

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

Promises of Quality Lives in the Community

Quality of Life	UN Convention (Article number)
Physical Well-Being <i>(Health, Safety, Fitness)</i>	Life (10) Health (25) Freedom from torture, degradation, exploitation, violence, abuse (15/16)
Material Well-Being <i>(Wealth, Housing, Tenure, Privacy, Neighbourhood, Transport)</i>	Access to physical environment, transport, info, communications & services (9) Privacy (22) Adequate standard of living & social protection (28)
Social Well-Being <i>(Relationships, Community Involvement)</i>	Respect for home & the family (23) Being included in the community (19)
Productive Well-Being <i>(Personal Development, Independence, Self-Determination, Occupation)</i>	Education (24) (Re)Habilitation (26) Living independently (19) Personal mobility (20) Work & employment (27) Participation in cultural life, recreation, leisure & sport (30)
Emotional Well-Being	Protecting the integrity of the person (17)
Civic Well-Being/Rights <i>(Protection under the law, participation in political and public life, state of the nation)</i>	Equality/non-discrimination (5-7) Equal recognition before the law (12) Access to justice (13) Liberty, security of person & nationality (14, 18) Freedom of expression (21) Participation in political & public life (29)

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

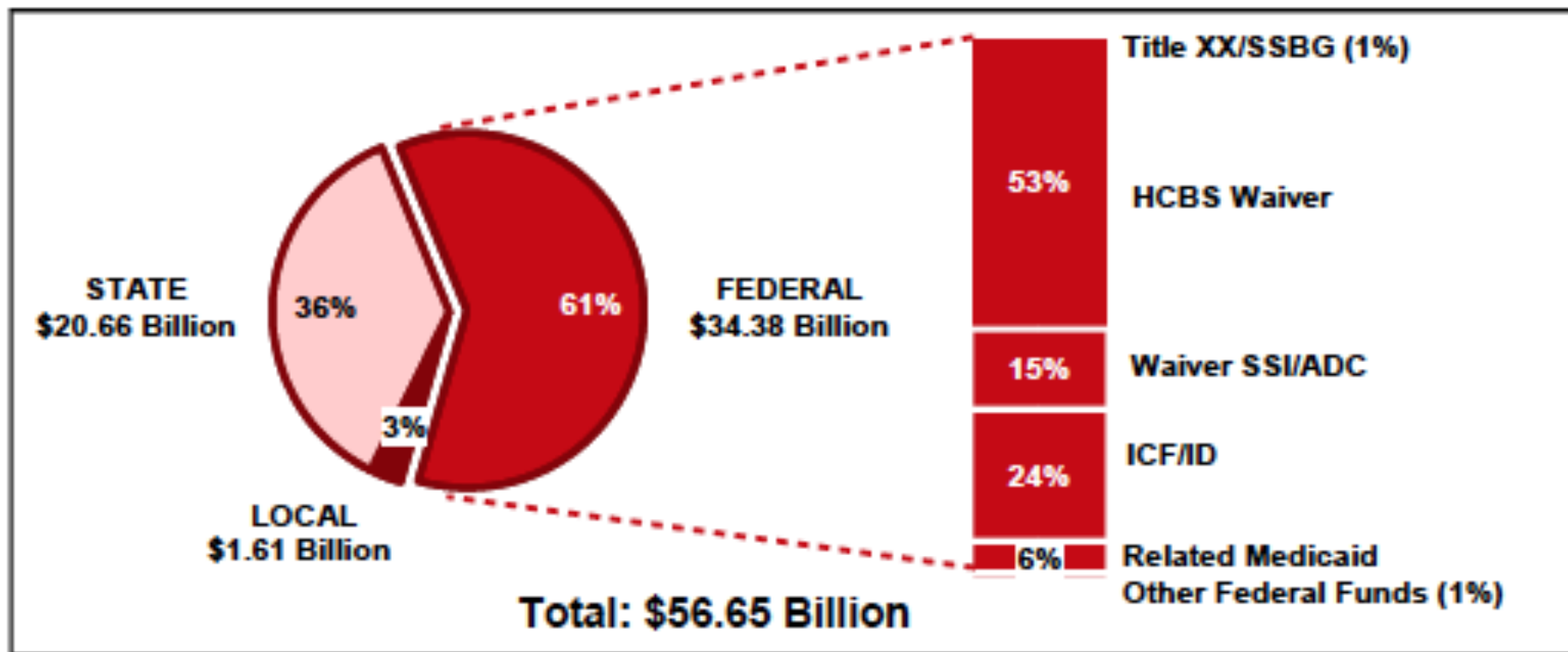
- Where and with whom a person **lives**;
- Where a person **works** and how they earn money;
- What a person **does** during the day;
- Quality of **relationships** developed with others;
- What and with whom a person does things of **personal interest**,
- **Health** (physical and emotional),
- Where 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

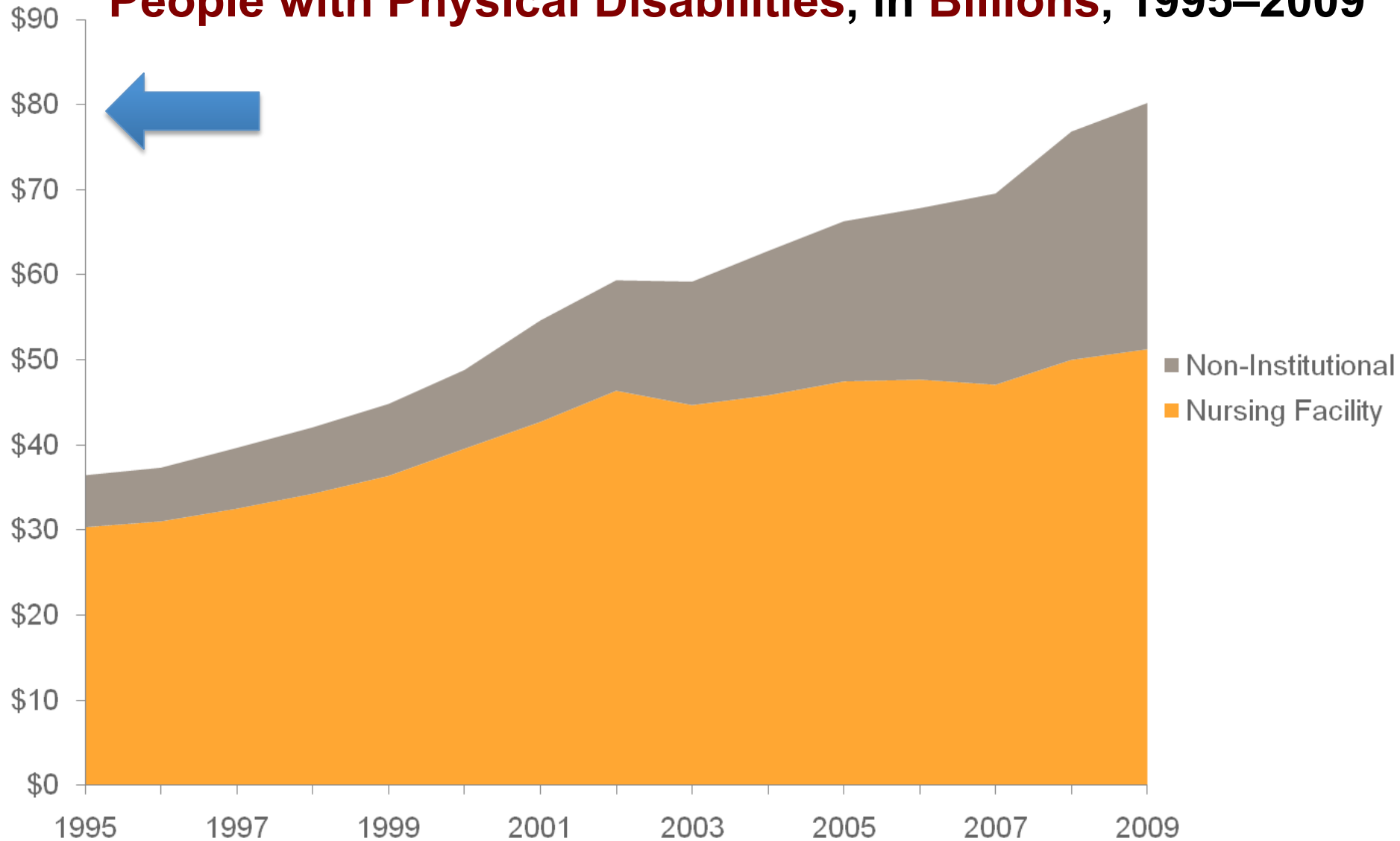
Butterworth et.al;, 2013; Braddock et al, 2013; Larson et al, 2013

