



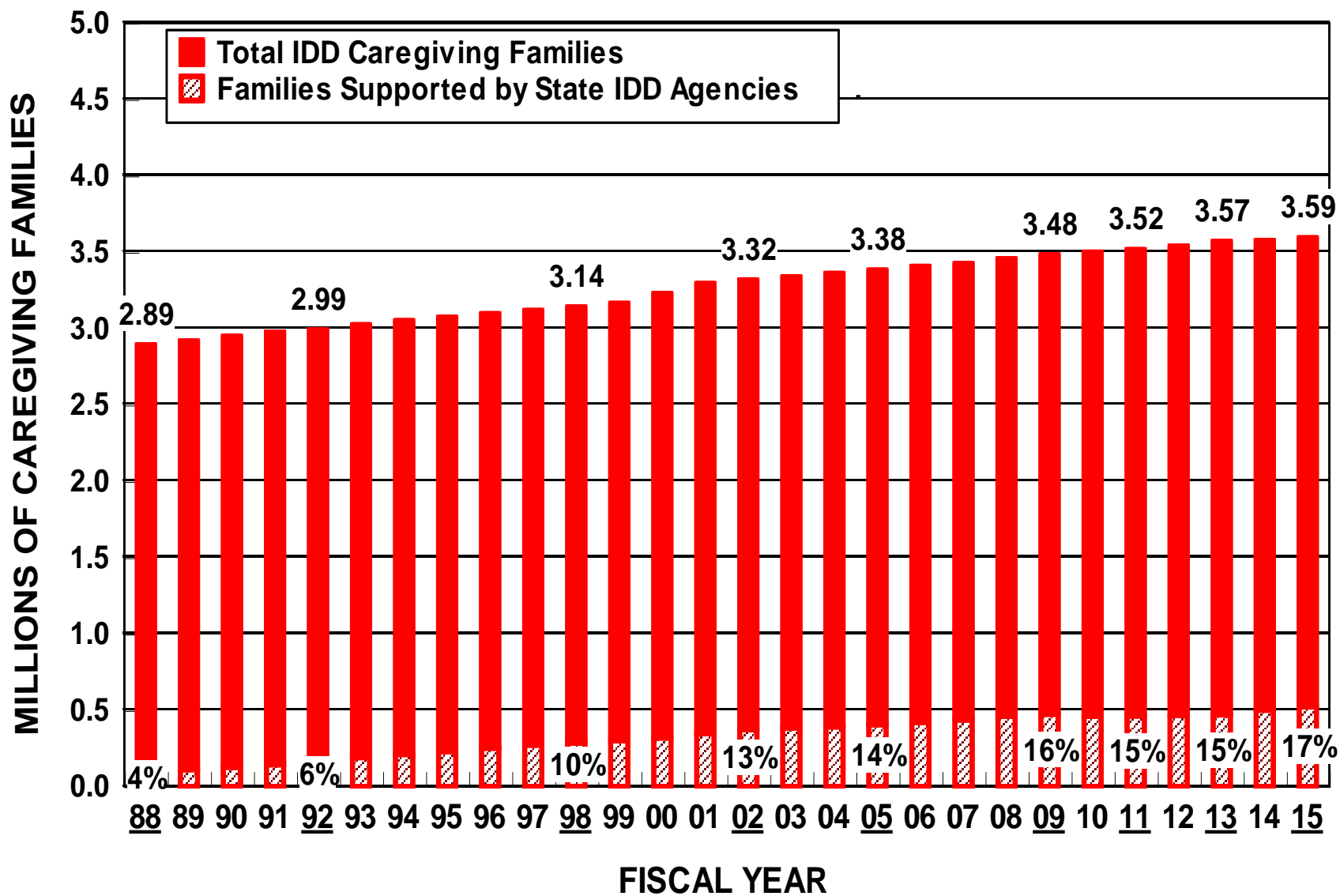
Updates: Administration on Intellectual and Developmental Disabilities

