

# Residential Information Systems Project (RISP) and Family Information Systems Project (FISP): AIDD Projects of National Significance



*Pacific Rim Conference, Oahu HI*

*April 29, 2013*

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# Research and Training Center on Community Living for People With IDD

- University of Minnesota, Institute on Community Integration (UCEDD)
- National Institute on Disability and Rehabilitation Research
  - AIDD, CDC, NIH, MCH, DOE, state/local, other
- Community Living
  - Residential services, Medicaid policy, direct support workforce, social inclusion, self-determination, self-advocacy, employment



# RISP/FISP Partners and Collaborators

## RISP/FISP Project Partners

- **RTC on Community Living, U of MN**
  - Sherri Larson, Amy Hewitt, Lynda Anderson
- **NASDDDS**
  - Nancy Thaler, Chas Moseley
- **HSRI - Human Services Research Institute**
  - Drew Smith, John Agosta

## FISP Only Collaborators

- **AUCD - Association of University Centers on Disability**
- **NADDC - National Association of DD Councils**
- **Family Advisory Panel**



# RISP/FISP General Project Objectives

- To ***collaborate with state and territory DD agencies to identify and collect data*** regarding residential services and services provided in individual and family homes.
- To ***collect and compile data annually from states and territories.***
- To ***interpret the data and translate it into actionable information*** to assist policy makers and others to make informed decisions over policy and practice.
- To ***disseminate our findings*** to territory, state and federal policy makers, self-advocate and family advocacy groups, national organizations and all others interested in residential services and supports to families.



# What is RISP?

- Annual state-by-state data since 1977 and longitudinal trends since 1950
- Publically funded residential services and long term supports and services for people with IDD
  - State and non-state settings
  - Congregate settings managed by a service provider (1-3 people, 4-6, 7-15, 16+)
  - People living in homes of their own
  - People living with family members
  - People living in foster family or host home settings



# RISP Data Overview

- Data source: State and Territory IDD agencies
  - 50 states and District of Columbia
  - 2013 proposal added U.S. territories
- Annual data collection and reporting
  - State public residential facilities (institutions)
  - Intermediate Care Facilities for Individuals with Intellectual and Developmental Disabilities (ICF-DD)
  - Home and Community Based Waiver Services (HCBS)
  - Other Medicaid funded in-home supports (state plan, managed care)

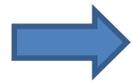


# Why is RISP Important?

- Key data source for tracking deinstitutionalization and community residential supports and services
  - Nationally
  - State-by-state
  - And now U.S. Territories
- Widely used by federal and state policy makers, advocates, and researchers
  - Advocate for new or different services
  - Monitor compliance with Olmstead Plans
  - Track own trends in context of U.S.
  - To provide data for AIDD's GPRA performance reporting to Congress



# Highlights From the RISP Report



Ten states no longer have large (16+) state-operated facilities for people with IDD



Between 2010 and 2011 the number of people living in large state-operated settings decreased from 31,101 to 25,735



In 2011 including nursing facilities and IDD settings

- 81.7% of residential service recipients lived in settings with 15 or fewer persons
- 69.8% lived in settings with 6 or fewer
- 44.9 % lived in settings with 3 or fewer

# Highlights From the RISP Report (Cont'd)

## Key findings



— In 2011, an estimated 76,602 were waiting for residential services. A decrease from 115,059 the year before.

↑ In 2011, an estimated 1,059,785 people with IDD received residential or in-home supports through state Medicaid systems.

↓ The role of the state as a residential service provider continues to decline (serving only 40,814 of 449,486 people in residential settings).

↑ Medicaid HCBS and other Waiver and state plan programs continue to grow, both in utilization and funding.

# Additions to the FY2010 PRF Survey

- The Public Residential Facilities (PRF) survey now includes questions about:
  - Individuals with Autism Spectrum Disorders (ASD) residing in large state-operated facilities (Table 1.18).
  - Individuals who have had involvement with the criminal justice system and residing in large state-operated facilities (Table 1.20).

|            | In facility due to behavior that led to criminal justice system involvement | Have been charged and court ordered to facility for competency training | Found incompetent to stand trial | Under parole supervision | Otherwise under jurisdiction of the criminal courts |
|------------|---|---|----------------------------------|--------------------------|---|
| US Average | 4.9%  | 1.2%  | 3.1%                             | 0.2%                     | 1.9%  |



