**Using Data on Long-Term Supports and Services for People with Intellectual or Developmental Disabilities (IDD) to Influence Change. May 18, 2015 Presentation at the Pacific Rim International Conference on Disability and Diversity.**

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Key Points

* Congress, state Legislatures and courts use Administration on Community Living data programs (RISP, FISP, State of the States, Statedata.info) to guide programs and policies.
* In 2015 the first report on services for people living in US Territories was released
* About 4.7 million people in the US have IDD. More than three of every four of those people live in the home of a family member.
  + About 1 million people received services through a state IDD agency. Of those 54% live with a family member but there are huge differences between states.
  + Of the 383,556 who did not live with a family member, about half lived with two or fewer other people with IDD.
* Federal programs, policies, and Supreme Court Decisions such as Medicaid, the Medicaid Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/ID), the Individuals with Disabilities Education Act, the Olmstead Decision, and the 2014 Medicaid Home and Community Based Settings (HCBS) rule shape where and how publicly funded LTSS are provided.
* In 1967, 194,650 people with IDD lived in 354 state operated IDD facilities located in each of the fifty states and the District of Columbia. In 2013 only 23,802 people remained in 172 state IDD facilities in 38 states. Current and new residents very different.
* 35 years of deinstitutionalization studies found that people have more skills, more choice, and generally more satisfying lives in small community homes or with family members than in an institution.
* Nearly all ICF/IID residents, about half of HCBS recipients living with family members, and almost all HCBS recipients in non-family settings are 22 years or older.
* Waiver expenditures are higher for adults than for children, and higher for people living in non-family settings
* National studies using National Core Indicators data show that people with IDD who receive LTSS in the home of a family member, a home they own or lease, a foster family or host home setting or a group home shared by three or fewer people with IDD experience better outcomes in most areas than people living in settings shared by four or more people with disabilities (Ticha, Nord, & Larson, 2013).

For handouts and other resources related to this presentation go to RISP.umn.edu.

For more information about **supporting individuals and families** go to FISP.umn.edu.

For data presented for **self-advocates** go to selfadvocacyonline.org.

For **resources on many disability topics** go to: qualitymall.org.

For more about our **research** go to rtc.umn.edu.

For **other data** projects (State of the States, StateData.info) go to <http://www.acl.gov/Data_Outcomes/Index.aspx#Data_and_Statistics>