TOTAL I/DD SPENDING BY REVENUE SOURCE: FY 2011



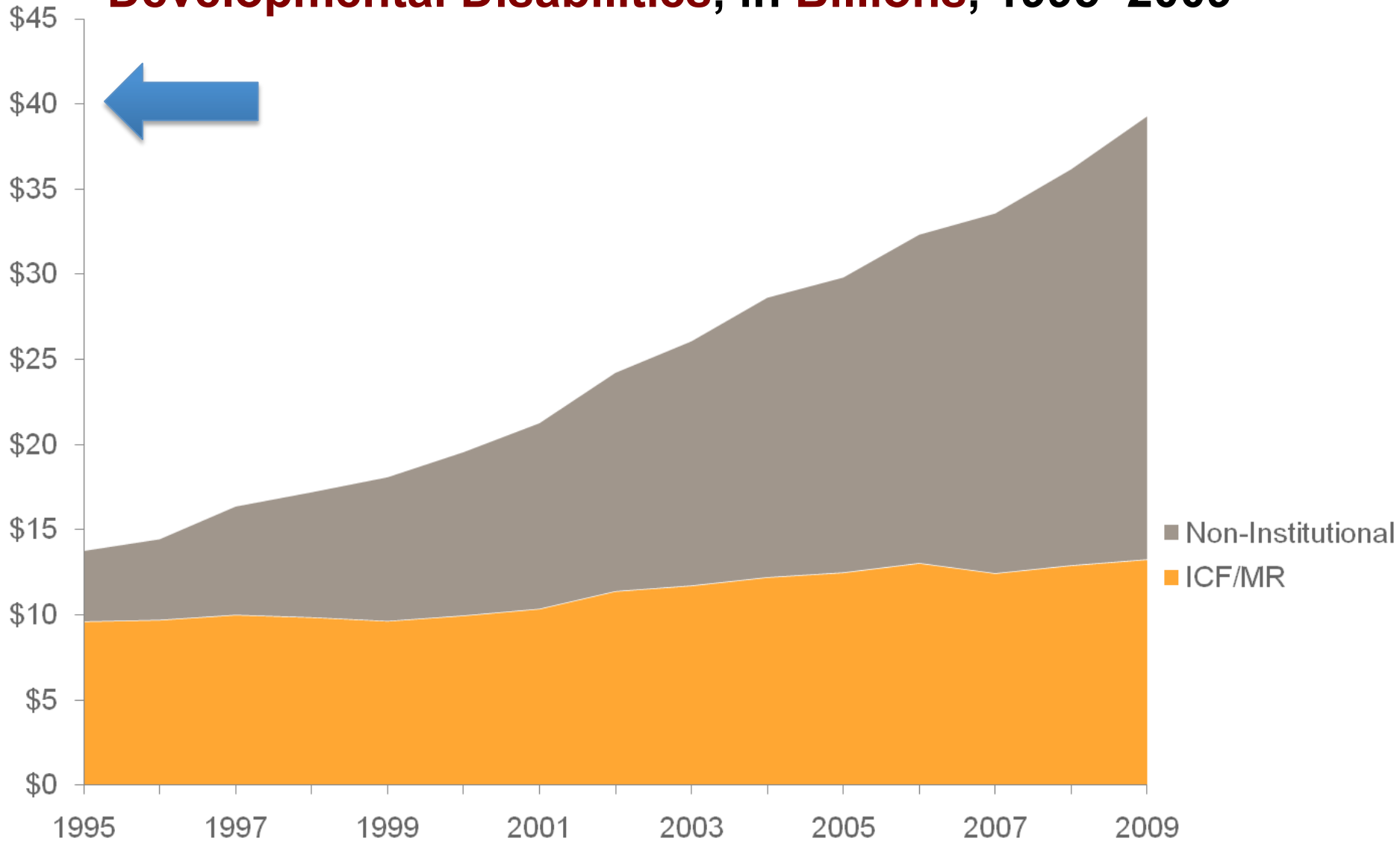
Braddock et al, 2013

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.

Medicaid LTSS Expenditures for People with Developmental Disabilities, in Billions, 1995–2009



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.

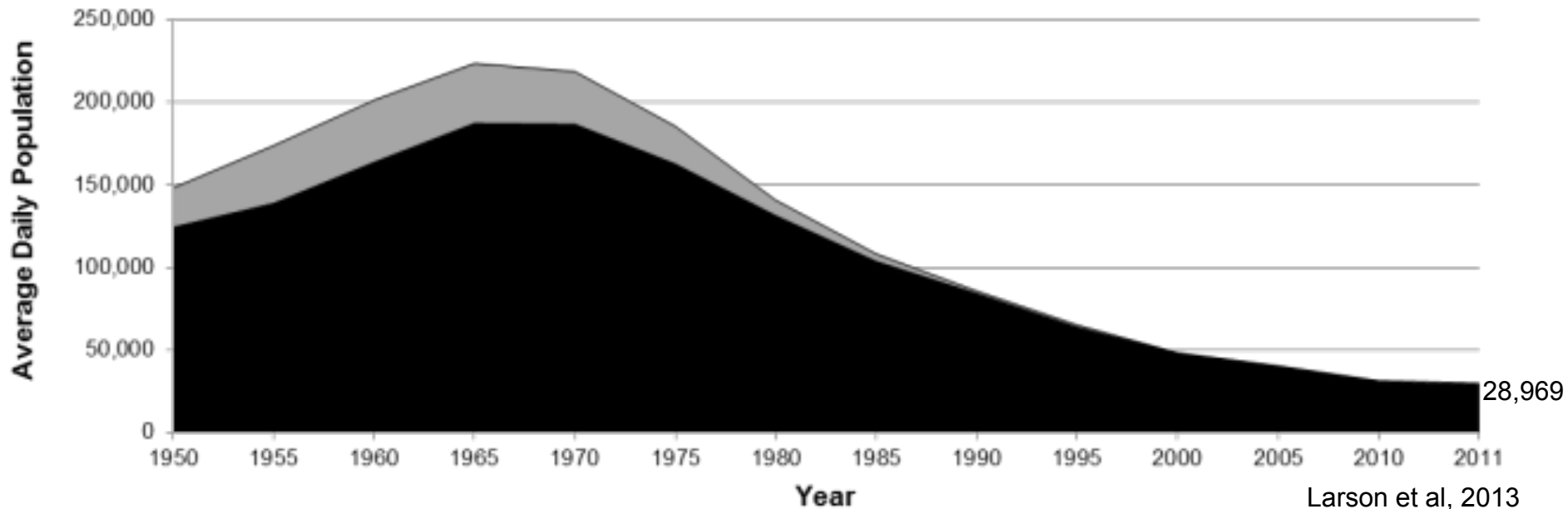
Greater Expectation for Outcomes

- 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
 - (Office of Management and Budget, p.1).*
 - *“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”*