# RISP Survey -- Operational Definitions

- Operational definitions enhance consistency between states on what data is collected under the different sections
- Definitions are available on the RISP website at <http://www.rtc.umn.edu/risp/main/index.asp> and are available as an appendix in the annual report beginning with FY 2011



# Operational Definitions -- Example

- Publicly-Funded Services include long-term supports and services funded by
  - Federal sources (most commonly Medicaid), including ICF-MR funded residences and long-term supports/services funded under one of the Medicaid Home and Community Based Waiver Programs.
  - State sources (for example a family support program)
- State Plan Services – some states offer some types of long-term supports and services under their Medicaid State Plan. Most commonly these are personal care attendant services offered to people living in homes of their own or with family members.
- Do not include educational services and supports offered to children and young adults ages birth to 21 years except as they are provided to residents of a residential facility.
- Number of residents or facilities with 6 or fewer residents
  - Please report the number separately for facilities with 1-3 residents versus those with 4 to 6 residents whenever possible.
  - If it is not possible to distinguish between settings of 1-3 residents and those with 4-6 residents, please note data not furnished for the 1-3 and 4-6 columns, and report the total in the 1-6 column.



# What is FISP?

- An ADD Project of National Significance
  - First funded in 2011
- An annual data collection effort that produces
  - Accurate, reliable and comparable
  - National, state-by-state and territory data
  - About family supports
    - including Federal, State and territory expenditures for services and supports provided in the family home
    - by age group and number of people receiving supports,
    - distinguishing between supports provided to the individual and supports provided to the family.





# FISP Project Elements

- Establish project advisory capacity
  - Technical Users Group
  - Family Advisory Committee
- Develop and implement a data collection process and instrumentation
- Develop and maintain an interactive project website
  - To gather and track data
  - To provide a data dashboard
  - To disseminate project products
- Conduct annual supplemental studies
- Provide technical and informational assistance regarding family support



