# The Impact of NCI Data for the Administration on Intellectual and Developmental Disabilities

Katherine Cargill-Willis
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ADMINISTRATION ON INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

ACL
Administration for Community Living

# NCI DATA IS IMPORTANT TO ACL AND AIDD BECAUSE IT MEASURES QUALITY OF LIFE

# QUALITY OF LIFE QUESTIONS:

- ✓ How often are you lonely?

- ✓ Do you feel safe?

- ✓ Not only, do you like your job, but are you working as many hours as you would like?

# THROUGH THE NCI WEBSITE THE PUBLIC, INCLUDING PEOPLE WITH I/DD AND THEIR FAMILY MEMBERS CAN:

- ✓ Examine the quality of life for people with intellectual and developmental disabilities in their state
- ✓ Compare data in their state to other states

# THE IMPACT OF THE DATA ON STATE SERVICES

State directors can track the state's progress

They can inform state agencies on their progress

Agency staff are trained on the agency's strengths and weaknesses

Staff can change the lives of people with I/DD

# STATE DIRECTORS CAN ALSO INFORM:

✓Their State Legislature

✓The Governor's Office

✓Other state agencies

✓DD Network partners

# THIS DATA IS IMPORTANT TO AIDD BECAUSE:

- ✓ The data can be tracked over time
- ✓ Comparisons can be made between states and regions
- ✓ The data can help tell a story of the person's whole life

# AIDD SHARES THIS IMPORTANT INFORMATION WITH:

✓Congress

✓The HHS Secretary

✓The Office of Budget and Management

✓CMS

✓Other agencies

In 2011 AIDD began supporting the project by funding the participation of a maximum of 5 new states every year for five years

# THROUGH THIS EFFORT 17 STATES HAVE JOINED NCI

- ✓ Maryland
- ✓ Connecticut
- ✓ Michigan
- ✓ South Carolina
- ✓ Virginia
- ✓ Mississippi
- ✓ Indiana
- ✓ Oregon
- ✓ Wisconsin

- ✓ Maine
- ✓ Kansas
- ✓ Tennessee
- ✓ Colorado
- ✓ Minnesota
- ✓ Delaware

- ✓ Vermont
- ✓ Rhode Island

# THANK YOU FOR PARTICIPATING IN THIS VERY IMPORTANT PROJECT!

# AIDD HAS FOUR OTHER DATA COLLECTION PROJECTS:

✓ State of the States on Developmental Disabilities

✓ The Residential Information Systems Project

✓ Access to Integrated Employment: National Data Collection on Day and Employment Services for Citizens with Disabilities

✓ Families Information Systems Project

# NEW INITIATIVES FROM AIDD

**The Self-Advocacy, the Supported Decision-Making and the Diversity Initiatives**

# THE SELF-ADVOCACY GRANTS

Prompted by the Self-Advocacy Summits held across the country, AIDD is funding 6 three-year projects to support the Self-advocacy movement

# 2013 GRANTS

| | |
|---|---|
| NEAT | Peer to Peer Connection in Vermont working with Self Advocacy Association of New York State; Green Mountain Self-Advocates in Vermont; Massachusetts Advocates Standing Strong; Advocates in Action Rhode Island; People First of New Hampshire; and Speaking Up For Us of Maine. |
| PASDA | Autistic Self Advocacy Network working with People First of Washington, ASAN-Seattle, ASAN- Portland, Oregon Self-Advocacy Coalition, People First Napa, People First San Diego, Statewide Self Advocacy Network, ASAN – Sacramento and People First California. |
| OCSS | People First of Alabama, People First Arkansas, People First of Georgia, FLSAND Florida Self Advocacy Network, People First of North Carolina, Oklahoma People First, People First of Tennessee and IMPACT South Carolina |

# 2014 GRANTS

| HSRN | Self-Advocate Coalition of Kansas, People First of Missouri, People First of Nebraska, and three local Iowa self-advocacy groups. |
|------|-----------------------------------------------------------------------------------------------------------------------------------|
| SWI | People First of Arizona, Youth Action Council of Arizona, Kayenta Dine, People First of Tucson, People First of Denver, People First of Albuquerque and the Texas Advocates |
| EPIC | Peer Power (Alaska), Self-Advocate Leadership Network (Idaho), People First of Wyoming, and People First of Nevada |

# HIGHLIGHTS FROM THE SA GRANTS

✓ All grantees are required to collect at least 1,200 surveys from self-advocates in their region about the needs of local self-advocacy groups

✓ Power Lunches- Organized online lunches where self-advocates and allies join in to talk about different topics. The lunches are facilitated by a volunteer from one of the states

✓ Leadership Institute - The 1st annual leadership academy covered topics such as leadership skills, organizing, and fund raising. It is expected that the academy will be held every year

✓ VLOGS (video blogs or logs) – Created 10-12 minute vlogs to be posted on the SABE YouTube channel with topics including fair wages and employment

# NEXT STEPS FOR SELF-ADVOCACY

As these projects come to an end, AIDD is holding a series of work groups to seek advice on the direction the agency should pursue to support self-advocacy

# SUPPORTED DECISION MAKING (SDM)

A five-year grant awarded to Quality Trust for People with Disabilities in 2014
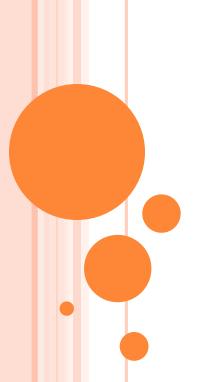
Components include:

- ✓ Literary review: Collecting information; building upon existing resources, and creating new ones regarding SDM
- ✓ Web-Site: Creating a web-based center to gather, organize, and disseminating accessible, high-quality resources and information related to SDM
- ✓ Training and Technical Assistance: Developing and providing technical assistance to the DD network, Parent Training and Information Centers, and people with IDD and their families
- ✓ Small State Grants: Designing and implementing small grants demonstration program to community organizations

# LEADERSHIP INSTITUTE

- ✓ A 5-year project awarded to the Georgetown University funded at $225,000.00 a year
- ✓ To create a leadership institute designed to advance and sustain cultural and linguistic competence for the DD Network programs

# THE DIVERSITY LEADERSHIP INSTITUTE:

✓ Offers interactive forums, face-to-face and web-based, to explore the unique role of those who currently lead or are interested in leading cultural and linguistic competence and diversity efforts within their settings

✓ Provides opportunities for participants to share and learn from experts, including peers and people with developmental disabilities, about the challenges and successes of leading cultural and linguistic competence and diversity

✓ Builds upon each cohort and create a Leadership Alumni that can support provide peer support and guidance over time

✓ Provides beginning, intermediate, and advanced learning opportunities about leadership for diversity, cultural and linguistic competence, and inclusion

# QUESTIONS?

# THANK YOU

**Katherine Cargill-Willis**
**Program Specialist**
**(202) 690-5791**
**katherine.cargill-willis@acl.hhs.gov**
**ACL Website: http://hhs.gov\acl**

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