0	8	1	0	88.89
Missouri	7	95	4	4	87	0	0	91.58
Montana	8	51	2	0	43	0	6	84.31
Nebraska	7	3	0	0	2	0	1	66.67

Nevada	9	11	0	5	6	0	0	54.55
New Hampshire	1	30	3	2	23	1	1	76.67
New Jersey	2	31	5	0	25	1	0	80.65
New Mexico	6	199	0	5	148	46	0	74.37
New York	2	32	0	0	2	0	30	6.25
North Carolina	4	28	3	2	13	0	10	46.43
North Dakota	8	30	0	0	30	0	0	100.00
N. Marianas	9	1	0	0	0	0	1	0.00
Ohio	5	130	1	15	78	1	35	60.00
Oklahoma	6	10	1	1	5	3	0	50.00
Oregon	10	14	0	2	11	1	0	78.57
Pennsylvania	3	47	0	0	42	0	5	89.36
Puerto Rico	2	22	13	3	1	1	4	4.55
Rhode Island	1	19	3	2	14	0	0	73.68
South Carolina	4	6	1	0	4	1	0	66.67
South Dakota	8	9	0	0	8	1	0	88.89
Tennessee	4	11	4	2	1	0	4	9.09
Texas	6	136	15	7	20	4	90	14.71
Utah	8	2	0	0	2	0	0	100.00
Vermont	1	27	4	4	16	3	0	59.26
Virgin Islands	2	1	0	0	1	0	0	100.00
Virginia	3	61	2	1	54	4	0	88.52
Washington	10	164	0	0	164	0	0	100.00
West Virginia	3	32	5	8	17	2	0	53.13
Wisconsin	5	18	3	2	13	0	0	72.22
Wyoming	8	12	1	0	10	1	0	83.33
Totals		2,021	169	129	1,282	138	303	62.66

Table 10b – Analysis of Alleged Neglect – FY2018

State/ Jurisdiction	HHS Region	Total Complaints Closed	Complaints withdrawn, no merit	Complaints withdrawn by Client	Resolved in client's favor	Not resolved in the client's favor	Successful outcomes from P&A involvement	Percentage Favorably Resolved
Alabama	4	59	4	4	31	20	0	52.54
Alaska	10	2	0	0	2	0	0	100.00
AIC	11	1	0	0	1	0	0	100.00
Am. Samoa	9	31	1	0	22	7	1	70.97
Arizona	9	35	0	0	35	0	0	100.00
Arkansas	6	5	0	2	3	0	0	60.00
California	9	23	1	3	19	0	0	82.61
Colorado	8	20	5	1	9	5	0	45.00
Connecticut	1	1	0	0	1	0	0	100.00
Delaware	3	34	2	0	32	0	0	94.12
DC	3	26	1	3	18	4	0	69.23
Florida	4	39	5	1	33	0	0	84.62
Georgia	4	105	5	10	89	1	0	84.76
Guam	9	4	0	0	4	0	0	100.00
Hawaii	9	7	4	0	2	1	0	28.57
Idaho	10	33	4	5	23	1	0	69.70
Illinois	5	59	6	6	24	23	0	40.68
Indiana	5	12	1	4	7	0	0	58.33
Iowa	7	15	8	1	3	0	3	20.00
Kansas	7	31	5	8	16	2	0	51.61
Kentucky	4	7	0	0	6	1	0	85.71
Louisiana	6	5	0	1	3	1	0	60.00
Maine	1	43	1	1	38	3	0	88.37
Maryland	3	19	4	3	12	0	0	63.16
Massachusetts	1	19	0	4	15	0	0	78.95
Michigan	5	22	2	2	12	6	0	54.55
Minnesota	5	34	2	6	24	2	0	70.59
Mississippi	4	8	2	0	6	0	0	75.00
Missouri	7	52	0	1	51	0	0	98.08
Montana	8	91	75	0	15	1	0	16.48
Nebraska	7	0	0	0	0	0	0	0.00

Nevada	9	8	4	2	1	1	0	12.50
New Hampshire	1	47	10	5	27	0	5	57.45
New Jersey	2	25	2	3	20	0	0	80.00
New Mexico	6	139	42	9	28	55	5	20.14
New York	2	28	0	3	12	0	13	42.86
North Carolina	4	7	1	0	6	0	0	85.71
North Dakota	8	40	0	4	35	1	0	87.50
N. Marianas	9	5	0	0	5	0	0	100.00
Ohio	5	68	1	8	58	1	0	85.29
Oklahoma	6	7	2	2	2	1	0	28.57
Oregon	10	4	2	0	2	0	0	50.00
Pennsylvania	3	26	0	0	25	1	0	96.15
Puerto Rico	2	2	0	0	2	0	0	100.00
Rhode Island	1	6	0	1	5	0	0	83.33
South Carolina	4	12	0	1	11	0	0	91.67
South Dakota	8	5	1	1	2	1	0	40.00
Tennessee	4	20	8	4	7	1	0	35.00
Texas	6	135	39	35	54	7	0	40.00
Utah	8	0	0	0	0	0	0	0.00
Vermont	1	25	4	2	17	2	0	68.00
Virgin Islands	2	9	0	0	5	4	0	55.56
Virginia	3	70	17	4	41	3	5	58.57
Washington	10	72	0	0	72	0	0	100.00
West Virginia	3	23	1	2	18	2	0	78.26
Wisconsin	5	21	2	3	11	5	0	52.38
Wyoming	8	8	0	0	8	0	0	100.00
Totals		1,654	274	155	1,030	163	32	65.83

