State of the Science: Outcomes and quality of life in community living

NAKU/NDCPD
Living Conditions and Quality of Life
Trondheim, Norway
June 20, 2013
Research and Training Center on Community Living for People With IDD

- 8 miles (13 km) connecting over 69 city blocks
- 90,000 miles (144,841 km) of shoreline
- Lutefisk capital of US
- 900,000 Norwegian Americans
<table>
<thead>
<tr>
<th>Quality of Life</th>
<th>UN Convention (Article number)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Physical Well-Being</strong> (Health, Safety, Fitness)</td>
<td>Life (10) Health (25) Freedom from torture, degradation, exploitation, violence, abuse (15/16)</td>
</tr>
<tr>
<td><strong>Material Well-Being</strong> (Wealth, Housing, Tenure, Privacy, Neighbourhood, Transport)</td>
<td>Access to physical environment, transport, info, communications &amp; services (9) Privacy (22) Adequate standard of living &amp; social protection (28)</td>
</tr>
<tr>
<td><strong>Social Well-Being</strong> (Relationships, Community Involvement)</td>
<td>Respect for home &amp; the family (23) Being included in the community (19)</td>
</tr>
<tr>
<td><strong>Emotional Well-Being</strong></td>
<td>Protecting the integrity of the person (17)</td>
</tr>
</tbody>
</table>
Promises of Quality Lives in the Community

- Legislation
  - ADA
  - Rehabilitation Act
  - DD Act
- Policy Initiatives
  - President’s “Year of Community Living”
  - U.S. DHHS Community Living Initiative
- Court Decisions
  - Olmstead v L.C.
- Expert panel and other reports
  - Future of Disability in America
  - Healthy People 2020
  - Wingspread Conference report
Community Living and Participation

- Where and with whom a person lives;
- Where a person works and how they earn money;
- What a person does during the day;
- Quality of relationships developed with others;
- What and with whom a person does things of personal interest,
- Health (physical and emotional),
- Where and with whom they worship or practice their faith;
- Interest in and opportunity to engage in learning and personal growth
- Ability to make decisions and choices about their own life and activities.
Substantial LTSS Investments

- HCBS FY 2011
  - 27.9 billion dollars
  - $45,000 per resident

- ICF-DD services FY 2011
  - 12.57 billion dollars
  - $148,000 per recipient

- State Operated Residential
  - $226,000 per person

- Employment
  - Supported employment $801,598,982
  - Medicaid $787,000,000

- PCA/HHA/other
  - 2 billion dollars

TOTAL I/DD SPENDING BY REVENUE SOURCE: FY 2011

STATE
$20.66 Billion
36%

FEDERAL
$34.38 Billion
61%

LOCAL
$1.61 Billion
3%

Total:
$56.65 Billion

Title XX/SSBG (1%)
HCBS Waiver (53%)
Waiver SSI/ADC (15%)
ICF/ID (24%)
Related Medicaid (6%)
Other Federal Funds (1%)

Braddock et al, 2013
Medicaid LTSS Expenditures for Older Adults and People with Physical Disabilities, in Billions, 1995–2009

Non-Institutional LTSS for older adults and people with physical disabilities includes Section 1915(a) programs and Section 1115 and 1915(c) waivers targeting older adults and/or people with physical disabilities, as well as the following services: personal care, home health, PACE, services authorized under Section 1915(j), and private duty nursing.

Eiken et al, 2011

Non-Institutional LTSS for people with developmental disabilities includes Section 1915(a) programs and Section 1115 and 1915(c) waivers targeting people with intellectual disability, autism spectrum disorder, and/or other developmental disabilities.