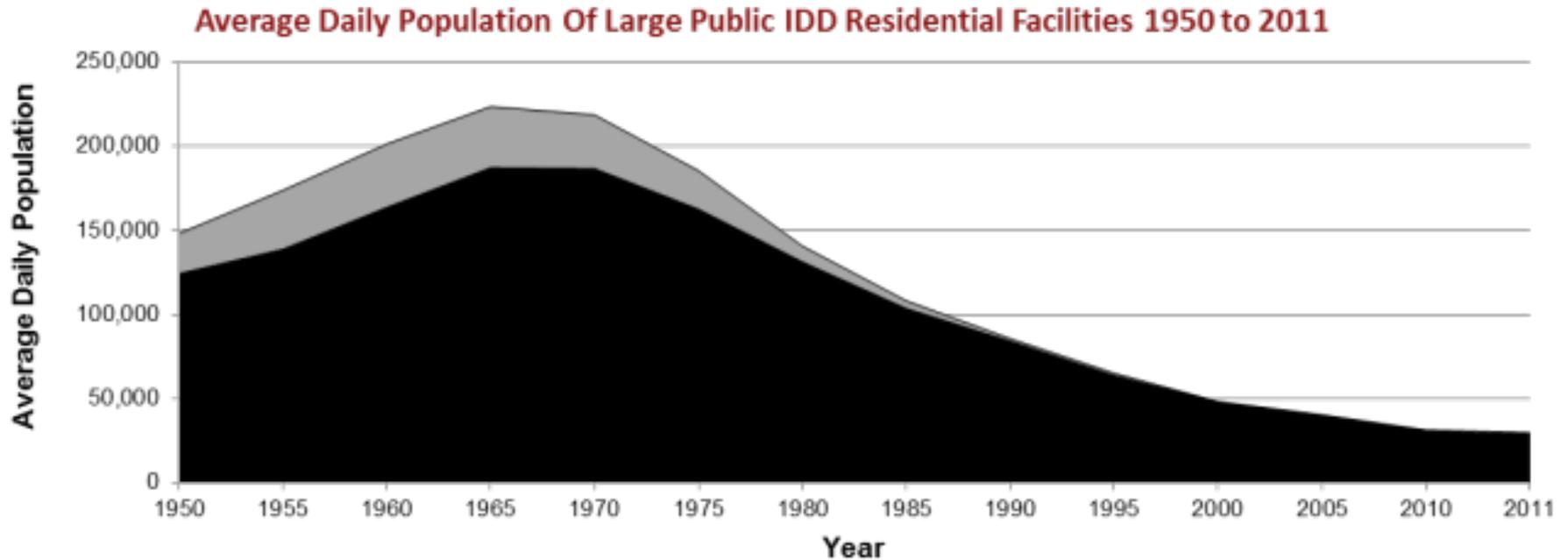


# How did we get here?

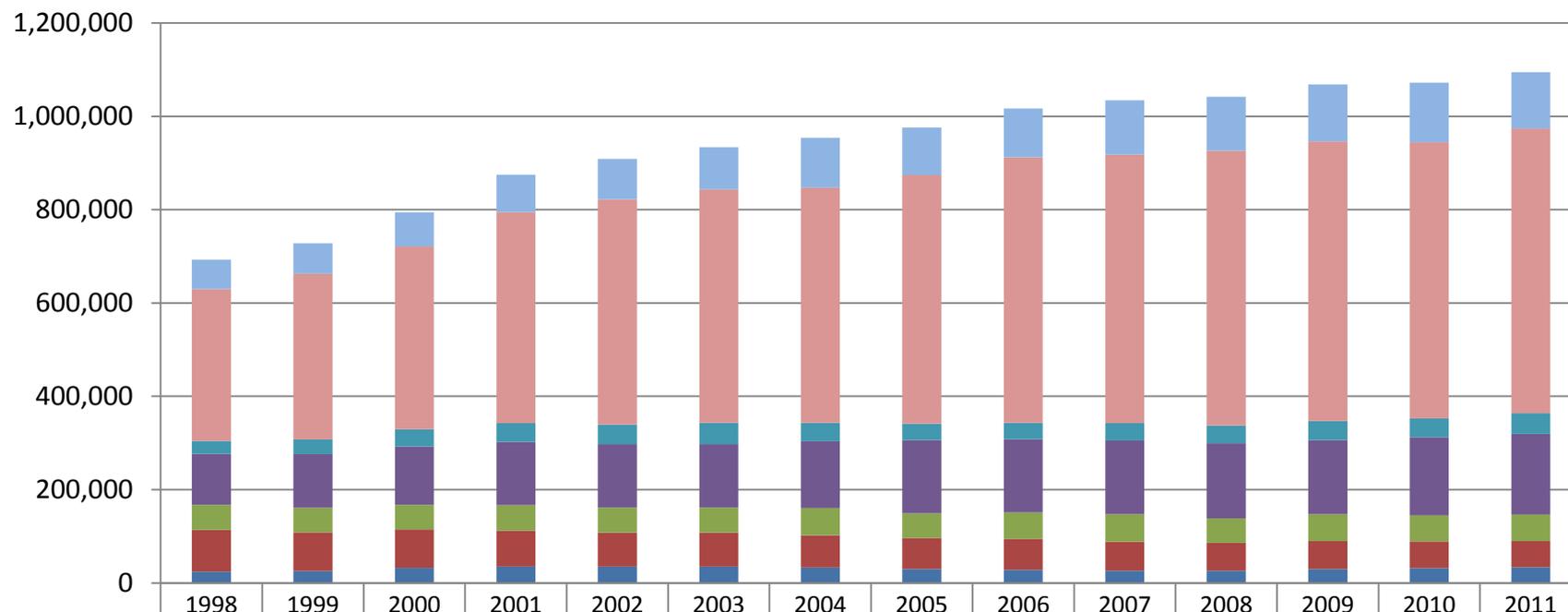
- Shifting emphasis of service delivery to refocus on supports in the family home
- Previous research on “family support”
- Directors’ concerns over difficulty comparing state data on family supports
- Previous NASDDDS initiatives
- Wingspread conference on family support
- AIDD RFP



