



Leading Change Together: Improving Healthcare for People with I/DD through Accessible Measurement and Improved Access to Data and Education

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Leading Change through Data: Healthcare Access of National Core Indicators People with Intellectual and Developmental Disabilities and Dual Diagnoses

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**DISABILITY AND
HUMAN
DEVELOPMENT
COLLEGE OF
APPLIED HEALTH
SCIENCES**



Background

- People with IDD at increased risk for mental health disabilities (IDDMH)
- People with IDDMH have worse health (Lennox, Van Driel & Van Dooren, 2015), experience healthcare disparities (Druss et al., 2002; Lunsky et al., 2006), and have low levels of physical activity, obesity and unique challenges (Heal et al., 2012)

Objective

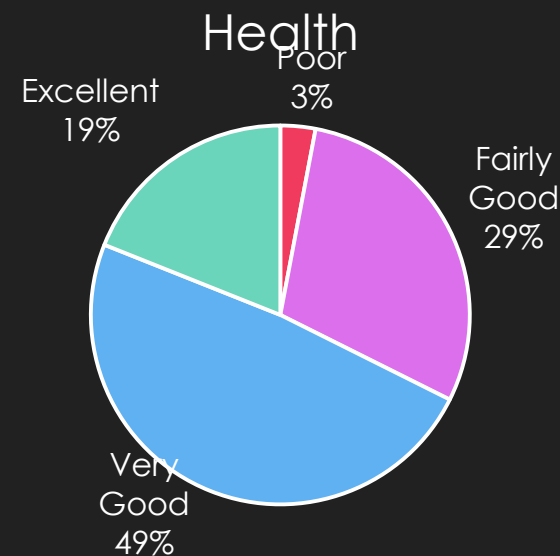
- To examine the demographic, environmental, and health behavior factors that impact health and access (utilization and unmet need) for healthcare services of people with IDD, .
- Determine if there are differential factors affecting health care access for people with dual diagnoses.

Outcomes

- Primary care provider
- Routine (physical, dental, eye, hearing)
- Flu shot
- Preventive (pap test, mammogram, colorectal cancer screening)
- Unmet healthcare need

Outcome Descriptives

Outcome	Received n (%)	Did Not Receive n (%)
Has PCP	16,748 (98.1%)	328 (1.9%)
Physical (Last Year)	14,006 (88.2%)	1,876 (11.8%)
Dental (Last Year)	11,832 (81.3%)	2,726 (18.7%)
Eye (Last Year)	7,601 (58.6%)	5,363 (41.4%)
Hearing (Last 5 Years)	5,294 (57.1%)	3,982 (42.9%)
Flu Vaccine (Last Year)	8,833 (74.7%)	2,997 (25.3%)
Pap Smear (Last 3 Years)	2,689 (65.0%)	1,446 (35%)
Mammogram (Last 2 Years)	1,903 (76.5%)	585 (23.5%)
Colorectal Cancer Screen (Last 5 Years)	1,665 (57.3%)	1,240 (42.7%)



Independent Variables

- Dual diagnosis
- Demographics (age, gender, race/ethnicity)
- Environmental factors (Rural/urban, living arrangement)
- Physical activity

Frequencies

Variable	n (%)
Age (n = 17,458)	M = 42.3 (SD = 15.2)
Dual Diagnosis (n = 17,682)	
No	8,186 (46.3%)
Yes	9,496 (53.7%)
Gender (n = 17,401)	
Male	10,101 (58.0%)
Female	7,300 (41.3%)
Race/Ethnicity (n = 17,170)	
White	12,047 (70.2%)
Black	3,273 (19.1%)
Hispanic	673 (3.9%)
Other	1,177 (6.9%)
Rural/Urban (n = 15,270)	
Non-Metropolitan	3,794 (24.8%)
Metropolitan	11,476 (75.2%)
Living Arrangement (n = 17,002)	
Institution	833 (4.9%)
Group Home	5,337 (31.4%)
Own Home	3,284 (19.3%)
Family Home	6,436 (37.9%)
Foster/Host Home	1,112 (6.5%)
Physical Activity (n = 16,960)	
No	4,072 (24.0%)
Yes	12,888 (76.0%)

Health, PCP, and Unmet Healthcare Need

Health		
Outcome	β	P-value
Age	-0.007	0.000***
Gender	-0.037	0.003**
Race	-0.004	0.603
Metropolitan Area	0.019	0.190
Living Arrangement	-0.005	0.298
Physical Activity	0.276	0.000***
Dual Diagnosis	-0.070	0.000***