Table 11a – Analysis of Alleged Rights Violations – FY2017

State/ Jurisdiction	HHS Region	Total Complaints Closed	Complaints withdrawn, no merit	Complaints withdrawn by Client	Resolved in client's favor	Not resolved in the client's favor	Percentage Favorably Resolved
Alabama	4	65	10	9	40	6	61.54
Alaska	10	29	7	1	16	5	55.17
AIC	11	13	1	1	9	2	69.23
Am. Samoa	9	25	1	0	24	0	96.00
Arizona	9	8	0	0	8	0	100.00
Arkansas	6	69	1	17	48	3	69.57
California	9	668	0	0	668	0	100.00
Colorado	8	14	8	6	0	0	0.00
Connecticut	1	1	0	1	0	0	0.00
Delaware	3	58	2	0	56	0	96.55
DC	3	32	0	5	27	0	84.38
Florida	4	47	9	6	31	1	65.96
Georgia	4	13	0	1	12	0	92.31
Guam	9	19	1	4	13	1	68.42
Hawaii	9	174	8	33	130	3	74.71
Idaho	10	46	6	37	0	3	0.00
Illinois	5	323	13	13	168	129	52.01
Indiana	5	37	0	0	37	0	100.00
Iowa	7	32	4	11	17	0	53.13
Kansas	7	325	75	51	179	20	55.08
Kentucky	4	45	1	3	39	2	86.67
Louisiana	6	48	5	5	35	3	72.92
Maine	1	85	7	23	50	5	58.82
Maryland	3	74	10	1	51	12	68.92
Massachusetts	1	76	1	9	66	0	86.84
Michigan	5	27	10	3	4	10	14.81
Minnesota	5	102	8	16	72	6	70.59
Mississippi	4	11	0	0	11	0	100.00
Missouri	7	130	10	5	109	6	83.85
Montana	8	59	12	0	39	8	66.10
Nebraska	7	3	0	1	2	0	66.67
Nevada	9	21	2	5	11	3	52.38

New Hampshire	1	119	17	8	93	1	78.15
New Jersey	2	70	4	21	45	0	64.29
New Mexico	6	44	1	1	35	7	79.55
New York	2	121	0	0	121	0	100.00
North Carolina	4	46	3	2	40	1	86.96
North Dakota	8	72	0	9	61	2	84.72
N. Marianas	9	2	0	1	0	1	0.00
Ohio	5	354	4	97	246	7	69.49
Oklahoma	6	11	2	1	8	0	72.73
Oregon	10	11	0	1	10	0	90.91
Pennsylvania	3	163	12	1	136	14	83.44
Puerto Rico	2	38	24	3	0	11	0.00
Rhode Island	1	62	12	17	30	3	48.39
South Carolina	4	15	0	2	11	2	73.33
South Dakota	8	29	0	4	21	4	72.41
Tennessee	4	24	2	10	12	0	50.00
Texas	6	213	71	36	3	103	1.41
Utah	8	111	5	7	98	1	88.29
Vermont	1	31	1	7	21	2	67.74
Virgin Islands	2	6	0	2	1	3	16.67
Virginia	3	12	0	0	12	0	100.00
Washington	10	289	0	0	289	0	100.00
West Virginia	3	29	2	5	22	0	75.86
Wisconsin	5	36	2	6	26	2	72.22
Wyoming	8	10	1	2	7	0	70.00
Totals		4,597	375	510	3,320	392	66.13

Table 11b – Analysis of Alleged Rights Violations – FY2018

State/ Jurisdiction	HHS Region	Total Complaints Closed	Complaints withdrawn, no merit	Complaints withdrawn by Client	Resolved in client's favor	Not resolved in the client's favor	Percentage Favorably Resolved
Alabama	4	42	3	5	33	1	78.57
Alaska	10	23	5	5	8	5	34.78
AIC	11	11	1	1	8	1	72.73
Am. Samoa	9	24	0	4	16	4	66.67
Arizona	9	27	0	0	27	0	100.00
Arkansas	6	57	2	12	37	6	64.91
California	9	570	4	14	535	17	93.86
Colorado	8	34	10	3	21	0	61.76
Connecticut	1	4	0	0	3	1	75.00
Delaware	3	49	1	5	43	0	87.76
DC	3	28	1	1	25	1	89.29
Florida	4	50	8	7	34	1	68.00
Georgia	4	5	2	0	3	0	60.00
Guam	9	10	0	0	10	0	100.00
Hawaii	9	99	2	21	75	1	75.76
Idaho	10	26	3	3	18	2	69.23
Illinois	5	234	9	11	111	103	47.44
Indiana	5	12	0	3	9	0	75.00
Iowa	7	21	3	2	16	0	76.19
Kansas	7	323	77	57	143	46	44.27
Kentucky	4	33	5	1	26	1	78.79
Louisiana	6	10	4	2	3	1	30.00
Maine	1	73	3	5	62	3	84.93
Maryland	3	19	3	3	13	0	68.42
Massachusetts	1	11	0	2	9	0	81.82
Michigan	5	51	0	0	51	0	100.00
Minnesota	5	51	6	12	33	0	64.71
Mississippi	4	4	0	0	4	0	100.00
Missouri	7	69	1	1	60	7	86.96
Montana	8	30	4	0	20	6	66.67
Nebraska	7	5	1	0	4	0	80.00
Nevada	9	22	5	2	15	0	68.18