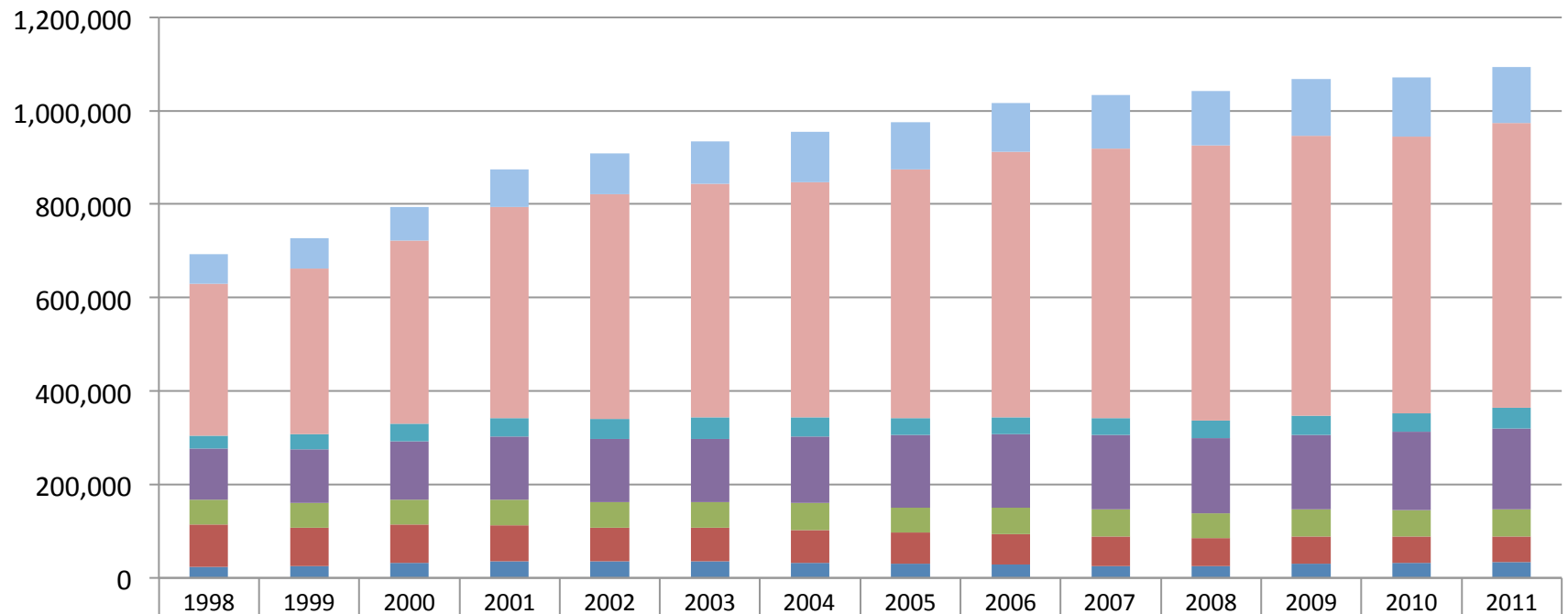
Decades of Deinstitutionalization

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



(Alaska, District of Columbia, Hawaii, Maine, Michigan, Minnesota, New Hampshire, New Mexico, Oregon, Vermont and West Virginia).

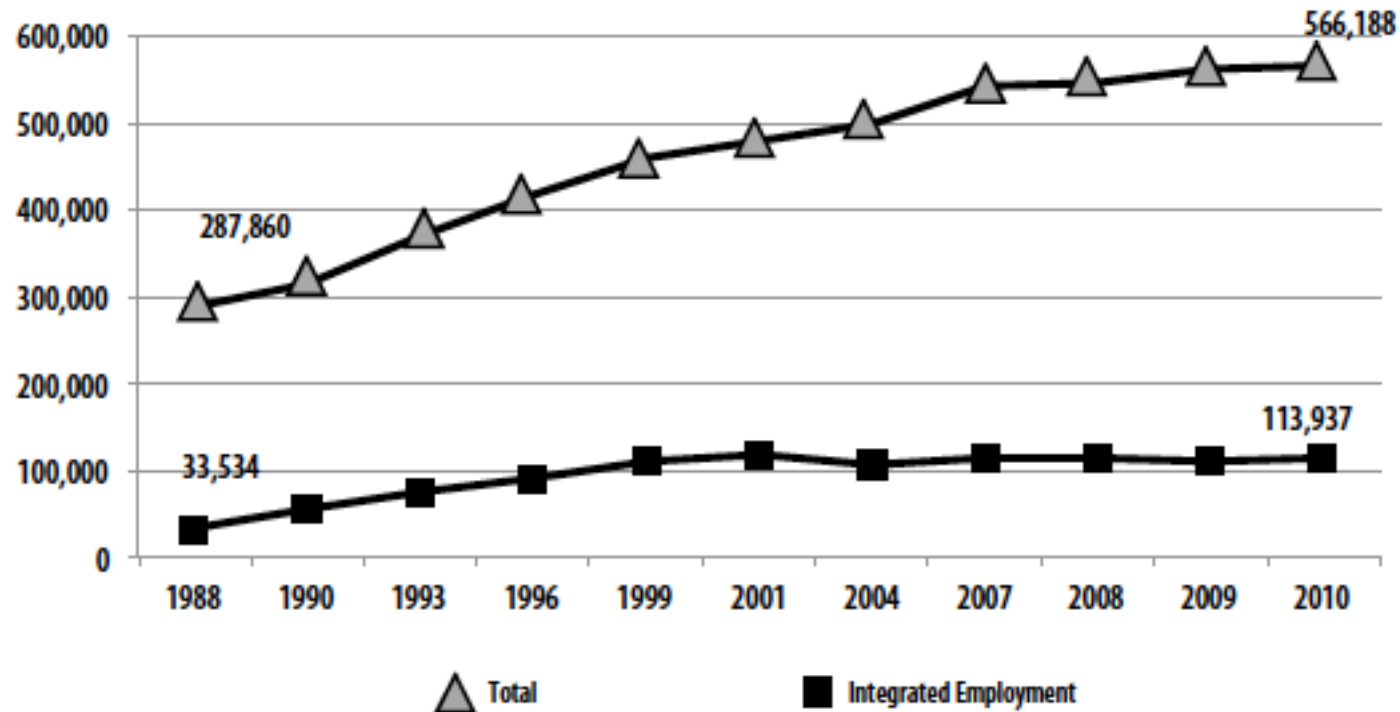
Place of Residence for Service Recipients with IDD 1998 to 2011