Variable	Primary Care OR (95% CI)	Unmet Healthcare Need OR (95% CI)
Age	1.01 (1.00 - 1.02)	1.00 (0.99 - 1.00)
Female	1.30 (1.01 - 1.69)*	1.08 (0.98 - 1.20)
Race/Ethnicity (Ref: White)		
Black	0.79 (0.58 - 1.06)	1.31 (1.16 - 1.49)***
Hispanic	1.35 (0.63 - 2.91)	1.28 (1.00 - 1.65)
Other	0.68 (0.43 - 1.08)	1.20 (0.97 - 1.49)
Metropolitan Area	0.78 (0.57 - 1.06)	1.40 (1.24 - 1.60)***
Living Situation (Ref: Group Home)		
Institution	0.56 (0.33 - 0.95)*	0.64 (0.48 - 0.85)**
Own Home	0.79 (0.54 - 1.16)	1.27 (1.10 - 1.47)***
Family Home	0.74 (0.53 - 1.04)	1.15 (1.00 - 1.31)*
Foster/Host Home	0.88 (0.49 - 1.55)	0.70 (0.54 - 0.91)**
Physical Activity	0.82 (0.60 - 1.11)	0.80 (0.71 - 0.89)***
Dual Diagnosis	1.22 (0.94 - 1.58)	1.04 (0.94 - 1.16)

Routine Exams

Variable	Physical OR (95% CI)	Dental OR (95% CI)	Eye OR (95% CI)	Hearing OR (95% CI)
Age	1.01 (1.00 - 1.01)**	0.99 (0.99 - 1.00)***	1.00 (1.00 - 1.01)**	1.01 (1.00 - 1.01)***
Female	0.96 (0.85 - 1.07)	1.05 (0.96 - 1.16)	1.07 (0.99 - 1.16)	0.94 (0.85 - 1.03)
Race/Ethnicity (Ref: White)				
Black	0.70 (0.62 - 0.81)***	0.62 (0.55 - 0.70)***	1.02 (0.92 - 1.13)	1.25 (1.10 - 1.42)***
Hispanic	1.25 (0.91 - 1.73)	1.12 (0.86 - 1.46)	1.05 (0.85 - 1.29)	1.53 (1.20 - 1.95)***
Other	0.85 (0.68 - 1.08)	0.74 (0.61 - 0.90)**	0.91 (0.77 - 1.08)	1.34 (1.09 - 1.66)**
Metropolitan Area	1.30 (1.14 - 1.47)***	1.08 (0.97 - 1.21)	0.97 (0.88 - 1.06)	1.34 (1.20 - 1.50)***
Living Situation (Ref: Group Home)				
Institution	1.56 (1.08 - 2.25)*	2.58 (1.83 - 3.63)***	1.52 (1.26 - 1.83)***	2.93 (2.31 - 3.71)***
Own Home	0.59 (0.50 - 0.70)***	0.52 (0.45 - 0.60)***	0.77 (0.69 - 0.86)***	0.59 (0.51 - 0.67)***
Family Home	0.51 (0.44 - 0.59)***	0.39 (0.35 - 0.45)***	0.52 (0.47 - 0.58)***	0.47 (0.41 - 0.53)***
Foster/Host Home	0.87 (0.67 - 1.13)	0.59 (0.48 - 0.72)***	0.63 (0.54 - 0.74)***	0.82 (0.67 - 1.01)
Physical Activity	1.01 (0.89 - 1.16)	1.44 (1.29 - 1.60)***	1.17 (1.06 - 1.28)**	1.15 (1.03 - 1.28)*
Dual Diagnosis	1.26 (1.12 - 1.41)***	1.06 (0.96 - 1.17)	1.13 (1.04 - 1.22)**	1.06 (0.96 - 1.17)