New Hampshire	1	162	52	7	102	1	62.96
New Jersey	2	57	3	2	52	0	91.23
New Mexico	6	32	15	0	17	0	53.13
New York	2	81	0	0	81	0	100.00
North Carolina	4	40	0	0	40	0	100.00
North Dakota	8	113	0	11	101	1	89.38
N. Marianas	9	4	0	0	4	0	100.00
Ohio	5	351	9	48	292	2	83.19
Oklahoma	6	7	0	1	4	2	57.14
Oregon	10	8	1	0	6	1	75.00
Pennsylvania	3	229	0	0	229	0	100.00
Puerto Rico	2	3	0	0	2	1	66.67
Rhode Island	1	17	4	3	10	0	58.82
South Carolina	4	19	1	3	11	4	57.89
South Dakota	8	12	0	2	9	1	75.00
Tennessee	4	20	4	8	8	0	40.00
Texas	6	250	51	61	118	20	47.20
Utah	8	134	11	22	95	6	70.90
Vermont	1	26	1	6	16	3	61.54
Virgin Islands	2	8	0	1	7	0	87.50
Virginia	3	25	3	2	18	2	72.00
Washington	10	261	0	0	261	0	100.00
West Virginia	3	36	2	7	27	0	75.00
Wisconsin	5	49	2	5	38	4	77.55
Wyoming	8	5	0	0	5	0	100.00
Totals		3,976	322	371	3,028	255	74.63

Table 12a – Intervention Strategies – FY2017

State/ Jurisdiction	HHS Region	Total Intervention Strategies	Short Term Assistance	Abuse & Neglect Investigations	Technical Assistance	Administrative Remedies	Negotiation/ Mediation	Legal Remedies
Alabama	4	176	44	52	45	2	20	13
Alaska	10	40	23	5	0	4	1	7
AIC	11	15	1	2	0	4	7	1
Am. Samoa	9	54	3	18	6	4	22	1
Arizona	9	24	19	3	1	0	1	0
Arkansas	6	106	70	20	3	9	0	4
California	9	850	828	4	2	4	5	7
Colorado	8	51	6	37	5	0	2	1
Connecticut	1	1	0	0	1	0	0	0
Delaware	3	74	28	8	6	17	15	0
DC	3	107	39	19	17	8	24	0
Florida	4	179	50	5	42	1	79	2
Georgia	4	149	25	34	10	0	80	0
Guam	9	28	7	7	0	1	8	5
Hawaii	9	199	126	25	7	13	28	0
Idaho	10	117	35	22	50	7	1	2
Illinois	5	536	343	11	129	10	38	5
Indiana	5	61	19	0	5	18	14	5
Iowa	7	33	7	7	1	1	10	7
Kansas	7	390	48	1	323	3	0	15
Kentucky	4	117	34	36	19	3	23	2
Louisiana	6	82	28	19	0	8	15	12
Maine	1	171	49	0	35	6	69	12
Maryland	3	149	27	63	37	2	7	13
Massachusetts	1	155	131	1	1	0	21	1
Michigan	5	77	11	44	5	6	5	6
Minnesota	5	146	64	12	46	10	8	6
Mississippi	4	81	10	22	0	5	14	30
Missouri	7	310	22	15	89	13	151	20
Montana	8	192	93	95	0	0	2	2
Nebraska	7	13	2	11	0	0	0	0
Nevada	9	40	23	0	17	0	0	0

New Hampshire	1	196	173	3	0	2	11	7
New Jersey	2	180	50	82	29	1	16	2
New Mexico	6	334	272	52	3	0	6	1
New York	2	200	104	4	60	7	24	1
North Carolina	4	95	63	13	3	0	8	8
North Dakota	8	139	55	62	5	0	15	2
N. Marianas	9	4	0	2	0	0	1	1
Ohio	5	624	487	81	33	2	18	3
Oklahoma	6	37	16	4	2	0	15	0
Oregon	10	42	11	29	0	1	1	0
Pennsylvania	3	238	122	1	69	9	14	23
Puerto Rico	2	65	5	15	0	9	33	3
Rhode Island	1	85	26	5	32	4	8	10
South Carolina	4	148	11	2	2	0	131	2
South Dakota	8	51	19	2	1	3	26	0
Tennessee	4	75	13	50	3	1	6	2
Texas	6	529	160	167	27	75	62	38
Utah	8	121	82	2	19	4	13	1
Vermont	1	105	69	31	0	2	0	3
Virgin Islands	2	8	5	2	0	1	0	0
Virginia	3	128	54	46	2	5	21	0
Washington	10	764	761	0	3	0	0	0
West Virginia	3	70	31	0	24	0	15	0
Wisconsin	5	70	28	8	3	3	27	1
Wyoming	8	48	9	33	0	0	5	1
Totals		9,079	4,841	1,294	1,222	288	1,146	288
Percentages		100.00	53.32	14.25	13.46	3.17	12.62	3.17