	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

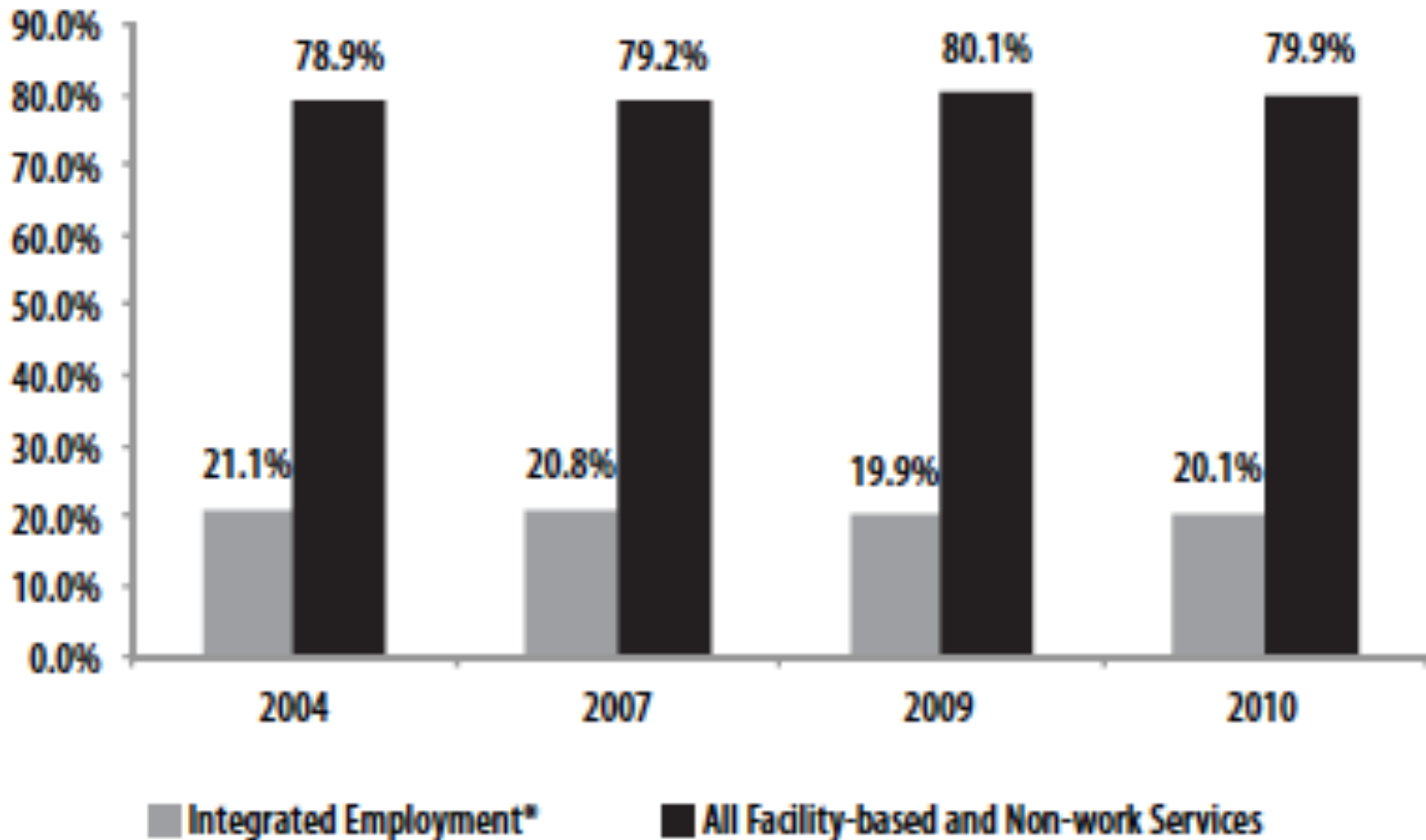
Larson et al, 2013

Estimated Total Number of People Served By IDD Employment Agencies



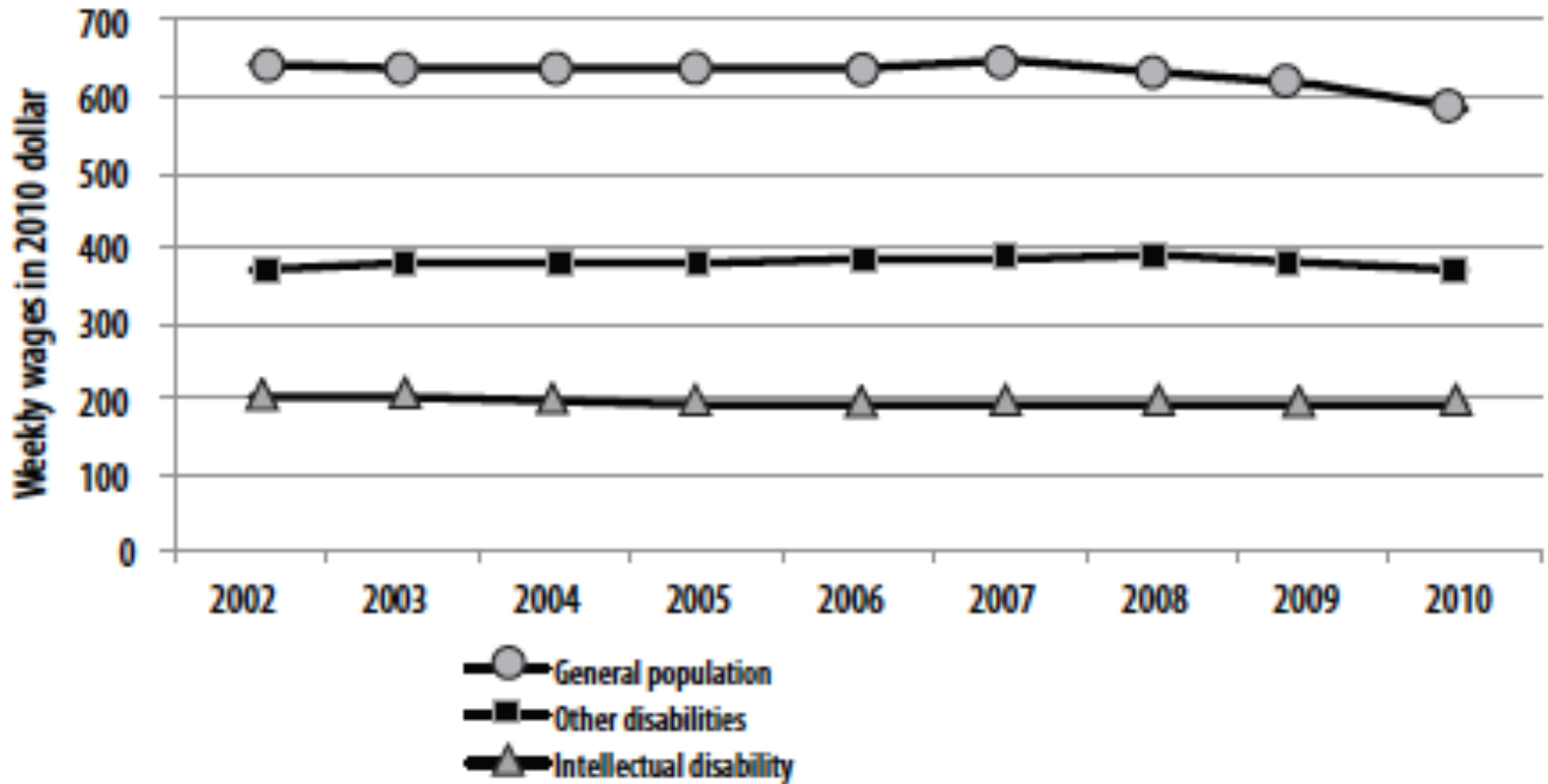
Butterworth et al, 2013

Estimated Service Distribution By Year



Butterworth et al, 2013

Weekly Wages By Year



Butterworth et al, 2013

UNIVERSITY OF MINNESOTA

Driven to DiscoverSM

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 Fuijiara
- 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 Sedlezky
- Tom Seekins
- Jasmina Sisirak
- Jerry Smith
- Roger Stancliffe
- Sarah Taub
- Ann Turnbull
- Rud Turnbull
- Mike Wehmeyer