Preventive Care

Variable	Flu Vaccine OR (95% CI)	Pap Smear OR (95% CI)	Mammogram OR (95% CI)	Colorectal Cancer OR (95% CI)
Age	1.03 (1.02 - 1.03)***	1.00 (1.00 - 1.01)	1.03 (1.01 - 1.04)***	1.01 (1.00 - 1.03)
Female	1.03 (0.94 - 1.14)	-	-	0.76 (0.64 - 0.89)***
Race/Ethnicity (Ref: White)				
Black	0.64 (0.57 - 0.73)***	1.85 (1.51 - 2.25)***	1.35 (1.00 - 1.81)*	1.03 (0.82 - 1.29)
Hispanic	0.80 (0.64 - 1.01)	1.60 (1.10 - 2.34)*	1.42 (0.75 - 2.68)	1.09 (0.62 - 1.93)
Other	0.92 (0.76 - 1.13)	1.08 (0.78 - 1.49)	0.83 (0.51 - 1.35)	0.84 (0.53 - 1.31)
Metropolitan Area	0.84 (0.75 - 0.94)**	1.28 (1.09 - 1.51)**	0.99 (0.78 - 1.25)	1.11 (0.93 - 1.32)
Living Situation (Ref: Group Home)				
Institution	2.90 (2.01 - 4.19)***	1.78 (1.16 - 2.72)**	1.70 (1.03 - 2.81)*	1.31 (0.97 - 1.78)
Own Home	0.46 (0.40 - 0.53)***	1.33 (1.07 - 1.65)**	1.27 (0.95 - 1.70)	0.91 (0.74 - 1.11)
Family Home	0.35 (0.31 - 0.40)***	0.36 (0.30 - 0.44)***	0.40 (0.30 - 0.52)***	0.55 (0.43 - 0.70)***
Foster/Host Home	0.72 (0.58 - 0.89)**	0.73 (0.54 - 0.98)*	0.80 (0.53 - 1.21)	0.71 (0.52 - 0.98)*
Physical Activity	1.05 (0.94 - 1.17)	1.25 (1.06 - 1.47)**	1.32 (1.05 - 1.67)*	1.13 (0.95 - 1.35)
Dual Diagnosis	0.99 (0.90 - 1.10)	1.35 (1.16 - 1.57)***	1.26 (1.01 - 1.56)*	1.13 (0.96 - 1.35)

Differential Factors for People with IDDMH

- Examined interaction of factors with dual diagnosis and findings were not significant
- Similar factors affect the health and health care access of adults with IDD and those with dual diagnosis

Discussion

- People with IDDMH:
 - Worse health and less physical activity
 - Need to target them for health promotion
 - More routine care of physicals and eye exams
 - More preventive screenings of pap smears and mammograms

Other Factors Affecting Health and Healthcare Access

- Low physical activity associated with poor health
- Blacks and Latinos less likely to get dental care
- Less likely to get routine and preventive care in family settings

Funding Source

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Leading Change Together:

An Example of Improving
Healthcare for People with I/DD
by Improving Access to
Information for Families and
Providers

Celia Schloemer, Raja Char & Ilka
Riddle

University of Cincinnati CEDD
(UCCEDD)