Table 12b – Intervention Strategies – FY2018

State/ Jurisdiction	HHS Region	Total Intervention Strategies	Short Term Assistance	Abuse & Neglect Investigations	Technical Assistance	Administrative Remedies	Negotiation/ Mediation	Legal Remedies
Alabama	4	123	29	41	30	1	5	17
Alaska	10	27	22	0	0	1	1	3
AIC	11	15	1	0	6	0	4	4
Am. Samoa	9	66	10	2	8	5	39	2
Arizona	9	91	79	3	7	1	1	0
Arkansas	6	78	41	6	18	8	1	4
California	9	647	624	0	0	14	7	2
Colorado	8	73	36	14	15	1	1	6
Connecticut	1	8	6	0	0	0	2	0
Delaware	3	98	53	11	4	17	13	0
DC	3	92	47	13	10	5	15	2
Florida	4	157	80	2	16	0	28	31
Georgia	4	144	15	52	1	1	75	0
Guam	9	16	6	4	0	0	3	3
Hawaii	9	111	68	12	10	4	16	1
Idaho	10	90	28	22	36	1	2	1
Illinois	5	424	303	0	81	6	25	9
Indiana	5	58	16	0	3	14	22	3
Iowa	7	40	9	13	1	5	8	4
Kansas	7	375	45	1	310	3	4	12
Kentucky	4	69	16	8	28	1	14	2
Louisiana	6	32	10	10	0	6	3	3
Maine	1	166	52	3	26	5	72	8
Maryland	3	126	16	42	52	1	6	9
Massachusetts	1	30	24	0	1	0	5	0
Michigan	5	169	9	36	7	18	12	87
Minnesota	5	118	62	22	9	4	20	1
Mississippi	4	26	4	19	0	3	0	0
Missouri	7	204	13	53	39	27	65	7
Montana	8	180	71	94	5	1	2	7
Nebraska	7	7	0	6	0	0	0	1
Nevada	9	30	22	0	7	1	0	0

New Hampshire	1	260	240	12	0	2	4	2
New Jersey	2	185	34	98	25	6	16	6
New Mexico	6	237	222	10	2	0	1	2
New York	2	108	57	1	31	1	17	1
North Carolina	4	64	41	3	2	3	13	2
North Dakota	8	184	75	67	1	1	39	1
N. Marianas	9	10	2	1	2	3	0	2
Ohio	5	476	382	17	56	6	15	0
Oklahoma	6	30	8	13	0	0	9	0
Oregon	10	25	9	13	1	0	0	2
Pennsylvania	3	273	165	3	97	2	3	3
Puerto Rico	2	5	1	0	1	0	3	0
Rhode Island	1	24	8	3	9	2	1	1
South Carolina	4	160	11	5	1	3	138	2
South Dakota	8	28	18	0	0	4	5	1
Tennessee	4	71	13	46	1	1	10	0
Texas	6	484	121	171	20	101	56	15
Utah	8	100	73	4	4	4	11	4
Vermont	1	90	69	12	0	3	1	5
Virgin Islands	2	30	15	5	1	4	3	2
Virginia	3	125	62	31	6	9	15	2
Washington	10	540	522	0	3	14	1	0
West Virginia	3	73	29	0	27	2	13	2
Wisconsin	5	83	44	3	10	3	23	0
Wyoming	8	34	3	21	0	1	9	0
Totals		7,589	4,041	1,028	1,030	329	877	284
Percentages		100.00	53.25	13.55	13.57	4.34	11.56	3.74

Table 13a – Non-Case Directed Services – FY2017

State/ Jurisdiction	HHS Region	Class Action Litigation			
		Total number of Individuals Impacted	Concluded Successfully	Concluded Unsuccessfully	Ongoing
Alabama	4	99,625	0	0	3
Alaska	10	0	0	0	0
AIC	11	1	0	0	1
Am. Samoa	9	0	0	0	0
Arizona	9	11,270	0	0	1
Arkansas	6	0	0	0	0
California	9	201	0	0	1
Colorado	8	275	0	0	1
Connecticut	1	178,000	0	0	1
Delaware	3	200	1	0	0
DC	3	200	0	1	0
Florida	4	376,744	3	0	3
Georgia	4	0	0	0	0
Guam	9	0	0	0	0
Hawaii	9	1,900	0	0	2
Idaho	10	0	0	0	0
Illinois	5	52,026	0	0	0
Indiana	5	0	0	0	0
Iowa	7	16,742	0	0	2
Kansas	7	10,000	0	0	1
Kentucky	4	0	0	0	0
Louisiana	6	1,625	0	0	3
Maine	1	5,000	0	0	0
Maryland	3	1,000	1	0	1
Massachusetts	1	0	0	0	0
Michigan	5	51	1	0	0
Minnesota	5	550	1	0	0
Mississippi	4	200	2	0	0
Missouri	7	0	0	0	0
Montana	8	0	0	0	0