Eiken et al, 2011
Greater Expectation for Outcomes

• Great Recession Recovery
  – revenues in a majority of states remain at or below 2008 levels
  – 42 states closed 103 billion deficit through cuts

• OMB Memo 2012
  – “Where evidence is strong we should act on it. Where evidence is suggestive, we should consider it. Where evidence is weak, we should build the knowledge to support better decision in the future”

(Office of Management and Budget, p. 1)
Decades of Deinstitutionalization

Average Daily Population of Large Public IDD Residential Facilities 1950 to 2011

Larson et al, 2013
Place of Residence for Service Recipients with IDD
1998 to 2011

Larson et al, 2013
Estimated Total Number of People Served By IDD Employment Agencies

Butterworth et al, 2013
Estimated Service Distribution By Year

Butterworth et al, 2013
Weekly Wages By Year

Butterworth et al, 2013
State of the Science Conference

Halifax, Nova Scotia
July 12th and 13th, 2012

“Community Living and Employment Outcomes for People with IDD”
SOSC Conference Purpose

- Research findings
- Debates and points of contention
- Emerging and unanswered questions
- Future research questions
SOSC Invited Participants

- Brian Abery
- John Agosta
- Angela Amado
- Julie Bershadsky
- Matt Bogenschutz
- Ivan Brown
- Ann Cameron Caldwell
- Dawn Carlson
- Kristin Dean
- Eric Emerson
- David Felce
- Glenn Fujiara
- Chris Hatton
- Tamar Heller
- Amy Hewitt
- Kathy Humphries
- George Jesien
- David Johnson
- Harold Kleinert
- Charlie Lakin
- Sherri Larson
- Rich Luecking
- David Mank
- Beth Marks
- Philip McCallion
- Mary McCarron
- Suzanne McDermott
- Keith McVilly
- Charles Moseley
- Derek Nord
- Lori Sedlezyk
- Tom Seekins
- Jasmina Sisirak
- Jerry Smith
- Roger Stancliffe
- Sarah Taub
- Ann Turnbull
- Rud Turnbull
- Mike Wehmeyer
Validating the SOSC Conference Findings

- Data/Information Gathering
  - Reinventing Quality strand
  - SABE conversations
  - Review and synthesis of SOSC conference summary by researchers
SOCIAL INCLUSION AND COMMUNITY PARTICIPATION
Social Inclusion

- Social networks primarily paid staff, Families, and peers with disabilities
- Relationships are mediated through the family
- People may be physically included but big gaps in social inclusion
- Different factors affect social inclusion
- Effective interventions increase inclusion
Schools with Peers
Work and Social Relationships with Co-workers
Community Living - Adults
Specialized Community Groups – Clubs
Specialized Community Groups – Faith Organizations
Effective Interventions

• Person-centered planning circles
• Social Inclusion Facilitators (Abery & Fahnestock, 1992)
• Community Mapping (Carlson, 2000)
Active Mentoring (Natural support)

- One day per week, instead of working, the person attends a **mainstream community group** of their choice and receives support from group members who volunteer to be **mentors**.

- Mentors trained to provide effective support and ensure activities are available.
Friendships, Social Inclusion and Community Participation: RTC/CL study

• Community friends: 16% to 78% by end
• Community group membership: 2% to 42%
• Community social roles: 3% to 36%

(Amado et al., 2010)
Larger Community-wide Approaches To Inclusion

1. Chicago – neighborhood organizations and leaders (Asset-Based Community Development)
2. Building Social Capital
3. Seattle - Department of Neighborhoods
4. Model Communities (DHSS)
5. Community Member Forums
Factors Affecting “Social” Inclusion

• Regular, ongoing social contact with meaningful interaction with
  – Community associations and groups
  – Faith communities
Social Inclusion Research Priorities

• Research focusing on bringing the community to the person with IDD
• Increase the understanding of the role of families in promoting social inclusion
• Understand what social inclusion outcomes exist for people with IDD who live with their families.
• Increase understanding of what inclusive communities are and their characteristics
• Develop and test interventions that are designed for community members.
• Take known effective interventions to scale
• Better understand the complex interactions among factors that affect social inclusion.
FAMILIES EXPERIENCES AND SUPPORT
“Family Support”

- Family support programs exist in all states (30 have legislative mandates)
- Family support included in service array.
- Great variation in “family support” program design.
“Family Support” Defined