# Decades of Deinstitutionalization



# Place of Residence for Service Recipients with IDD 1998 to 2011



|              | 1998    | 1999    | 2000    | 2001    | 2002    | 2003    | 2004    | 2005    | 2006    | 2007    | 2008    | 2009    | 2010    | 2011    |
|--------------|---------|---------|---------|---------|---------|---------|---------|---------|---------|---------|---------|---------|---------|---------|
| Own Home     | 62,669  | 65,006  | 73,147  | 80,242  | 86,694  | 90,597  | 107,157 | 101,143 | 104,386 | 115,659 | 115,873 | 122,088 | 127,455 | 120,313 |
| Family       | 325,650 | 355,192 | 391,859 | 451,677 | 482,479 | 500,004 | 503,641 | 533,048 | 569,020 | 576,163 | 588,594 | 599,152 | 592,180 | 610,299 |
| Host Home    | 28,122  | 31,884  | 37,367  | 40,688  | 42,272  | 45,759  | 39,857  | 35,386  | 35,302  | 36,972  | 38,262  | 40,967  | 40,060  | 44,214  |
| 1 to 6       | 108,844 | 114,546 | 124,469 | 135,322 | 135,571 | 135,569 | 142,918 | 156,610 | 157,082 | 157,765 | 160,477 | 158,621 | 167,874 | 172,769 |
| 7 to 15      | 53,940  | 52,863  | 52,818  | 54,333  | 54,031  | 54,325  | 58,503  | 52,888  | 56,572  | 59,002  | 53,198  | 58,235  | 55,682  | 57,486  |
| 16+          | 89,348  | 82,718  | 82,582  | 77,180  | 72,742  | 72,474  | 69,148  | 66,501  | 66,125  | 62,496  | 59,447  | 59,604  | 57,028  | 55,572  |
| Nursing Home | 24,144  | 25,533  | 32,195  | 35,155  | 34,820  | 35,005  | 32,899  | 30,027  | 28,206  | 26,013  | 26,080  | 29,608  | 31,832  | 33,661  |



# Family Support: Wingspread Definition

- Strategies designed to **ensure that families have access** to person-centered and family centered resources, supports, services and other assistance.
- These strategies are **directed to the family unit** but ultimately benefit the individual.
- **Examples** of supports included in this definition are:
  - family-centered planning,
  - service coordination,
  - cash assistance,
  - professionally provided services,
  - information and training
  - emergency assistance and crisis support
  - in-kind assistance
  - peer mentoring/ family-family support
  - assistive technology
  - home modifications
  - goods or products,



# What is Family Support?

A value-based approach to providing services to families and their family member with ID/DD:

- driven by the family and family member with ID/DD
- recognizes the family as a system
- focuses on the strengths, capacity and diversity of family
- Builds on network of all family members and community

## **Instrumental Supports:**

### ***Day-to-Day Needs***

- Respite/Childcare
- Adaptive equipment
- Home modifications
- Financial assistance
- Service Coordination
- Cash Subsidies
- Person/family- centered planning

## **Emotional Supports:**

### ***Mental Health and Self-efficacy***

- Parent-to-Parent Support
- Self-advocacy organizations
- Sib-shops
- Support Groups
- Professional Counseling
- Non-disability community support

## **Information and Training Supports:**

### ***Knowledge and skills***

- Information on disability
- Knowledge about best practices and values
- Skills to navigate and access services
- Ability to advocate for services and policy change