Validating the SOSOC Conference Findings

- Data/Information Gathering
 - Reinventing Quality strand
 - SABE conversations
 - Review and synthesis of SOSOC conference summary by researchers

SOCIAL INCLUSION AND COMMUNITY PARTICIPATION

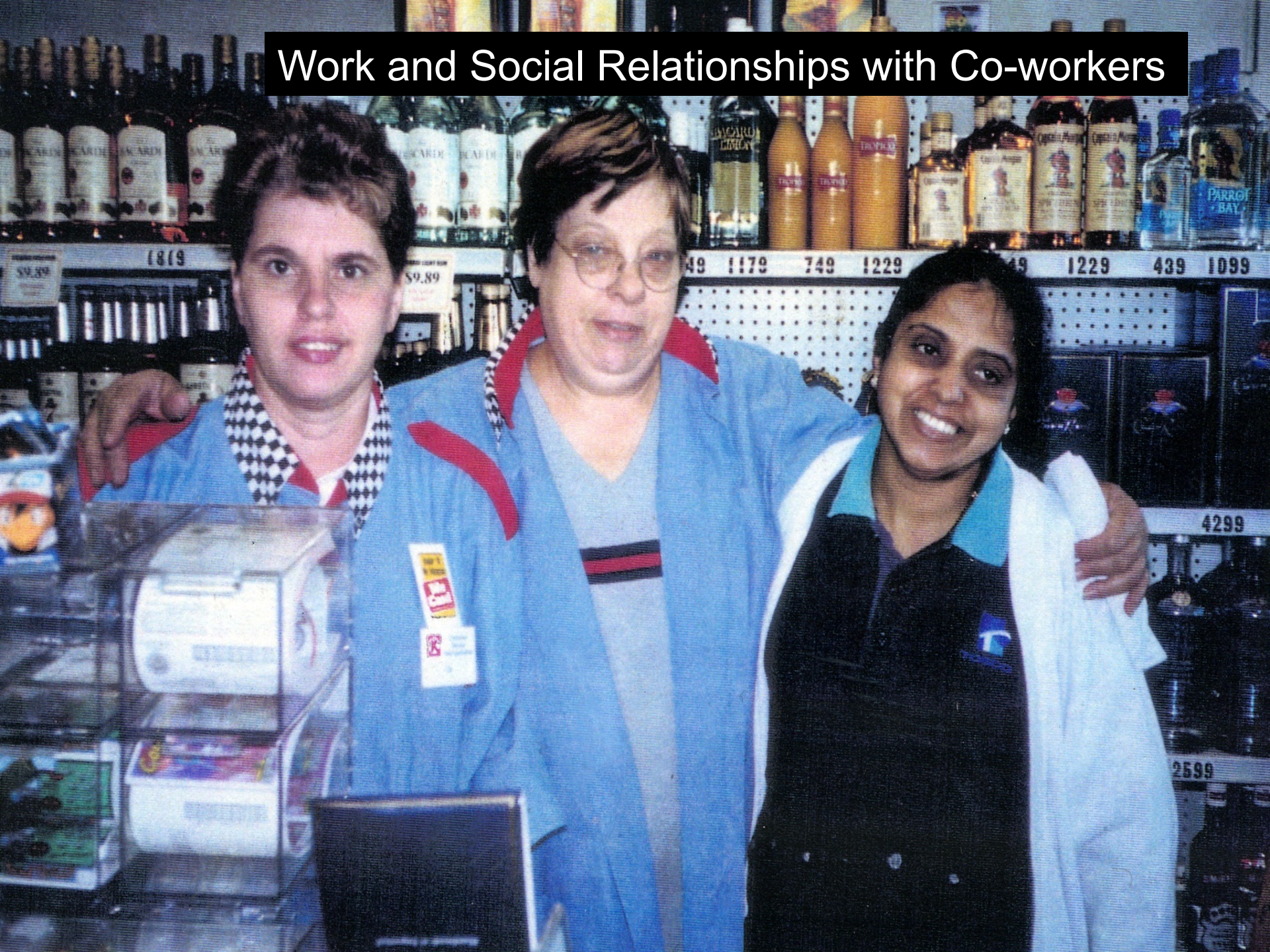
Social Inclusion

- 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)