• There is no single definition of “family support.”
• There is no agreement on what services are “family support.”
Siblings: Psychosocial Outcomes

• Negative affect on siblings
  – Greater pessimism, distress, and demands (Griffiths & Unger, 1994)
  – As mother’s health declines, brothers perceive less positive affect from their siblings with a disability (Orsmond, 2000)
  – Less contact and less positive for siblings of people with autism (Orsmond, 2007)

Tamar Heller, 2012
Siblings: Psychosocial Outcomes

• Positive effect on siblings
  – Mothers report positive effect on other children (Carr, 2004)
  – Functioning well, good health, low depression, and high reward being a sibling of a person with disabilities (Hodapp & Urbano, 2007)
  – Relationships with parents more positively affected for siblings of adults with Down syndrome versus autism (Orsmond & Seltzer, 2007)
Sibling Support Needs

• Getting support for their caregiving role
  – support groups (Arnold et al., in press; Heller & Kramer, 2009)
  – inclusive definition of family (Arnold et al., in press)

• Enhancing the formal support system to address sibling needs (Arnold et al., in press)
  – Improved residential supports, service coordination, transportation
  – Better pay and career advancement for direct support professionals
  – More funding for financial support
  – In-home and out-of-home respite services

Tamar Heller, 2012
Gaps in Sibling Research

- Demography-No good estimates
- Diversity of families (poverty, racial/ethnic)
- Perspectives of people with disabilities
- Longitudinal studies across the lifespan
- Practice and policy interventions to support siblings

Tamar Heller, 2012
Family Caregiving Experiences

- Family caregivers provide a range of supports

Hours/Week

- 40% <15 hrs
- 21% 15 - 40 hrs
- 21% 41 - 80 hrs
- 18% 80+

Ann Cameron Williams- Caldwell, 2012
Sources of funding for supports

- Parent/family income: 52%
- Parent/family savings: 12%
- PW/IDD income: 21%
- PW/IDD savings: 3%
- Medicaid HCBS: 50%
- Private Insurance: 8%
- Special needs trust: 3%
- Other: 19%

Ann Cameron Williams- Caldwell, 2012
Family Support Points of Confusion/Debate

• Changes over life course
• Great range of family support needs
• Theoretical construct or service type
• Are/should supports be for the “family” or “individual”
• Varied program design
Family Research Priorities

• Define “family support”
• Gather basic data
  – Siblings
  – People with IDD at home
• Purposeful sampling of families from diverse families
• Better understand sibling support across lifespan

• Sibling experiences, from person with IDD lens
• Develop models for blended funding
• Better understand experiences and effects of aging caregivers
• Intervention to support adult siblings
EMPLOYMENT AND ECONOMIC SELF-SUFFICIENCY
Suite of Effective Practices

• Individual-level
  – Instruction
  – Self management
  – Natural supports
  – Person center career planning

• Organizational-level
  – Organizational change
  – Self & customized employment
Cost Benefit

• Supported employment has:
  – Higher social benefit
  – Greater employment outcomes
  – Less reliance on other programs
SOSC Employment Research Priorities

• Discern effective interventions that result in increased wages, hours and advancement
• Identify key characteristics of personal networks and communities
• Identify strategies to effectively develop, facilitate and access the personal network and social capital
• Develop strategies to raise employment expectations
• Implement system change activities designed to improve system expectations and outcomes related to employment
HEALTH AND WELLNESS
67 Studies on Physical Activity and IDD

- Below average levels of fitness
- More likely to be sedentary
- Poor fitness is associated with obesity and physical deconditioning
- Lower cardiorespiratory fitness, strength, more secondary conditions
- Proportion overweight similar to general population
- Physical activity interventions (treadmill walking, step/bike/elliptical, and circuit weight training) increased aerobic capacity

Rimmer & Hiss (2005).
Overweight and Obesity (BMI $\geq 25.0$) (NCI, 2009)

• People with IDD vs. General population
  – All people IDD (62.2%) significantly less than US (68.0%)
  – Men IDD (60.5%) significantly less than US (72.30%)
  – Women IDD (64.5%) not significantly different from US (64.1%)

