ADD
Projects of National Significance
Data Collection

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Data Collection Projects

- CO Health Sciences Center – *State of the States in Developmental Disabilities (DD)*
- MA Institute on Community Inclusion – *The National Report on Employment Services and Outcomes*
- MN Institute on Community Integration – The Research & Training Center – *Quality Mall* and *Residential Information Systems Project (RISP)*
- The Arc of the U.S. – *The Medicaid Reference Desk*

Data Collection

- Analysis of trends and innovations in Medicaid spending
- Research on the nature of day and employment services for individuals with developmental disabilities
- Examination and study of housing related activities
- Support of the web-based Medicaid Reference Desk

CO – State of the States in DD

- Nationwide study of state services & funding for intellectual & developmental disabilities (I/DD)
- 7th Edition, 2008 benchmark - extends longitudinal trends analysis 1977-2006 – 30 years
- Analyzes I/DD financial & programmatic data from states for fiscal years 2005-06
- Also utilizes national data sources – SSI state supplements; Medicaid Statistical Info System beneficiary data; CMS Online Survey Certification & Reporting system; U.S. Census Bureau data, etc.

MA – The National Report on Employment Services & Outcomes - 2008

- Covers 20-year period, uses four data sets for state profiles;
  - ICI's ID/DD Agency National Survey of Day and Employment Outcomes ('88, '90, '93, '96, '99, '01, '04, '07)
  - Social Security Administration (SSA)
  - Vocational Rehabilitation (VR)
  - American Community Survey (ACS)
- Data addresses status of employment & self-sufficiency for individuals with intellectual and developmental disabilities (ID/DD)
- Website generates customized charts of state, national, and individual disability data. Accessible text versions are automatically created by the charting software.

MN – National Residential Information Systems Project - 2008

- Gathers and reports statistics on people with ID/DD receiving residential and Medicaid-funded services in the United States.
- This report covers the year ending June 30, 2008
- This report is based primarily on two data collection activities.
  - a four part survey of designated state agencies and key respondents to gather aggregated state statistics.
  - The second is a survey of administrators of all large (16 or more residents) state ID/DD facilities.
- Sources of longitudinal data include the NIMH's surveys of "Patients in Institutions;" surveys of the National Association of Superintendents of Public Residential Facilities for People with MR, now the Association of Public DD Administrators; NIMH surveys of "Patients in State & County Mental Hospitals"

The Arc of the U.S. – The Medicaid Reference Desk

- Maintains and expands web site that provides Medicaid information for individuals with I/DD and their families.

- Site includes interactive map that links to state specific fact sheets on eligibility, and services under four categories –Community, Health, At Home, Work.

- Other options: ask questions, Q's &A's, information about Medicaid, other websites, and "My Plan" interactive for making individual plan based on goals and dreams and for making life decisions.

Websites

- www.statedata.info
- http://www.cu.edu/ColemanInstitute/stateofthestates/index.html
- http://rtc.umn.edu/main/
- www.QualityMall.org
- www.thedesk.info