Tamar Heller, 2012

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

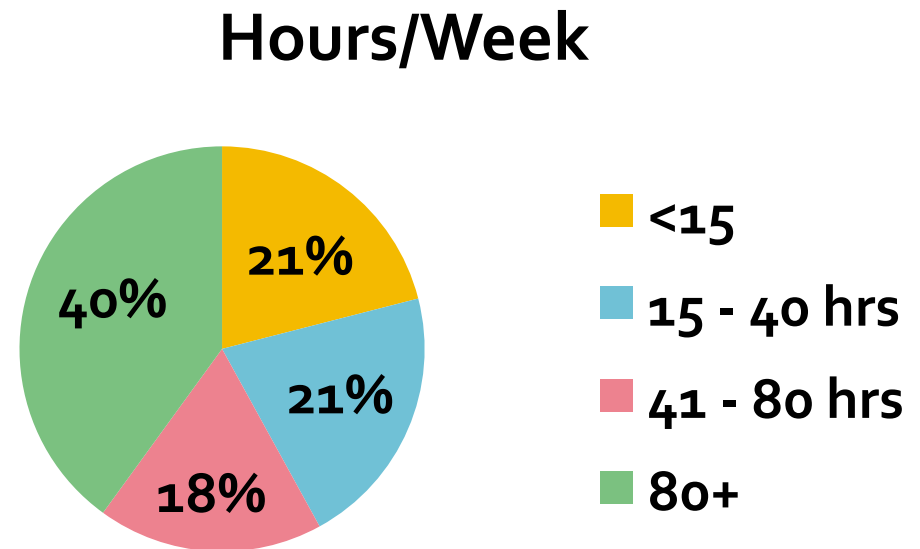
Gaps in Sibling Research

- 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

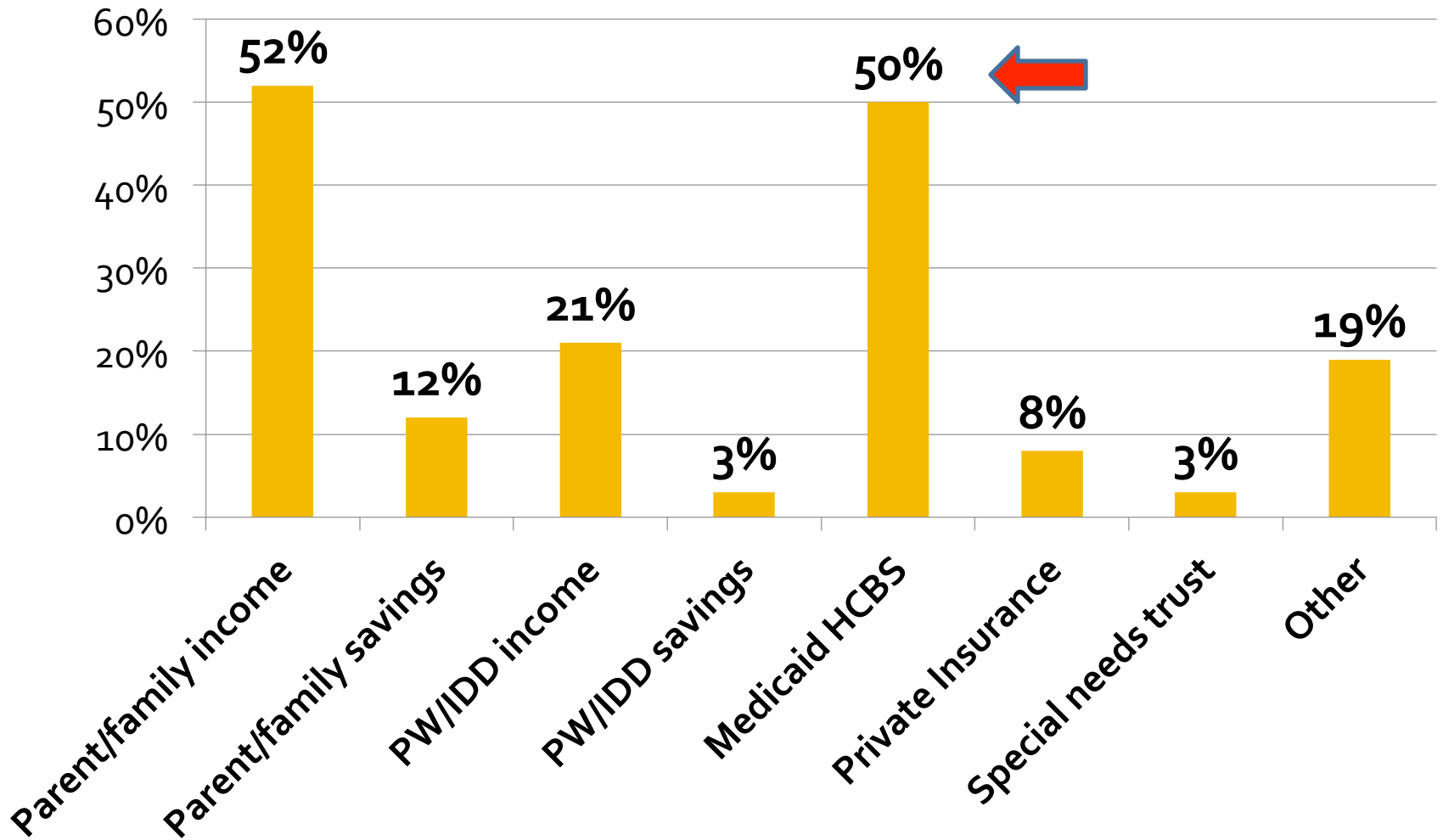
Family Caregiving Experiences

- Family caregivers provide a range of supports



Ann Cameron Williams- Caldwell, 2012

Sources of funding for supports



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

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

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

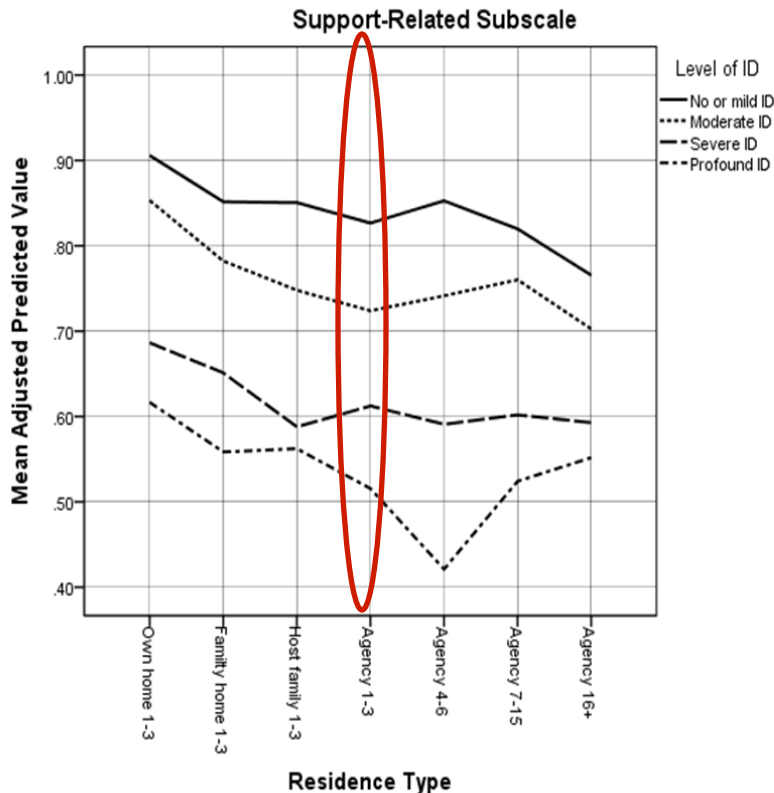
Setting Type	Setting Size	
Own Home	1-3	
Family Home	1-3	
Host Family/Foster	1-3	
Group residence	1-3	1-3
Group residence		4-6
Group residence		7-15
Group residence		16+

Other Key Predictors: NCI Choices

Everyday Choice		
Block	Factors	Adj. R2
1	Level of ID	0.31*
2	Mobility, vision or hearing impairment	0.32*
3	Age	0.33*
4	Problem behavior, mental health DX, ASD	0.33*
5	Report for self; primary means of expression	0.40*
6	Setting size and type	0.42*
7	State	0.44*

Support Related Choice		
Block	Factor	Adj. R2
1	Level of ID	0.09*
2	Mobility, vision or hearing impairment	0.09
3	Age	0.09
4	Problem behavior, mental health DX, ASD	0.10*
5	Report for self; primary means of expression	0.12*
6	Setting size and type	0.20*
7	State	0.31*

People in smaller settings make more *Big* choices (NCI 2009)