Nebraska	7	0	0	0	0
Nevada	9	0	0	0	0
New Hampshire	1	10,000	0	0	1
New Jersey	2	0	0	0	0
New Mexico	6	0	0	0	0
New York	2	17,020	2	0	9
North Carolina	4	575	1	0	0
North Dakota	8	0	0	0	0
N. Marianas	9	0	0	0	0
Ohio	5	1,510,050	0	2	1
Oklahoma	6	0	0	0	0
Oregon	10	0	0	0	0
Pennsylvania	3	0	0	0	0
Puerto Rico	2	0	0	0	0
Rhode Island	1	0	0	0	0
South Carolina	4	3,400	1	0	1
South Dakota	8	0	0	0	0
Tennessee	4	0	0	0	0
Texas	6	1,200	0	0	1
Utah	8	2,000	1	0	2
Vermont	1	0	0	0	0
Virgin Islands	2	0	0	0	0
Virginia	3	586	1	0	0
Washington	10	61,228	3	0	4
West Virginia	3	83,000	0	0	1
Wisconsin	5	0	0	0	0
Wyoming	8	0	0	0	0
Total		2,444,669	18	3	40

Table 13b – Non-Case Directed Services – FY2018

State/ Jurisdiction	HHS Region	Class Action Litigation			
		Total number of Individuals Impacted	Concluded Successfully	Concluded Unsuccessfully	Ongoing
Alabama	4	100,625	1	0	3
Alaska	10	0	0	0	0
AIC	11	9,260	0	0	2
Am. Samoa	9	0	0	0	0
Arizona	9	0	0	0	0
Arkansas	6	0	0	0	0
California	9	964	0	0	1
Colorado	8	500	0	0	1
Connecticut	1	178,200	0	0	2
Delaware	3	0	0	0	0
DC	3	3,162	0	0	1
Florida	4	54,100	2	1	5
Georgia	4	153,063	0	0	4
Guam	9	0	0	0	0
Hawaii	9	1,900	0	0	2
Idaho	10	0	0	0	0
Illinois	5	147,740	0	0	4
Indiana	5	0	0	0	0
Iowa	7	16,742	1	0	1
Kansas	7	0	0	0	0
Kentucky	4	0	0	0	0
Louisiana	6	2,750	0	0	4
Maine	1	5,000	0	0	1
Maryland	3	0	0	0	0
Massachusetts	1	0	0	0	0
Michigan	5	134,255	0	0	2
Minnesota	5	200	0	0	1
Mississippi	4	100	1	0	0
Missouri	7	0	0	0	0
Montana	8	0	0	0	0

Nebraska	7	0	0	0	0
Nevada	9	0	0	0	0
New Hampshire	1	50,000	0	0	1
New Jersey	2	0	0	0	0
New Mexico	6	4,737	0	0	1
New York	2	14,977	4	0	8
North Carolina	4	1,000	0	0	1
North Dakota	8	0	0	0	0
N. Marianas	9	0	0	0	0
Ohio	5	50,170	0	0	3
Oklahoma	6	0	0	0	0
Oregon	10	0	0	0	0
Pennsylvania	3	800	0	0	2
Puerto Rico	2	0	0	0	0
Rhode Island	1	0	0	0	0
South Carolina	4	3,400	1	0	1
South Dakota	8	0	0	0	0
Tennessee	4	0	0	0	0
Texas	6	1,200	0	0	1
Utah	8	800	0	0	2
Vermont	1	0	0	0	0
Virgin Islands	2	41,000	1	0	0
Virginia	3	15,500	4	0	0
Washington	10	537,076	3	0	7
West Virginia	3	83,000	0	0	1
Wisconsin	5	0	0	0	0
Wyoming	8	0	0	0	0
Total		1,612,221	18	1	62

Table 13c – Non-Case Directed Services – FY2017

State/ Jurisdiction	HHS Region	Non Litigation Advocacy			
		Total number of Individuals Impacted	Concluded Successfully	Concluded Unsuccessfully	Ongoing
Alabama	4	1,282,001	25	15	39
Alaska	10	323	3	13	0
AIC	11	17	0	0	17
Am. Samoa	9	812	58	13	6
Arizona	9	53,889	23	0	6
Arkansas	6	2,630	20	0	5
California	9	831,350	1	0	10
Colorado	8	4,816	43	0	5
Connecticut	1	248,000	0	0	5
Delaware	3	2,470	16	0	16
DC	3	24,600	9	0	8
Florida	4	2,557,829	12	0	34
Georgia	4	615,967	73	64	64
Guam	9	6	1	0	0
Hawaii	9	215	0	0	2
Idaho	10	94,032	3	0	11
Illinois	5	703,871	6	23	32
Indiana	5	2,650	152	0	1
Iowa	7	907,210	63	0	13
Kansas	7	2,050	0	0	4
Kentucky	4	874,000	8	0	10
Louisiana	6	44,315	3	1	17
Maine	1	21,000	55	0	21
Maryland	3	14,500	0	1	7
Massachusetts	1	4,000	51	0	8
Michigan	5	221,373	90	6	2
Minnesota	5	76,765	54	0	3
Mississippi	4	4,776	36	0	0
Missouri	7	412	3	0	2
Montana	8	23,735	5	0	10