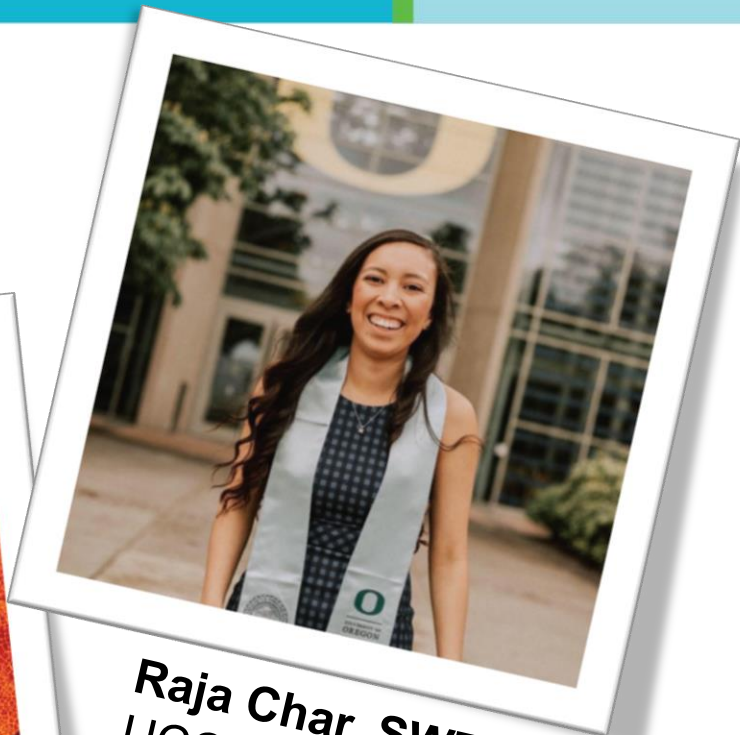
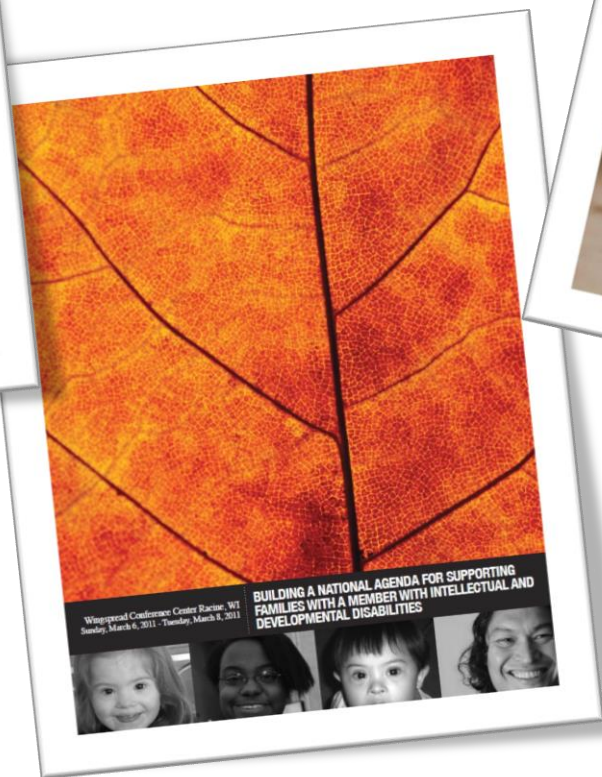
AUCD Conference
November 19, 2019



Family Support Vision



Celia Schloemer
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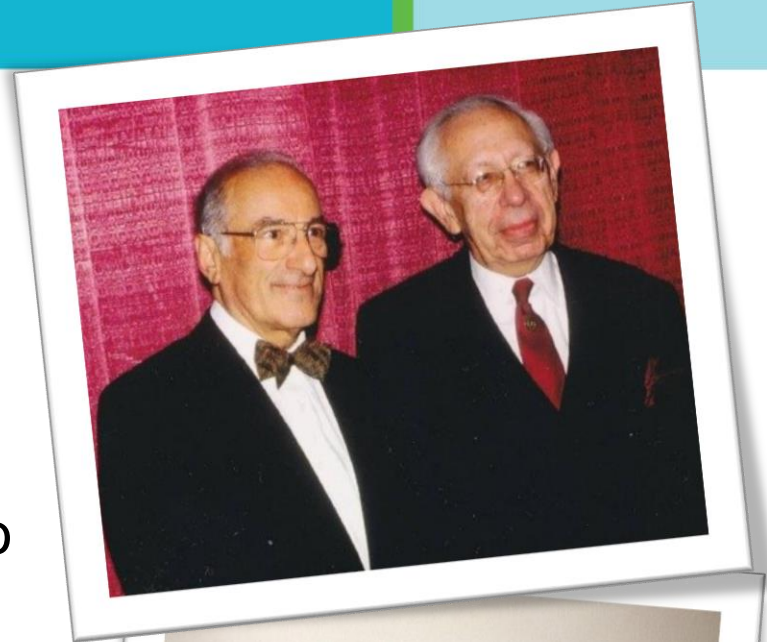
Rubinstein-Taybi Syndrome (RTS)

- Rare syndrome that affects approximately 1 in 100,000 to 125,000
- Common physical characteristics: large angular thumbs and toes, a distinct nose, small stature, thick hair and eyelashes, downward slanting eyes and a narrow palate
- Intellectual disability is common and can range from mild to severe
- Medical concerns are typical, but vary for each individual