The Choices

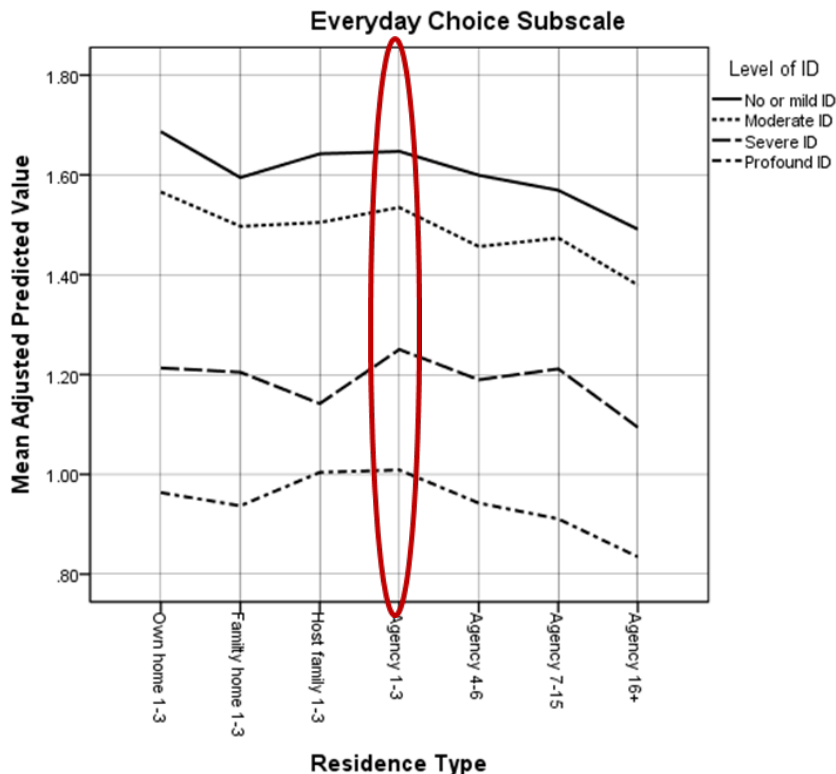
- The people I live with
- The place I live
- The person who assists me at home
- Where I work
- The person who assists me at work
- The person who helps me get the services I need.

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)

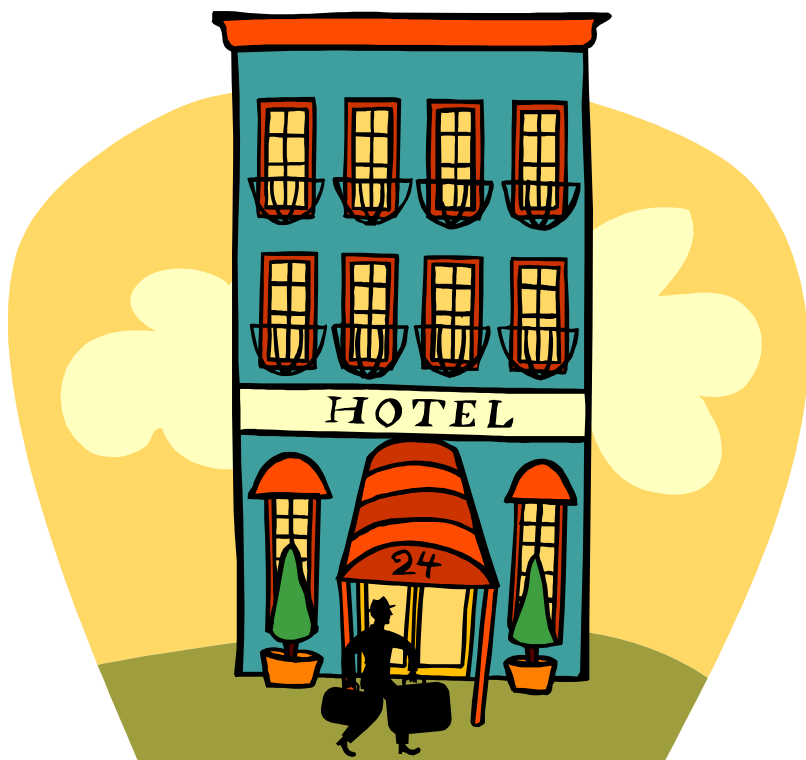
N = 8,892, 23 states Ticha, Lakin, Larson, Stancliffe (2012) National Core Indicators; $R^2 = .44$

Access to Preventative Care (NCI, 2009)

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

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



Factors	Effect
Organizational readiness	Ready, Remediate or Reject
Organizational champion	<ul style="list-style-type: none">• Intervention start• Intervention sustained
Supervisor stability	<ul style="list-style-type: none">• Intervention start• Intervention sustained
Direct support staff turnover	<ul style="list-style-type: none">• Intervention dose<ul style="list-style-type: none">• Proportion of staff trained• Training elements completed by each person<ul style="list-style-type: none">• 12 hours class• 1 on 1 on site mentoring• 6 month follow up• Retention of trained staff• Training/retraining for new staff

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



National Alliance for Direct Support Professionals

Code of Ethics

Person-Centered Supports: As a DSP, my first allegiance is to the person I support; all other activities and functions I perform flow from this allegiance.

Promoting Physical and Emotional Well-Being: As a DSP, I am responsible for supporting the emotional, physical, and personal well-being of the individuals receiving support. I will encourage growth and recognize the autonomy of the individuals receiving support while being attentive and energetic in reducing their risk of harm.

Integrity and Responsibility: As a DSP, I will support the mission and vitality of my profession to assist people in leading self-directed lives and to foster a spirit of partnership with the people I support, other professionals, and the community.



Minot State University Online Programs in

Developmental Disabilities

Offered by - North Dakota Center for Persons with Disabilities



Road Map of Core Competencies for the Direct Service Workforce



Phase I: Direct Service Worker Competency Inventory

Phase II: Competency Analysis (in development)

Phase III: Synthesis and Validation (in development)



May 31st, 2011

College of Direct Support



Direct Support

A Realistic Job Preview

Research and Training Center on Community Living

WY WAGE INITIATIVE

PREPARED By the University of Minnesota Research and Training Center on Community Living, with input from The Lewin Group, PHI, The Annapolis Coalition for the Behavioral Health Workforce, and Westchester Consulting
PREPARED For the CENTERS for MEDICAID & MEDICARE SERVICE



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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*)