November 9, 2017



Supporting Families and Caregivers Pillar

- AIDD data projects examining families supporting individuals with ID/DD:
 - 57% of individuals with ID/DD receiving supports are living with families [Source: The Residential Information Systems Project (RISP)]
 - 17% of caregiving families received formal IDD agency supports [Source: The State of the States]



Supporting Families and Caregivers Pillar

- The Institute on Disability & Human Development (Illinois UCEDD) has the Rehabilitation Research and Training Center on Family Support which aims to contribute to a better understanding of the phenomenon of family support and disseminates information and products and providing technical assistance to state agencies, organizations and families.

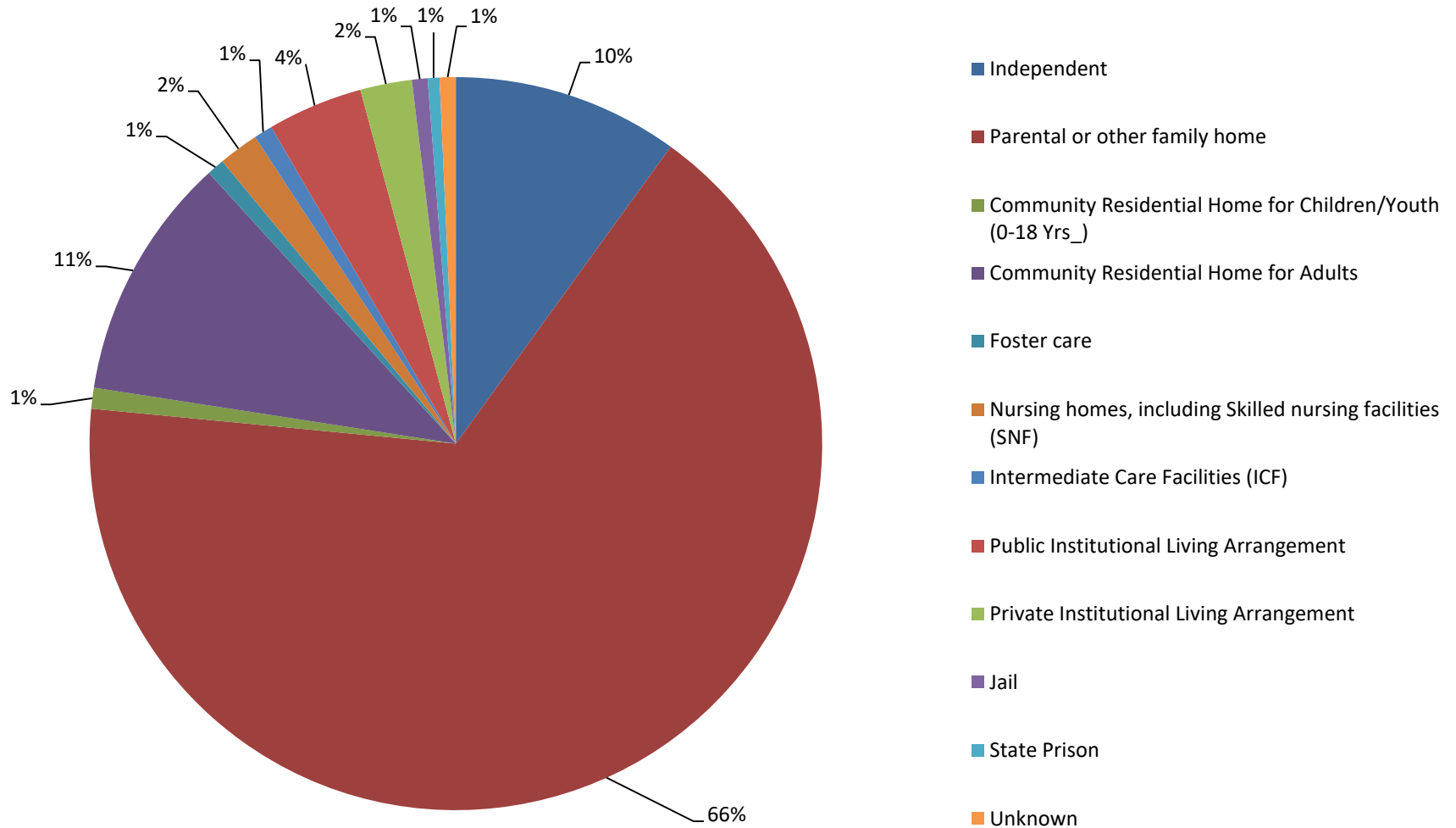
Supporting Families and Caregivers Pillar