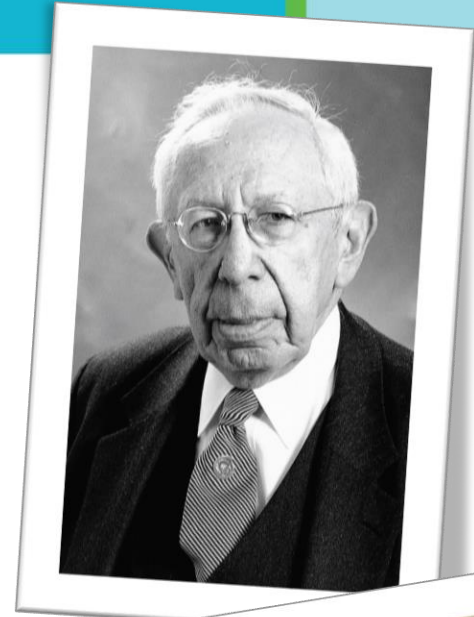
History of RTS

- Dr. Jack H. Rubinstein was a developmental pediatrician at the University of Cincinnati Medical Center
- Dr. Rubinstein and Dr. Hoosang Taybi combined their efforts and research to identify RTS
- Families with a child with a rare diagnosis experience high levels of stress
- In the late 1990's Dr. Rubinstein formulated RTS-OKI Family Support Group and the Rubinstein Foundation



Partners in our Commitment to Families

- The UCCEDD has a strong commitment to supporting families.
- Division for Developmental and Behavioral Pediatrics (DDBP) has a commitment to the families of individuals with family members with RTS through the legacy of Jack H. Rubenstein
- Developed a vision for transformational change in how we support RTS-OKI families



Series of Projects to Support Families

- Quarterly meetings to gather in the community, connect families to other families and share information
- A family-centered publication to give families important information, allow them to share and educate their community and to offer hope
- A series of videos to educate medical providers
- Provide a quick reference in areas of concern by specialty

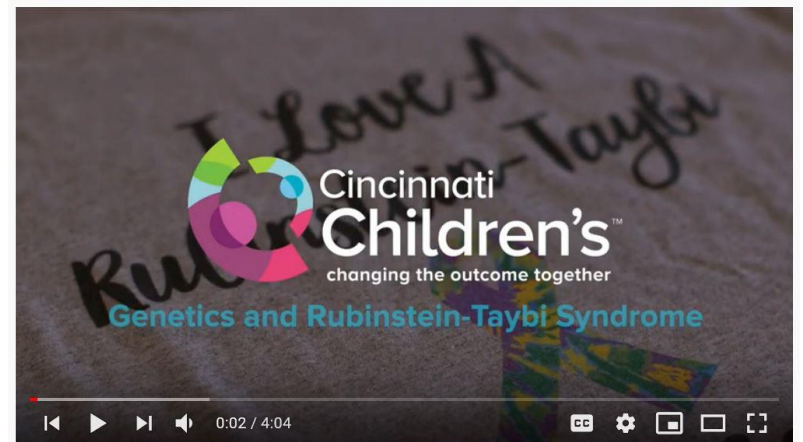


Educational Video Modules

- Developed with medical providers in mind
- For families to share with medical providers



2019 CCHMC RTS Ophthalmology V1



2019 CCHMC RTS Genetics V1



Educational Video Modules

- Developed with families in mind
- Focus on families of children with a new diagnosis
- Collaboration with families of *RTS-OKI Support Group*



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Partnering with People with Developmental Disabilities to Create Valid and Accessible Health Measures

Rosemary B. Hughes, PhD
The University of Montana - UCEDD
2019 AUCD Annual Meeting
November 19, 2019

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The Partnering Project



partnering

*With People with Developmental Disabilities
on Health and Safety*



- RTOI 5U01DD000231-03 funded by AUCD/CDC under a cooperative agreement awarded to the University of Montana. Rosemary Hughes, Principal Investigator
- Collaborating Institutions: Portland State University and Oregon Health & Science University
- Multi-site partnership between academics and people with DD to study the relationship between violence and health in people with DD



-
- Used a Community-based Participatory Research (CBPR) approach to include people with developmental disabilities as equal partners in all phases of the research
 - Teams met locally in Oregon and Montana



The Partnering Project included three studies:

- The Measurement Adaptation Study
- CBPR Evaluation Study
- Disability, Violence, and Health Survey

Measurement Adaptation

- Identified constructs or main ideas to study
- Selected possible instruments to measure the constructs
- The CABs looked at each instrument and said:
 - ✓ What they liked about it
 - ✓ What they did not like about it and
 - ✓ How much they would have to change it
- The CABs voted for the instrument they liked best

Measurement Adaptation

- Investigators explained that items or questions could only be changed if they caused significant problems. For example, if CAB members
 - ✓ Could not understand the items
 - ✓ Thought many other people with developmental disabilities would not be able to understand the items

Measurement Adaptation

- **OK** to change prefaces to make instructions clearer

Original

During the past 4 weeks, how much have you been bothered by any of the following problems?