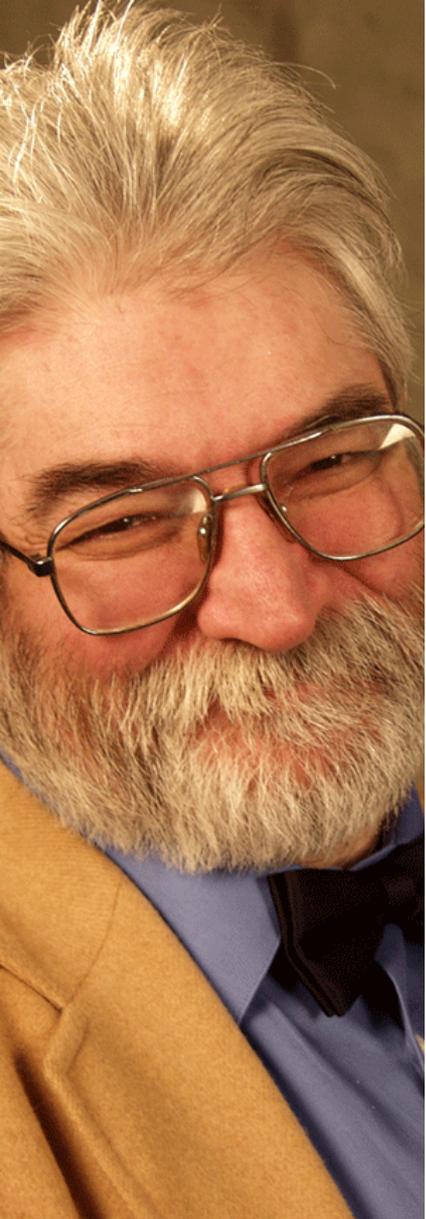




# Why is FISP Important?

- The ID/DD support paradigm is changing
  - From facility-based program models to flexible person-centered, in-home support strategies
  - The majority of people receiving support live in families
- States (and stakeholders) need accurate, timely data on the nature and costs of:
  - Instrumental supports received by people with disabilities and their families
  - Emotional supports receive by family members with and without disabilities
  - The information needed by families and people with disabilities to build their knowledge and skills





# Take Away Message: *FISP offers a unique opportunity...*

- *Not only* to establish a multi-state/territory database to track trends, costs and outcomes
- *But also* to:
  - Set new service delivery expectations in states and territories with respect to families and the supports furnished to people living in the family home (*what gets counted gets done*)
  - Establish an outcome based format for effective collaborations between state and federal policymakers, researchers, families, people with disabilities, providers and others
  - Build an evidence base in support of key policy changes at both the state and national levels.



# RISP/FISP DATA COLLECTION AND DISSEMINATION



# Online Data Entry

- State and Territories provide data
- Electronic data collection allows for real time data updates as well as easier communication between data respondents and RISP staff.
- Data entry website is password protected for each entity



# Online Data Entry (Cont'd)

The form will read 'complete'  
There are four approval codes that the RISP team will assign:  
Not Approved, Locked, Verified, Publish



<< Previous page or Go to State Survey Report Page 2 of 3 Next page >>

## RESIDENTIAL INFORMATION SYSTEMS PROJECT - FISCAL YEAR 2010 (Wyoming)

Current Completion Status of this page: **Complete**

Current Approval Status of this page: **Verified**

### Part 2. Nonstate Residences of Persons with Intellectual Disabilities (Mental Retardation) and Developmental Disabilities (ID/DD)

Click the link in each cell to enter data. Please select the appropriate "Data Code" to indicate Estimated numbers (e), Data Not Furnished (DNF), or other than date of entry (o). Last year's data is listed in parentheses in each cell.