• Obesity (BMI $> 30.0$) rates highest to lowest
  – *By setting type:* own home/apartment, family home, (host/ foster home, group home), institution
  – By diagnosis: Down Syndrome, Intellectual disability only, Autism, Cerebral Palsy
  – By level of ID: highest for those with mild IDD
## Wellness Curricula for Adults with Disabilities

<table>
<thead>
<tr>
<th>Title</th>
<th>Target Population</th>
<th>Developer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Continuing to Live Well with a Disability: A companion course to Living Well with a Disability</td>
<td>Adults with Disabilities</td>
<td>Center for Disabilities and Development, University of Iowa</td>
</tr>
<tr>
<td>Healthy Lifestyles for People with Disabilities</td>
<td>Adults with Disabilities</td>
<td>Center on Community Accessibility, Oregon Heath &amp; Science University</td>
</tr>
<tr>
<td>Steps to your Health (McDermitt)</td>
<td>IDD</td>
<td>South Carolina Department of Disabilities and Special Needs</td>
</tr>
<tr>
<td>Health Advocacy Program</td>
<td>IDD</td>
<td>NY State Institute for Basic Research in DD</td>
</tr>
<tr>
<td>MENU-AIDDS: Materials for supporting nutrition and education with adults with intellectual or developmental disabilities</td>
<td>IDD</td>
<td>Rural Institute, University of Montana</td>
</tr>
<tr>
<td>Women Be Healthy, A Curriculum for Women with Mental Retardation and Other Developmental Disabilities</td>
<td>Women with Disabilities</td>
<td>North Carolina Office on Disability and Health, Frank Porter Graham Child Development Institute</td>
</tr>
<tr>
<td>Exercise and Nutrition Health Education Curriculum for Adults with Developmental Disabilities</td>
<td>IDD</td>
<td>RTC on Aging with DD, University of IL, Chicago</td>
</tr>
<tr>
<td>Health Matters: The exercise and nutrition health education curriculum for people with developmental disabilities</td>
<td>IDD</td>
<td>RTC on Aging with DD, University of IL, Chicago</td>
</tr>
<tr>
<td>Living Well with a Disability</td>
<td>Adults with Disabilities</td>
<td>Rural Institute, University of Montana</td>
</tr>
</tbody>
</table>
Continued Challenges

• Providers lack knowledge or are not prepared to share decision making with people with IDD
• Most everyday health information does not use universal design principles
• People with IDD and care givers lack information
• Cultural gaps (providers, individuals, caregivers)
Health and Wellness Research Priorities

- Examine how the environments in which people with IDD live and participate affect their health.
- Understand the changing health care delivery landscape and its effects on people with IDD.
- Examine the manifestation of typical age-related conditions (e.g., cancer, arthritis, hypertension) in people with IDD.
- Establish appropriate care guidelines.
- Identify specialized health intervention for people with IDD.
SELF-DETERMINATION
Self-Determination - Defined

• Control over day to day decisions
• Control over big decisions
• Supporting people to make things happen they want
Self-Determination Research

- Previous research suggests a number of ecological characteristics related to self-determination including:
  - Organizational climate
  - Agency policies & regulations, and
  - The knowledge, skills, and attitudes/beliefs possessed by DSPs
  - The behaviors of DSPs
Mediating Factors

- **Social Inclusion**: societal acceptance of persons with disabilities in school, work, and community contexts.
  - Degree of inclusion has an impact on opportunities for self-determination
SD: What We Know

• Self-determination results from an interaction between the individual and the environment.
  – SD always occurs within a social context

• The manner in which people view and express self-determination is affected by their:
  - Family
  - Age
  - Sex
  - Culture
SD: What We Know

• Youth and adults with IDD are less self-determined than peers w/o IDD
• SD predicts higher QOL after school
• Adults with IDD value SD more than professionals/families
• Students who leave H.S. with greater self-determination have better outcomes
• IQ is not predictive of self-determination
• Social abilities and adaptive behavior are related to SD
SD Intervention Research

