Identifying Differences in Safety and Quality of Life Based on Self-report or Proxy Report for People with Intellectual and Developmental Disabilities

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Terminology & Accessibility Notes

• Care partner vs. Caregiver

• Self vs. Proxy Reporter

• Intellectual and developmental disabilities (IDD)

• Quality of Life (QOL)

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Nearly 3 in 4 of NIH-funded clinical trials assessed had eligibility criteria excluding people with IDD.

(McDonald et al., 2022)

- Cognitive impairment or IDD diagnosis
- Ability to read/write
- Using long-term care services
- Assistive devices or supported decision-making
- Research staff discretion, with or without justification

DeCormier Plosky et al., 2022; McDonald et al., 2022; Rios et al., 2016
Exclusion of People with IDD: Other Ways

“I worry about the fine line between protecting people from research harm and making decisions for others/limiting their rights ... decisions that are different from what I might personally believe is best”

(McDonald et al., 2017)

- Inaccessible study documents or measures
- Environmental barriers
- IRB: protection → prevention
- Misconceptions about ability or interest in participation
- Gatekeeping

Carlson, 2013; DeCormier Plosky et al., 2022; Horner-Johnson et al., 2013; McDonald et al., 2016; McDonald et al., 2022; Rios et al., 2016; Sabatello et al., 2019; St John et al., 2022
People with IDD face discrimination and exclusion from health research despite benefitting from findings.

Unequal representation of people with IDD in health research limits applicability and generalizability of findings to patient populations

(Rios et al., 2016)
Methods

Measures
- Online Qualtrics survey
- Part of larger project

Participants
- Person with IDD or care partner of person with IDD
  - 2017 (n=350)
  - 2021 (n=194)

Analysis
- Independent sample T tests
- Frequency counts
Purpose

Identify differences in reporters (self vs. proxy) on safety and QOL items using data from people with IDD in Wisconsin receiving long-term care services.
Results - Demographics

2017
17% (n=61) 83% (n=289)

2021
11% (n=22) 89% (n=172)
How would you rate your quality of life?

1 : Very poor
2 : Poor
3 : Neither poor nor good
4 : Good
5 : Very good
Results - Quality of Life (QOL) - BOTH

2017 vs 2021 Mean Quality of Life Score

M = 3.14 (SD = 0.76)*

M = 2.99 (SD = 0.77)*
Results - Quality of Life (QOL) - 2017

2017 Mean QOL Scores by Reporter Status

M = 2.95 (SD = 0.87)*

M = 3.18 (SD = 0.73)*
Results - Quality of Life (QOL) - 2021

2021 Mean QOL Scores by Reporter Status

M = 2.77 (SD = 0.81)  
M = 3.02 (SD = 0.76)
Results - Quality of Life (QOL)

**Significant difference** in mean QOL scores, regardless of reporter status, between cohorts

↓ **QOL for all reporters in 2021** compared to 2017

**Significant difference** between mean QOL based on reporter status for 2017

Proxy = ↑ QOL

**No significant difference** for reporter status in 2021
Results - Quality of Life (QOL) - BOTH

Mean QOL by Year & Reporter Status

- 2017 - Self Report: $M = 2.95$ (SD = 0.87)
- 2017 - Proxy Report: $M = 3.18$ (SD = 0.73)
- 2021 - Self Report: $M = 2.77$ (SD = 0.81)
- 2021 - Proxy Report: $M = 3.02$ (SD = 0.76)
Results - Quality of Life (QOL) - BOTH

Mean QOL by Year & Reporter Status

- 2017 - Self Report: M = 2.95 (SD = 0.87)
- 2017 - Proxy Report: M = 3.18 (SD = 0.73)
- 2021 - Self Report: M = 2.77 (SD = 0.81)
- 2021 - Proxy Report: M = 3.02 (SD = 0.76)
Reporter status was a significant predictor of QOL for 2017 \((p=0.032)\) but not 2021 \((p=0.160)\) but not maintained when controlling for age & sex.
Results - Safety

2017

Do you have any safety concerns for yourself at the present time regarding your current living situation?

1: Not at all
2: A little
3: Some
4: A great deal

2021

In the past year, was there somewhere you felt unsafe? (Y/N)
Where did you feel unsafe?

1: Home
2: Work
3: Community
4: Someplace else (tell us where)
Results - Safety

In 2017, PWIDD self-reported as having slightly higher safety concerns than their care partners reported for them (M=1.41, SD = 0.775; M = 1.37, SD = 0.779)

In 2021, PWIDD significantly self-reported having more safety concerns than their care partners reported for them (p=0.020).

We were not able to compare between 2017 and 2021 due to question wording.
Do you have any safety concerns for yourself at the present time regarding your current living situation?

1 : Not at all
2 : A little
3 : Some
4 : A great deal

If you have safety concerns for yourself at the present time regarding your current living situation, please describe them here:
Results - Safety (2017)

**SELF REPORT** (n=15)

1. Inaccessible environment impacting independence
2. Fall risk or condition-related concerns, including medication management
3. Social Isolation
4. Winter

**PROXY REPORT** (n=61)

1. Staffing (high turnover, lack of knowledge, inattention leading to injury or disease)
2. Constant supervision, especially for elopement or wandering concerns
3. Fall risk due to conditions or diagnosis
4. Other residents
5. Maintenance of the physical state of the home
Discussion: Implications for OS

- Observed differences on safety and QOL items based on reporter status
  - How are we asking these questions in clinical & research contexts?

- QOL: reporter status vs. age & sex
The future of OS must …

Recognize that not all people have the same opportunities for health & health promotion

- Consider vulnerable & underrepresented groups as populations of interest for OS research

Meaningfully consider roles of people with IDD in research, and not just their care partners

- Dyad studies

[Link to NIH article about disability as a health disparity]
Thank you!

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Discussion Questions

1. We are about to launch our 2023 survey. Considering the COVID-19 pandemic and our current context, how do you think these results would or would not change in the 2023 cohort?

2. How does the future of your occupational science practice or research incorporate diverse perspectives?