Nebraska	7	784	0	0	784
Nevada	9	3,000	2	0	1
New Hampshire	1	335	0	0	4
New Jersey	2	328,300	2	0	6
New Mexico	6	150,102	0	0	6
New York	2	319,157	53	1	38
North Carolina	4	243,262	2	0	8
North Dakota	8	137	6	0	1
N. Marianas	9	100	0	0	100
Ohio	5	7,741	28	0	8
Oklahoma	6	30,722	2	0	14
Oregon	10	13,558	7	0	13
Pennsylvania	3	121,002	0	0	5
Puerto Rico	2	1,644	21	1	32
Rhode Island	1	3,077	2	0	6
South Carolina	4	173,350	2	0	6
South Dakota	8	934	4	0	3
Tennessee	4	449,207	38	5	58
Texas	6	60,660	41	3	63
Utah	8	34,497	26	1	10
Vermont	1	4,760	2	0	9
Virgin Islands	2	21,435	17	0	1
Virginia	3	43,844	3	0	3
Washington	10	582,011	30	0	50
West Virginia	3	194,394	83	0	6
Wisconsin	5	1,020,011	1	0	4
Wyoming	8	1,844	35	0	13
Total		12,429,482	1,220	147	1,610

Table 13d – Non-Case Directed Services – FY2018

State/ Jurisdiction	HHS Region	Non Litigation Advocacy			
		Total number of Individuals Impacted	Concluded Successfully	Concluded Unsuccessfully	Ongoing
Alabama	4	3,245,828	17	1	32
Alaska	10	1,188	3	9	12
AIC	11	45,286	0	0	10
Am. Samoa	9	980	71	15	7
Arizona	9	53,853	0	0	33
Arkansas	6	2,711	3	0	10
California	9	10,451	1	0	3
Colorado	8	3,700	0	0	4
Connecticut	1	420,716	0	0	13
Delaware	3	2,233	16	0	19
DC	3	24,700	17	0	5
Florida	4	1,045,944	30	0	59
Georgia	4	766,381	17	0	23
Guam	9	46	6	0	0
Hawaii	9	215	1	0	1
Idaho	10	27,489	24	1	8
Illinois	5	3,440	9	23	31
Indiana	5	1,400	0	0	2
Iowa	7	851,548	61	2	7
Kansas	7	1,530	0	0	13
Kentucky	4	194,280	11	0	0
Louisiana	6	76,590	2	4	14
Maine	1	21,003	30	17	30
Maryland	3	22,110	26	0	10
Massachusetts	1	35,080	12	0	18
Michigan	5	435,652	37	4	48
Minnesota	5	103,729	52	0	14
Mississippi	4	3,982	49	0	0
Missouri	7	1,576	9	0	0
Montana	8	6,850	6	0	10

Nebraska	7	5,950	29	0	4
Nevada	9	2,200	1	0	3
New Hampshire	1	546,777	2	0	37
New Jersey	2	3,034	0	0	6
New Mexico	6	151,002	2	0	1
New York	2	168,661	25	0	36
North Carolina	4	243,300	2	0	8
North Dakota	8	86	5	0	0
N. Marianas	9	100	0	0	1
Ohio	5	231,644	97	0	36
Oklahoma	6	29,149	39	0	4
Oregon	10	16,596	6	0	33
Pennsylvania	3	1,816	7	0	19
Puerto Rico	2	1,410	35	0	25
Rhode Island	1	679	0	0	6
South Carolina	4	172,320	1	0	6
South Dakota	8	4,445	6	0	8
Tennessee	4	0	0	0	0
Texas	6	100,294	75	1	39
Utah	8	155,400	21	0	12
Vermont	1	9,160	6	0	17
Virgin Islands	2	41,200	17	0	1
Virginia	3	9,610	34	0	0
Washington	10	731,503	36	0	30
West Virginia	3	144,339	105	1	16
Wisconsin	5	10,857	3	0	14
Wyoming	8	1,603	27	0	16
Total		10,193,626	1,091	78	814

Table 13e – Non-Case Directed Services – FY2017

State/ Jurisdiction	HHS Region	Legislative & Regulatory Advocacy			
		Total number of Individuals Impacted	Concluded Successfully	Concluded Unsuccessfully	Ongoing
Alabama	4	428,538	4	0	5
Alaska	10	1,074	0	0	1
AIC	11	0	0	0	0
Am. Samoa	9	459	3	2	1
Arizona	9	40,284	1	0	0
Arkansas	6	14,100	4	1	4
California	9	0	0	0	0
Colorado	8	1,000	1	0	0
Connecticut	1	70,005	0	0	1
Delaware	3	0	0	0	0
DC	3	20,000	1	0	2
Florida	4	2,453,000	10	0	14
Georgia	4	670,876	2	2	2
Guam	9	0	0	0	0
Hawaii	9	500	0	0	1
Idaho	10	122,000	3	3	3
Illinois	5	0	0	0	3
Indiana	5	850	0	0	1
Iowa	7	0	0	0	0
Kansas	7	0	0	0	0
Kentucky	4	0	0	0	0
Louisiana	6	35,000	2	0	0
Maine	1	0	0	0	0
Maryland	3	25,000	0	0	2
Massachusetts	1	0	0	0	0
Michigan	5	180	1	0	0
Minnesota	5	3,770	0	0	2
Mississippi	4	0	0	0	0
Missouri	7	0	0	0	0
Montana	8	12,000	1	0	0