- Efficacy data exists on models
  - Steps to SD (Hoffman & Field, 1995)
  - TAKE CHARGE FOR THE FUTURE (Powers et al, 2001)
  - Self-Determination Model... (Wehmeyer et al, 2000)
Self-Determination Research Priorities

- Ecological factors, intervention efficacy in underrepresented groups
- Develop better global measures of SD
- Develop valid and reliable approaches to actually observe the exercise of self-determination
- Identify relationship factors that facilitate or cause barriers
- Evidence-based practices in SD with outcomes related to independence and inclusion
CROSS CUTTING ISSUES AND PREDICTORS OF OUTCOMES
Predictors and Covariates of Outcomes

• Factors associated with outcomes
  – Policy (State, National and International)
  – Setting type and size
  – Organizational and family culture
  – Individual characteristics
IMPACT of Setting

- People who moved from institutions experience increases in adaptive behavior over time and in comparison to people who did not move.
  — Lakin & Larson, 2012

<table>
<thead>
<tr>
<th>Setting Type</th>
<th>Setting Size</th>
</tr>
</thead>
<tbody>
<tr>
<td>Own Home</td>
<td>1-3</td>
</tr>
<tr>
<td>Family Home</td>
<td>1-3</td>
</tr>
<tr>
<td>Host Family/Foster</td>
<td>1-3</td>
</tr>
<tr>
<td>Group residence</td>
<td>1-3</td>
</tr>
<tr>
<td>Group residence</td>
<td>1-3</td>
</tr>
<tr>
<td>Group residence</td>
<td>4-6</td>
</tr>
<tr>
<td>Group residence</td>
<td>7-15</td>
</tr>
<tr>
<td>Group residence</td>
<td>16+</td>
</tr>
</tbody>
</table>
# Other Key Predictors: NCI Choices

<table>
<thead>
<tr>
<th>Block</th>
<th>Everyday Choice</th>
<th>Support Related Choice</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Factors</td>
<td>Adj. R2</td>
</tr>
<tr>
<td>1</td>
<td>Level of ID</td>
<td>0.31*</td>
</tr>
<tr>
<td>2</td>
<td>Mobility, vision or hearing impairment</td>
<td>0.32*</td>
</tr>
<tr>
<td>3</td>
<td>Age</td>
<td>0.33*</td>
</tr>
<tr>
<td>4</td>
<td>Problem behavior, mental health DX, ASD</td>
<td>0.33*</td>
</tr>
<tr>
<td>5</td>
<td>Report for self; primary means of expression</td>
<td>0.40*</td>
</tr>
<tr>
<td>6</td>
<td>Setting size and type</td>
<td>0.42*</td>
</tr>
<tr>
<td>7</td>
<td>State</td>
<td>0.44*</td>
</tr>
</tbody>
</table>
People in smaller settings make more **Big choices** (NCI 2009)

The Choices
- The people I live with
- The place I live
- The person who assists me at home
- Where I work
- The person who assists me at work
- The person who helps me get the services I need.

After accounting for
- Level of ID,
- Challenging behavior,
- Able to talk,
- State of residence
- (Mobility, vision, age)

N = 6,179, 19 states Ticha, Lakin, Larson, Stancliffe (2012), National Core Indicators, $R^2 = 31\%$
People in smaller settings make more Daily choices (NCI, 2009)

The Choices

• When I get up, eat, go to bed (48% choose alone, 23% have help, 19% decided by someone else)
• How I spend my free time
• What to buy with my spending money

After accounting for

• Level of ID,
• Mobility
• Challenging behavior,
• Able to talk,
• State of residence
• (Vision, age)

N = 8,892, 23 states Ticha, Lakin, Larson, Stancliffe (2012) National Core Indicators; $R^2 = .44$
## Access to Preventative Care (NCI, 2009)