| Type of Nonstate Residence: Please exclude respite care placements. Please count only residents with ID/DD receiving services. Please do not make entries in the shaded cells.  | Number of residential settings |                          |                           |                       | Total 1-6 residents | with 7-15 residents | with 16+ residents | Total Residences | with 1-3 residents | with 4-6 residents | Total 1-6 residents | with 7-15 residents | with 16+ residents | Total Residents           | Number of HCBS recipients living (on June 30, 2010), in each of the residential types listed. |
|---|--------------------------------|--------------------------|---------------------------|-----------------------|---------------------|---------------------|--------------------|------------------|--------------------|--------------------|---------------------|---------------------|--------------------|---------------------------|---|
|   | with 1-3 residents             | with 4-6 residents       | Total 1-6 residents       | with 7-15 residents   |                     |                     |                    |                  |                    |                    |                     |                     |                    |                           |   |
| Please report ONLY nonstate ICFs-MR in Type I   |                                |                          |                           |                       |                     |                     |                    |                  |                    |                    |                     |                     |                    |                           |   |
| Type I. Nonstate ICFs-MR.   |                                | 0<br>(0)                 | 0<br>(0)                  | 0<br>(0)              |                     |                     |                    |                  |                    |                    |                     |                     |                    |                           |   |
| Please do not report ICFs-MR, nursing homes or "congregate personal care facilities" in Types II through VI.  |                                |                          |                           |                       |                     |                     |                    |                  |                    |                    |                     |                     |                    |                           |   |
| Type II. A residence owned, rented or managed by the residential services provider, or the provider's agent, to provide housing for persons with ID/DD in which staff provide care, instruction, supervision, and other support for residents with ID/DD. | 138 <sup>e</sup><br>(114)      | 99 <sup>e</sup><br>(129) | 237 <sup>e</sup><br>(243) | 8 <sup>e</sup><br>(4) |                     |                     |                    |                  |                    |                    |                     |                     |                    |                           |   |
| Type III. A home owned or rented by an individual or family in which they live and provide care for one or more unrelated persons with ID/DD (e.g., host family/family foster care).  | 42 <sup>e</sup><br>(47)        | 0 <sup>e</sup><br>(0)    | 42 <sup>e</sup><br>(47)   | 0 <sup>e</sup><br>(0) |                     |                     |                    |                  |                    |                    |                     |                     |                    |                           |   |
| Type IV. A home owned or rented by one or more persons with ID/DD as the person(s)' own home in which personal assistance, instruction, supervision and other support is provided as needed.  | 127 <sup>e</sup><br>(91)       | 0 <sup>e</sup><br>(0)    | 127 <sup>e</sup><br>(91)  |                       |                     |                     |                    |                  |                    |                    |                     |                     |                    |                           | 253 <sup>e</sup><br>(181)   |
| Type V. A residence of person(s) with ID/DD which is also the home of related family members in which the person(s) with ID/DD and/or their family members receive supportive services (e.g., respite care, homemaker services, personal assistance).     | 467 <sup>e</sup><br>(455)      | 0 <sup>e</sup><br>(0)    | 467 <sup>e</sup><br>(455) |                       |                     |                     |                    |                  |                    |                    |                     |                     |                    | 933 <sup>e</sup><br>(910) | 933 <sup>e</sup><br>(910)   |
| Type VI. Other residential types (please specify):  | 0 <sup>e</sup><br>(0)          | 0 <sup>e</sup><br>(0)    | 0 <sup>e</sup><br>(0)     | 0 <sup>e</sup><br>(0) |                     |                     |                    |                  |                    |                    |                     |                     |                    | 0 <sup>e</sup><br>(0)     | 0 <sup>e</sup><br>(0)   |
| Type of Nonstate Residence: Please exclude respite care placements. Please count only residents with ID/DD receiving services. Please do not make entries in the shaded cells.  |                                |                          |                           |                       |                     |                     |                    |                  |                    |                    |                     |                     |                    |                           |   |
| Number of residential settings on June 30, 2010   |                                |                          |                           |                       |                     |                     |                    |                  |                    |                    |                     |                     |                    |                           |   |
| Number of residents in residential settings on June 30, 2010  |                                |                          |                           |                       |                     |                     |                    |                  |                    |                    |                     |                     |                    |                           |   |

Previous year's data.

Data codes include: Estimate, Data Not Furnished and Not

Notes that are entered can be

If the data is not for the specific FY, but is the number used in the previous year, enter that year here.

**Type II - 1-3 Residents**

# of Settings:

Data Code:

Notes:

Other Date:

If your definitions differ from above, or you have any other notes regarding the information on this page, please explain: [\(Add/Edit Notes\)](#)

This Page Completed by: [\(Add/Edit Completed by info\)](#)

Name: Kevin Malm  
Phone: 307-777-7618  
Email: kevin.malm@health.wyo.gov



# Printed and On-Line Reports



- <http://rtc.umn.edu/RISP/main/>

## Residential Services for Persons with Intellectual and Developmental Disabilities: Status and Trends Through Fiscal Year 2011

National Residential Information Systems Project (RISP)

Research & Training Center on Community Living  
Institute on Community Integration (UCEDD)

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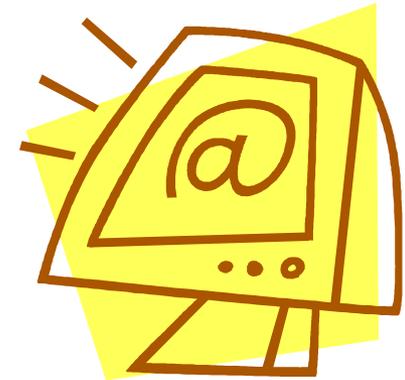
Research and Training Center on Community Living



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# Build a Report

- The Build a Report section of the RISP website allows public users to develop and run different reports online using published RISP data.
- Functions of Build a Report
  - Cross state comparisons
  - Multi-year comparisons
  - 34 report types and growing
- Build a Report can be found at <http://www.rtc.umn.edu/risp/build/index.asp>



# RISP/FISP

## Technical Assistance



The RISP/FISP team members are available to all states and territories for providing technical assistance related to this project.

- Each state/territory has a designated contact person
- Discussion about state and national trends
- Troubleshooting data collection
- Please do not hesitate to contact any of the RISP/FISP Team should you need Technical Assistance in either of these areas, or others that may arise.

# Contact Information

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