Nebraska	7	20,000	0	0	0
Nevada	9	0	0	0	0
New Hampshire	1	0	0	0	0
New Jersey	2	0	0	0	0
New Mexico	6	1,300	0	0	1
New York	2	0	0	0	0
North Carolina	4	0	0	0	0
North Dakota	8	0	0	0	0
N. Marianas	9	0	0	0	0
Ohio	5	642,386	10	0	7
Oklahoma	6	500	0	0	1
Oregon	10	3,000	0	0	0
Pennsylvania	3	0	0	0	0
Puerto Rico	2	0	0	0	0
Rhode Island	1	8,800	2	0	2
South Carolina	4	1,000	0	0	2
South Dakota	8	0	0	0	0
Tennessee	4	448,000	0	0	1
Texas	6	379,956	1	2	6
Utah	8	20,000	9	0	0
Vermont	1	422	1	0	1
Virgin Islands	2	20,600	0	0	1
Virginia	3	2,878	0	0	1
Washington	10	124,760	2	0	10
West Virginia	3	83,000	0	0	1
Wisconsin	5	4,557,097	1	0	4
Wyoming	8	0	0	0	0
Total		10,212,335	59	10	80

Table 13f – Non-Case Directed Services – FY2018

State/ Jurisdiction	HHS Region	Legislative & Regulatory Advocacy			
		Total number of Individuals Impacted	Concluded Successfully	Concluded Unsuccessfully	Ongoing
Alabama	4	283,920	5	0	7
Alaska	10	0	0	0	0
AIC	11	41,000	1	0	1
Am. Samoa	9	509	3	1	1
Arizona	9	40,284	0	0	4
Arkansas	6	14,989	0	0	1
California	9	0	0	0	0
Colorado	8	300	0	0	1
Connecticut	1	0	0	0	0
Delaware	3	0	0	0	0
DC	3	20,000	4	0	1
Florida	4	356,277	0	0	4
Georgia	4	763,602	8	0	16
Guam	9	0	0	0	0
Hawaii	9	500	0	0	1
Idaho	10	262,000	7	6	4
Illinois~	5	0	0	0	0
Indiana	5	0	0	0	0
Iowa	7	0	0	0	0
Kansas	7	0	0	0	0
Kentucky	4	0	0	0	0
Louisiana	6	70,000	3	1	0
Maine	1	0	0	0	0
Maryland	3	0	0	0	0
Massachusetts	1	0	0	0	0
Michigan	5	275,264	0	1	2
Minnesota	5	1,500	0	0	1
Mississippi	4	0	0	0	0
Missouri~	7	0	0	0	0
Montana	8	30,000	0	0	4

Nebraska	7	36,286	10	18	4
Nevada	9	500	1	0	0
New Hampshire	1	500	1	0	0
New Jersey	2	0	0	0	0
New Mexico	6	8,104	0	0	1
New York	2	739,140	6	1	1
North Carolina	4	0	0	0	0
North Dakota	8	0	0	0	0
N. Marianas	9	0	0	0	0
Ohio	5	0	2	0	22
Oklahoma	6	236,032	6	0	2
Oregon	10	0	0	0	0
Pennsylvania	3	1,763,000	1	0	3
Puerto Rico	2	0	0	0	0
Rhode Island	1	5,000	0	0	1
South Carolina	4	1,000	0	0	2
South Dakota	8	10	0	1	0
Tennessee	4	0	0	0	0
Texas	6	17,689	0	3	7
Utah	8	3,000,000	5	0	9
Vermont	1	500	1	0	1
Virgin Islands	2	1	1	0	0
Virginia	3	10,500	11	0	0
Washington	10	326,290	2	0	20
West Virginia	3	83,000	2	0	3
Wisconsin	5	350,000	1	0	6
Wyoming	8	0	0	0	0
Total		8,737,697	81	32	130

Table 14a – Information/Referral/Public Education/Awareness & Training Activities – FY2017

State/ Jurisdiction	HHS Region	Number of PAIMI Program Information & Referral Services	A. Number of public awareness activities or events	B. Number of education/training activities undertaken	C. Number (approximate) of persons trained in B.
Alabama	4	693	4	28	1,405
Alaska	10	382	8	84	424
AIC	11	18	9	8	422
Am. Samoa	9	168	9	4	765
Arizona	9	143	8	16	249
Arkansas	6	149	21	11	324
California	9	49	243	785	11,815
Colorado	8	134	36	20	415
Connecticut	1	88	9	1	40
Delaware	3	89	9	27	564
DC	3	268	27	111	2,127
Florida	4	2,175	55	19	1,540
Georgia	4	399	31	43	1,822
Guam	9	35	12	8	350
Hawaii	9	939	226	62	816
Idaho	10	309	21	40	296
Illinois	5	765	57	137	4,013
Indiana	5	568	33	16	420
Iowa	7	280	11	15	524
Kansas	7	18	143	37	1,945
Kentucky	4	717	7	23	402
Louisiana	6	534	9	44	1,687
Maine	1	583	148	123	3,041
Maryland	3	282	2	13	280
Massachusetts	1	105	4	6	200
Michigan	5	1,418	12	8	116
Minnesota	5	347	5	33	2,999
Mississippi	4	134	9	22	6,410
Missouri	7	717	24	14	450
Montana	8	336	9	9	307
Nebraska	7	243	30	4	197