<table>
<thead>
<tr>
<th>Preventative Care</th>
<th>Institution</th>
<th>Community-based group residence</th>
<th>Independent home/ apt</th>
<th>Parent/ relative home</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sample Size</td>
<td>1,163</td>
<td>3,899</td>
<td>1,498</td>
<td>3,554</td>
</tr>
<tr>
<td>Physical exam in last year</td>
<td>96%</td>
<td>96%</td>
<td>91%</td>
<td>87%</td>
</tr>
<tr>
<td>Dentist visit in last year</td>
<td>96%</td>
<td>93%</td>
<td>76%</td>
<td>74%</td>
</tr>
<tr>
<td>Eye exam in last year</td>
<td>76%</td>
<td>74%</td>
<td>62%</td>
<td>50%</td>
</tr>
<tr>
<td>Hearing test in last 5 years</td>
<td>92%</td>
<td>81%</td>
<td>55%</td>
<td>54%</td>
</tr>
<tr>
<td>Flu vaccine in last year</td>
<td>94%</td>
<td>83%</td>
<td>65%</td>
<td>56%</td>
</tr>
<tr>
<td>Pneumonia vaccine ever</td>
<td>63%</td>
<td>38%</td>
<td>27%</td>
<td>23%</td>
</tr>
<tr>
<td>Pap test in last 3 years</td>
<td>86%</td>
<td>85%</td>
<td>81%</td>
<td>55%</td>
</tr>
<tr>
<td>Mammogram in last 2 years (women over 40)</td>
<td>90%</td>
<td>86%</td>
<td>84%</td>
<td>65%</td>
</tr>
<tr>
<td>PSA test in last year (men over 50)</td>
<td>72%</td>
<td>59%</td>
<td>47%</td>
<td>40%</td>
</tr>
</tbody>
</table>

NCI, 11,000 surveys of adults in 20 states
Have We Created a “Hotel” Model?

- People are disengaged.
- Staff do for or to the person rather than supporting person to do.
- People with the most needs get the least support to be engaged.
- Individuals with disabilities are spectators in their own lives.
- Staff can be considered glorified domestic servants.
# Organizational Context

<table>
<thead>
<tr>
<th>Factors</th>
<th>Effect</th>
</tr>
</thead>
<tbody>
<tr>
<td>Organizational readiness</td>
<td>Ready, Remediate or Reject</td>
</tr>
<tr>
<td>Organizational champion</td>
<td>• Intervention start</td>
</tr>
<tr>
<td></td>
<td>• Intervention sustained</td>
</tr>
<tr>
<td>Supervisor stability</td>
<td>• Intervention start</td>
</tr>
<tr>
<td></td>
<td>• Intervention sustained</td>
</tr>
<tr>
<td>Direct support staff turnover</td>
<td>• Intervention dose</td>
</tr>
<tr>
<td></td>
<td>• Proportion of staff trained</td>
</tr>
<tr>
<td></td>
<td>• Training elements completed by each person</td>
</tr>
<tr>
<td></td>
<td>• 12 hours class</td>
</tr>
<tr>
<td></td>
<td>• 1 on 1 on site mentoring</td>
</tr>
<tr>
<td></td>
<td>• 6 month follow up</td>
</tr>
<tr>
<td></td>
<td>• Retention of trained staff</td>
</tr>
<tr>
<td></td>
<td>• Training/retraining for new staff</td>
</tr>
</tbody>
</table>
Direct Support Workforce in IDD: What do we know?

- Wages, turnover, benefits in many states
- Factors that influence turnover
- Supervisors are important
- Wages are higher, benefits are better in more congregate care; wages are better but benefits are worse in self-directed models
- Training interventions seem to work
- Core competencies for DSPs and FLS
- Low investment in training across states
- DSPs have little voice
- We can reduce turnover; we have the tools and knowledge
DSP Workforce Interventions
Direct Support Workforce in IDD: What don’t we know?