- In September, AIDD funded an evaluation of the Community of Practice for Supporting Families (CoP) funded at the NASDDDS with the following objectives:
 - Conduct an outcome evaluation of the Life Course Framework by establishing specific benchmarks and performance measures consistent with the Life course Principles and assess them with the current 6 CoP states as well as the 11 expansion CoP states
 - Use the benchmarks to evaluate the fidelity of practice for the Life Course Framework for current and new sites
 - Use the findings from this outcome evaluation to provide AIDD with recommendations vital to continue Family Support Activities.

Protecting Rights and Preventing Abuse Pillar

- P&A individual clients in FY16 = 15,655
- P&A Problem areas addressed:
 - Education: 43%
 - Home and Community Based Services including discharge planning: 12%
 - Healthcare : 9%
 - Neglect: 6%
 - Medicaid: 6%
 - Abuse : 6%
 - Government Benefits/Services: 4%
 - Guardianship/Conservatorship/Substitute Decision maker: 4%
 - Failure to Provide Necessary or Appropriate Personal Care & Services: 3%
 - Housing: 3%
 - Physical, Verbal, & Sexual Assault: 2%
 - Employment Discrimination: 2%

Living Conditions of P&A Clients



P&A Monitoring Activities

People with ID/DD whose living, working and/or other circumstances were monitored	Cases opened for health and safety issue investigation	Health and/or safety violations validated by the P&A	Rights violations (not health or safety) identified and addressed as a result of P&A monitoring	Complaints referred to regulatory agencies or investigative organizations
424,053	369	1,480	1,548	365

Protecting Rights and Preventing Abuse Pillar

- P&A and LTCO collaboration
- Institute for Human Development (MO UCEDD) is developing an iPad and iPhone application on Self-Determination and the Prevention of Sexual Abuse.
 - Designed for use by persons with disabilities, family members, and care providers.
 - Available and accessible to people that receive support from the Missouri DMH/DDD, as well as individuals in the community at large.

Protecting Rights and Preventing Abuse Pillar

- Supporting self advocacy
 - DD Councils support self advocacy organizations and in FY 2016 trained 52,701 individuals in leadership, self-advocacy, and self-determination
 - Self-Advocacy Resource Center (SARTAC) is an AIDD grant to Self-Advocates Becoming Empowered that is:
 - Developing self-advocacy resources on 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 organizations in addition to the more than 1,000 established self-advocacy organizations across the nation for advising, building consensus, recruiting youth, supporting grant writing, developing leaders, and more
 - Establishing disability fellowships that offer leadership development and employment opportunities for fellows.

Protecting Rights and Preventing Abuse Pillar

- The role of Supported Decision Making
 - AIDD grant to Quality Trust created the Supporting the National Resource Center to:
 - Provide training and technical assistance
 - Opportunities for information sharing, including a web portal
 - Encouraging research on supported decision making and working with older adults and people with I/DD who use supported decision making to develop potential outcome measures to capture the use of supported decision making.

Protecting Rights and Preventing Abuse Pillar

- Living Well grants
 - AIDD funded in September (3) 5-year grants under the Projects of National Significance (total for year 1: \$1.305 million)
 - Purpose to develop and test model approaches for enhancing the quality, effectiveness, and monitoring of home and community-based services (HCBS) for people with developmental disabilities.
 - Focused on building the capacity of HCBS systems and enhancing community monitoring to prevent abuse, neglect, and exploitation.