Nevada	9	400	7	4	565
New Hampshire	1	404	7	40	3,780
New Jersey	2	537	50	36	1,251
New Mexico	6	540	16	62	1,620
New York	2	701	15	20	709
North Carolina	4	137	1	15	453
North Dakota	8	321	16	30	309
N. Marianas	9	35	34	2	2,809
Ohio	5	755	31	36	1,305
Oklahoma	6	158	12	12	970
Oregon	10	576	9	10	243
Pennsylvania	3	444	5	4	2,337
Puerto Rico	2	1,107	59	51	1,777
Rhode Island	1	172	8	12	335
South Carolina	4	628	10	24	732
South Dakota	8	170	78	17	587
Tennessee	4	591	151	13	632
Texas	6	1,151	9	106	5,227
Utah	8	671	15	11	1,260
Vermont	1	828	15	43	311
Virgin Islands	2	7	10	4	50
Virginia	3	474	14	30	2,698
Washington	10	62	16	26	1,576
West Virginia	3	256	23	22	988
Wisconsin	5	412	44	26	1,737
Wyoming	8	142	24	9	127
Totals		24,764	1,910	2,436	80,753

Table 14b – Information/Referral/Public Education/Awareness & Training Activities – FY2018

State/ Jurisdiction	HHS Region	Number of PAIMI Program Information & Referral Services	A. Number of public awareness activities or events	B. Number of education/training activities undertaken	C. Number (approximate) of persons trained in B.
Alabama	4	515	10	30	1,639
Alaska	10	333	9	28	421
AIC	11	3	2	4	343
Am. Samoa	9	339	19	4	558
Arizona	9	119	9	18	712
Arkansas	6	116	22	14	799
California	9	24	102	692	9,730
Colorado	8	158	34	13	412
Connecticut	1	194	16	9	240
Delaware	3	113	11	24	473
DC	3	234	64	68	1,271
Florida	4	1,658	36	24	1,148
Georgia	4	406	29	28	2,183
Guam	9	28	45	26	738
Hawaii	9	891	208	58	533
Idaho	10	265	40	31	575
Illinois	5	381	54	120	3,279
Indiana	5	519	4	4	200
Iowa	7	0	39	31	1,249
Kansas	7	19	227	42	2,348
Kentucky	4	675	21	3	394
Louisiana	6	598	8	19	462
Maine	1	705	164	374	10,316
Maryland	3	219	15	19	59
Massachusetts	1	313	8	5	144
Michigan	5	1,631	7	6	241
Minnesota	5	225	18	27	1,487
Mississippi	4	129	13	25	3,837
Missouri	7	660	20	14	431
Montana	8	256	4	8	662
Nebraska	7	262	99	5	109

Nevada	9	420	1	28	1,207
New Hampshire	1	96	37	4	250
New Jersey	2	491	41	40	1,625
New Mexico	6	468	16	60	578
New York	2	767	10	9	609
North Carolina	4	142	1	13	312
North Dakota	8	361	14	40	275
N. Marianas	9	12	13	32	1,222
Ohio	5	563	21	25	544
Oklahoma	6	277	11	8	82
Oregon	10	393	11	2	30
Pennsylvania	3	656	11	31	2,970
Puerto Rico	2	955	57	36	597
Rhode Island	1	222	14	9	414
South Carolina	4	687	6	24	594
South Dakota	8	178	154	19	291
Tennessee	4	553	117	30	667
Texas	6	960	19	96	3,792
Utah	8	578	14	6	220
Vermont	1	889	0	44	2,797
Virgin Islands	2	8	6	4	550
Virginia	3	384	18	15	1,995
Washington	10	127	12	26	1,047
West Virginia	3	218	50	31	783
Wisconsin	5	441	26	20	1,891
Wyoming	8	195	18	3	352
Totals		23,029	2,055	2,428	72,687

ACRONYMS

AoD	Administration on Disabilities
ACL	Administration for Community Living
ACT	Assertive Community Treatment
ADA	Americans with Disabilities Act
ADX	Administrative Maximum Facility
AIC	American Indian Consortium
AIDD	Administration on Intellectual and Developmental Disabilities
BOP	Bureau of Prisons
CHA	Children's Health Act
CMHS	Center for Mental Health Services
CMS	Centers for Medicare & Medicaid Services
CPS	Child Protective Services
CSA	Core Service Agency
DD Act	Developmental Disabilities Assistance and Bill of Rights Act
DBH	Department of Behavioral Health
DMAT	Decision-Making Assessment Tool
DMH	Department of Mental Health
DOC	Department of Corrections
DPC	Delaware Psychiatric Center
DWCC	David Wade Correctional Center
FY	Fiscal Year
HHS	Department of Health and Human Services
HIPAA	Health Insurance Portability and Accountability Act
IAA	Interagency agreement
MMIC	Mercy Maricopa Integrated Care
NDDOL	North Dakota Department of Labor
OIG	Office of Inspector General
P&A	Protection and Advocacy systems
PAC	PAIMI Advisory Council
PADD	Protection and Advocacy for Developmental Disabilities Program
PAIMI	Protection and Advocacy for Individuals with Mental Illness
POA	Power of Attorney
PPR	Program Performance Report
PTSD	Post Traumatic Stress Disorder
RSA	Rehabilitation Services Administration
RCA	Root Cause Analysis
RTC	Residential Treatment Center
SAMHSA	Substance Abuse and Mental Health Services Administration
SCM	Safe Crisis Management
SED	Serious Emotional Disturbance
SMI	Serious Mental Illness

TASC	Training Advocacy and Support Center
T/TA	Training and technical assistance
WSH	Wyoming State Hospital