- Nothing nationally outside of public residential facilities since Braddock study
  - Numbers (how many are there?)
  - Staff to person served ratios
  - Average wage, turnover

- No longitudinal trends
  - Descriptive data on workforce
  - Outcomes of any interventions

- Differences across service type based on size/type
- Differences across states
- Policy influences that matter
- Quantified differences between LTC sectors
CCI and Predictors of Outcomes

Research Priorities

- Use large public extant data sets for systems level research questions
- Identify policy initiatives as predictors of outcomes
- Identify significant predictors in the areas of wellbeing, satisfaction, and health outcomes
- Focus on setting as a predictor of outcomes
- Describe organizational factors that predict intervention success across studies.
- Understand workforce predictors in family context
OUTCOME MEASUREMENT AND METHODOLOGICAL ISSUES
Using Outcome Data to Answer Important Questions

• How are people with intellectual disability doing relative to the general community?
• Are disability services and policies achieving their intended effects?
  – Are some service types more effective? For whom?
• Is this intervention (more) effective?
• Are people with a disability experiencing better outcomes than in the past?
Outcome Measurement Challenges

• No single overarching measurement for any single outcome
• Proxy vs. self-report issue
• Extant data sets for general population
  – Rarely identify people with IDD
  – Often include complexity and lower response rates
Assessments of Loneliness

GENERAL COMMUNITY

UCLA Loneliness Scale:
• The 20-item self-report UCLA Loneliness Scale (Version 3) is the most frequently used measurement of loneliness in research (Russell, 1996). Designed for the general community.

4-point response scale (Never, Rarely, Sometimes, Often)

INTELLECTUAL DISABILITY

Modified Worker Loneliness
• The Modified Worker Loneliness Questionnaire (Chadsey-Rusch et al., 1992) has 12 items; designed for people with intellectual disability.

3-point response scale (No, Sometimes, Yes)

Item 12. How often do you feel that your relationships with others are not meaningful?

Item 10. Are you lonely?

University of Minnesota
Driven to Discover™
Assessing Loneliness

Responsiveness by Adults with and without Primary Intellectual Disability (N = 60)

\[ \chi^2 = 11.12, p = .001 \]

<table>
<thead>
<tr>
<th>Assessment Type</th>
<th>ID</th>
<th>Non-ID</th>
</tr>
</thead>
<tbody>
<tr>
<td>UCLA Loneliness (mainstream)</td>
<td>26</td>
<td>72</td>
</tr>
<tr>
<td>Loneliness Questionnaire (ID-specific)</td>
<td>81</td>
<td>100</td>
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Percentage of Respondents

Research & Training Center on Community Living

University of Minnesota
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Methodological Research Priorities

• Relationship between outcomes identified by proxy and self-report on outcomes data
• Review and consider revising instruments where both proxy and self-report measures are used
• Acknowledge constraints and difficulties in identifying people with IDD and in sampling people with IDD in large public data sets and when interpreting research
Beyond the SOSC Conference

SO WHAT??

- Future Research Agenda
- Knowledge Translation
KNOWLEDGE + ACTION = POWER

by JOHN ANTONIOS
www.selfadvocacyonline.org
May 23, 2013 7:43pm
I am watching Geoffrey explore the Self Advocacy On Line for the first time. He is watching video after video. Learning. Thank you, UMN for developing this amazing tool!
### Special Issue

**Intellectual and Developmental Disabilities (AAIDD)**

#### Researchers and Practitioners

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Available online at [www.aaidd.org](http://www.aaidd.org)

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**RTC**

Research & Training Center on Community Living

**University of Minnesota**

Driven to Discover™
State of the science

Theories, concepts, and evidence guiding knowledge and practice in inclusion, employment, and self-determination for people with disabilities.

July 2012, Halifax, Nova Scotia

Conference strands

www.rtc.umn.edu/sosc
TBD Monograph

Practitioners, families
RTC/CL: Future Research Agenda

• Commitment to knowledge translation
• Responsive to SOSC Priorities
• Evidence based policy focus
Concluding Thoughts

• Cannot lose site of the 29,000 human being still in institutions
• We know, why can’t we “do” in a BIG way?
• Integrated funding models
• Family context as “setting”
• Cross sector “slippage” for people with IDD
• “Research For All”
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