Adapted

The next questions ask about your physical health during the past 4 weeks.

Measurement Adaptation

- **OK to add** graphics or pictures to response options. For example, During the past four weeks, how much have you been bothered by *chest pain*?

Original

Response options:

Not bothered at all -----

Bothered a little -----

Bothered a lot -----

Adapted

Added graphics to response option:

Smiley face

Neutral face

Sad face

Measurement Adaptation

- **OK to use** graphics/icons for response options using Likert-type scales. For example, How much of a problem has pain been for you in the last two months?



Not been a problem



A little problem



A medium problem



A big problem

Measurement Adaptation

- **OK** to change a few words to increase clarity as long as the underlying idea remained the same

Original

“feel confident about your ability to handle your personal problems”

Adapted

“felt you could handle your personal problems”

Measurement Adaptation

- **OK** to change a few words to increase clarity as long as the underlying idea remained the same

Original

“feeling as if your future will somehow be cut short”

Adapted

“feeling as if your life would end quickly”

Measurement Adaptation

- **OK** to add a hotlink to a “text box” with definitions of difficult or vague terms or to offer examples

Original

“Have you had contractures in the last two months?”

Text Box

For example, when your arms or legs are stuck in the same position

As an adult, has anyone you know touched you in a sexual way that you did not want?

Yes
No

Measurement Adaptation

- **OK** to add a hotlink to a “text box” with definitions of difficult or vague terms or to offer examples

- Original

“As an adult, has anyone ever touched you in a sexual way that you did not want?”
made

Text box

Grab, pet, or play with body parts such as your breast, penis, or between your legs in a way that you uncomfortable. For example, an adult may have put their hand or mouth on some part of your body.

Measurement Adaptation

- **OK** to add pictures or diagrams to illustrate difficult ideas
- **OK** to change person of pronouns (e.g., “I” to “You”)
- **Ok** to simplify sentence structure
- **Ok** to change from passive to active voice

Measurement Adaptation

- **Not OK** to split items or to remove entirely
- **Not OK** to change number of items
- **Not OK** to change scoring
- **Not OK** to change the meaning of an item

Measurement Adaptation

7. Someone to confide in or talk to about yourself or your problems.

1
None of
the time

2
A little of
the time

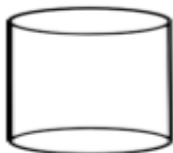
3
Some of
the time

4
Most of
the time

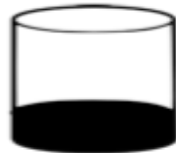
5
All of
the time

New

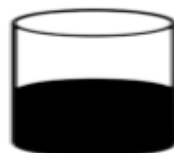
7. How often do you have someone with whom you can share personal information about yourself or your problems?



None of
the time



A little of
the time



Some of
the time



Most of
the time



All of
the time

Effect on Data Collection

- The improved accessibility of instruments enhanced the accessibility of the data collection itself
- Accessible, private process allowed for collection of abuse data without the need for mandatory abuse reporting (even with >60% disclosing abuse)
- Adapted instruments had high internal consistency reliability and construct validity

Feedback from CAB Members

“The project is very important because sometimes people don’t realize people with disabilities are capable of doing things like this.”

“It seems more accurate because then the questions change so they would understand it and they would be answered more accurate that way too.”

“Often we stop things and go back and make sure that, you know, one or more people who have expressed confusion about what we are talking about, we can address that.”

CBPR Considerations

- We'd say it's worth it, no matter what type of research you do – but you need to decide for yourself
- It takes a LOT of thought and effort!
- Are you willing to share power?
- Think about how and where inclusion of people with DD or other stakeholders will benefit your work
- Think about the level of involvement that is desirable and feasible

CBPR Considerations

- Who needs to be included? People with DD, caregivers, clinicians, disability professionals, others?
- Which organizations can you partner with?
- Think about how to avoid tokenism, breaking trust, pretending to do something you are not doing...
- Go for it!

Conclusion

- Measurement adaptation:
 - Can be done with people with developmental disabilities by actively engaging their expertise
 - Does not violate the integrity of the original measures
 - Can lead to improved data collection

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Thank you!

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