Protecting Rights and Preventing Abuse Pillar

- Living Well grants
 - Grantees will work 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
 - Increase the capacity of states to provide HCBS in integrated settings.

Protecting Rights and Preventing Abuse Pillar

- Three University Centers for Excellence in Developmental Disabilities (UCEDDs) received grants:
 - The Institute on Human Development and Disability at the University of Georgia
 - The Institute on Disability at the University of New Hampshire,
 - Partnership for People with Disabilities at Virginia Commonwealth University

HHS Office of Inspector General Workgroup

- Congress requested a review of deaths and cases of abuse of individuals with developmental disabilities residing in group homes.
- OIG conducted audits in NY, CT, MA and ME
- Findings:
 - The State agencies did not comply with Federal waiver and State requirements on reporting and monitoring critical incidents.
 - State agencies did not ensure that:
 - All critical incidents were reported.
 - All critical incidents were reported correctly.
 - All reported critical incidents were recorded.
 - All critical incident data was analyzed to detect unreported incidents.

HHS Office of Inspector General

- OIG created workgroup to address problems found during OIG audits to provide multiple perspectives and depth of expertise across knowledge areas:
 - US HHS/OIG
 - US HHS/OCR
 - US HHS/ACL
 - US DOJ/CRT



HHS Office of Inspector General

Developed a set of model practices that provide States with a roadmap for how to implement better health and safety practices many of which are already required in the Act 1915(c) Medicaid HCBS Waiver, Appendix G.


HHS Office of Inspector General

- Coordination with CMS:
 - Provided CMS with draft of model practices for discussion.
- Outreach to national organizations:
 - National Association of States United for Aging and Disabilities
 - National Association of State Directors of Developmental Disabilities Services
 - National Association of State Mental Health Program Directors



HHS Office of Inspector General

Four Model Practices:

- Incident Management and Investigation Program
 - Quality Assurance Program
 - Mortality Review Program
 - Incident Management Audit Program
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Connecting People to Resources Pillar

- From 2012 – 2016 Councils trained an average of 55,902/year
- Number of P&A information and referrals = 35,695
- UCEDDs developed and disseminated 8,184 unique products

Employment of People with Disabilities Pillar


- Economic disparities between people with and without ID/DD persist.
- State investment in supports continues to emphasize facility-based and non-work services, rather than integrated employment services.
- In the ID/DD system, national estimates suggest that there has been only modest growth in the number of individuals in integrated employment services since 1988.
- The estimated percentage of individuals participating in integrated employment services was 18.6% in FY2015, similar to the figure of 19.1% for FY2014, while investment in non-work services continues to expand.
 - FY2015 data do suggest slight growth in the number of people in integrated employment services over the last five years. Several states each reported an increase of more than 500 individuals in integrated employment services over that five-year period.

Employment of People with Disabilities Pillar

- Partnerships in Employment Systems Change (PIE)
 - 5-year projects
 - Up to 14 states
 - Current: District of Columbia, Hawaii, Kentucky, Massachusetts, South Carolina, and Utah
 - Goal: Transform state systems to promote competitive integrated employment outcomes for youth and young adults with intellectual and developmental disabilities (I/DD)
 - PIE aims to:
 - Support the increasing abilities of individuals with I/DD to exercise greater choice and self-determination
 - Support youth and young adults with I/DD to achieve improved employment outcomes consistent with the interests, strengths, priorities, abilities, and capabilities of the individual
 - Strengthen collaboration across local and state systems to support full participation and economic self-sufficiency for all people with I/DD



HHS Priorities

- Opioids
 - Childhood Obesity
 - Serious Mental Illness
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Data in ID/DD population

- AIDD conducting review of the current data collection projects (State of the State, RISP, employment)
- Health surveillance on individuals with intellectual and developmental disabilities

Questions? Comments?

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