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

INTELLECTUAL DISABILITY

Modified Worker Loneliness

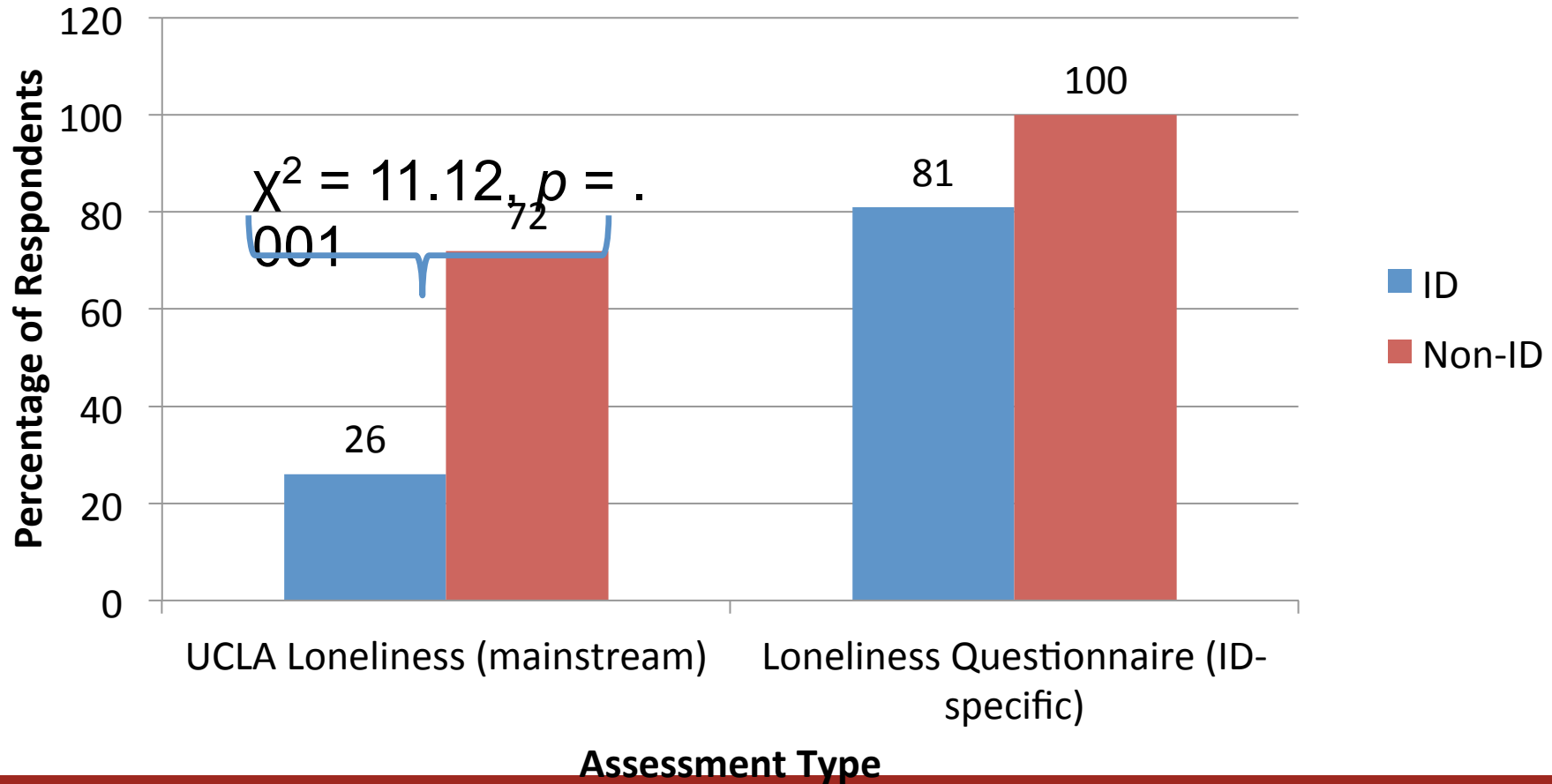
- The *Modified Worker Loneliness Questionnaire* (Chadsey-Rusch et al., 1992) has 12 items; **designed for people with intellectual disability.**

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

Item 10. *Are you lonely?*

Assessing Loneliness

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



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???

- Knowledge Translation
- Future Research Agenda

KNOWLEDGE
≠
POWER

KNOWLEDGE + ACTION
=
POWER

BY
JOHN ANTONIOS

SELF-ADVOCACY ONLINE



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Research for All



www.selfadvocacyonline.org



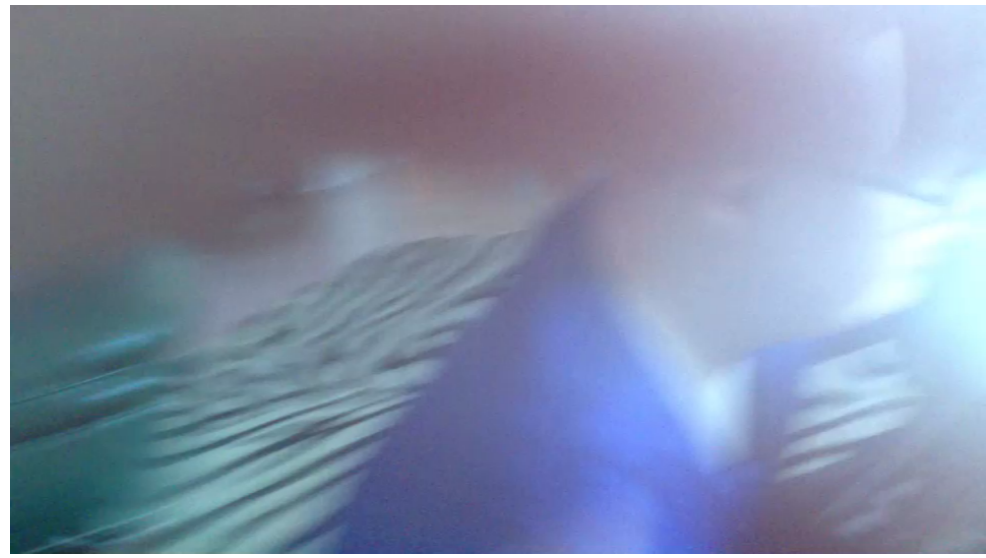
Ann Cameron

May 23 near Palatine, IL 



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!



Intellectual and Developmental Disabilities



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INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

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Special Issue Intellectual and Developmental Disabilities (AAIDD)

Researchers and Practitioners

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

Strands

Presenters

Conference strands

 Introduction	 Predictors of outcomes	 Health and wellness	 Community inclusion	 Employment
 Quality of life indicators	 Outcome data	 Methodological issues	 Self-determination	 Family-support



State of the science



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www.rtc.umn.edu/sosc



TBD Monograph

Practitioners, families

RTC/CL: Future Research Agenda

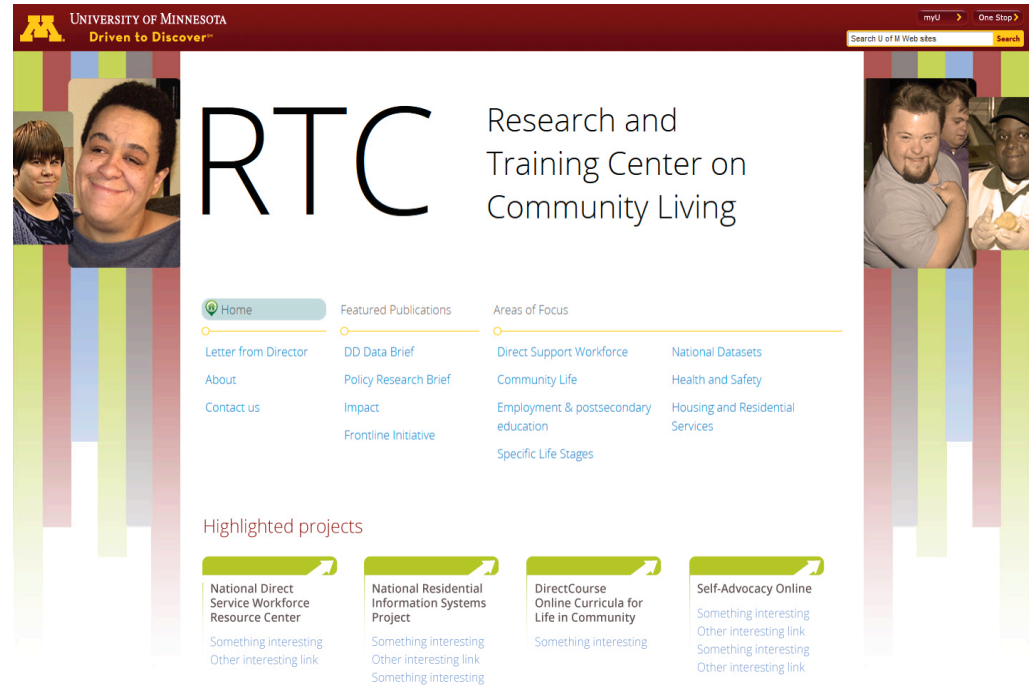
- Commitment to knowledge translation
- Responsive to SOSC Priorities
- Evidence based policy focus

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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