



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

Allison Caudill, OTR, PhD Candidate; Emily Hickey, PhD;
Hannah Laufenberg, BS, OTD/S; Leann DaWalt, PhD; Karla
Ausderau, OTR, PhD, FAOTA



Terminology & Accessibility Notes



- Care partner vs. Caregiver
- Self vs. Proxy Reporter
- Intellectual and developmental disabilities (IDD)
- Quality of Life (QOL)



This work was supported by the Wisconsin Partnership Program #AAJ8474 (KKA); and in part by a core grant to the Waisman Center from the Eunice Kennedy Shriver National Institute of Child Health and Human Development (P50HD105353).



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



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



**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

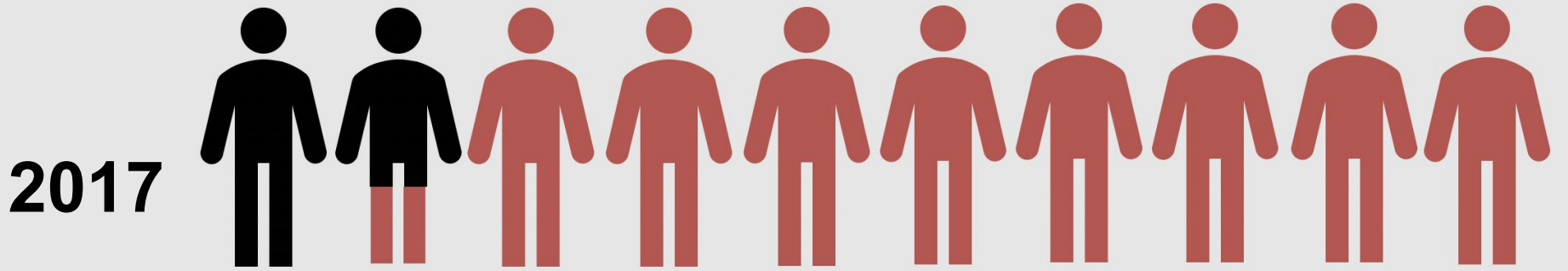
Frequency counts



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

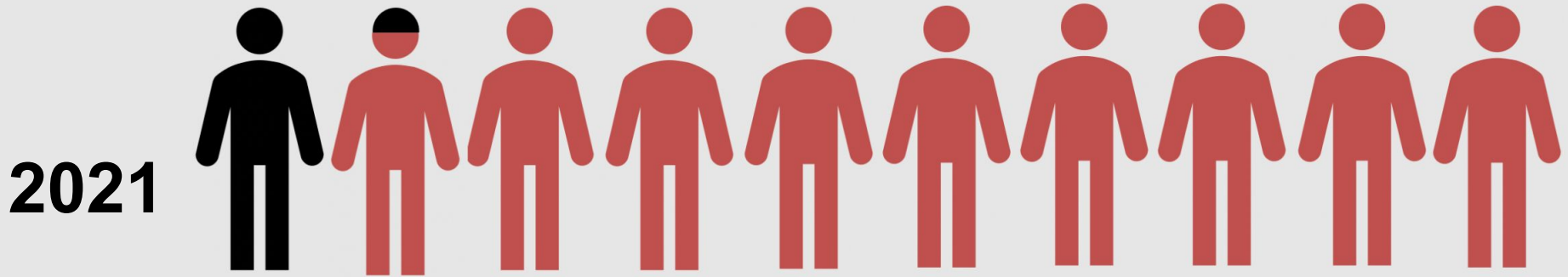


Results - Demographics



17% (n=61)

83% (n=289)



11% (n=22)

89% (n=172)



Self Report



Proxy Report



How would you rate your quality of life?

1 : Very poor

2 : Poor

3 : Neither poor nor good

4 : Good

5 : Very good

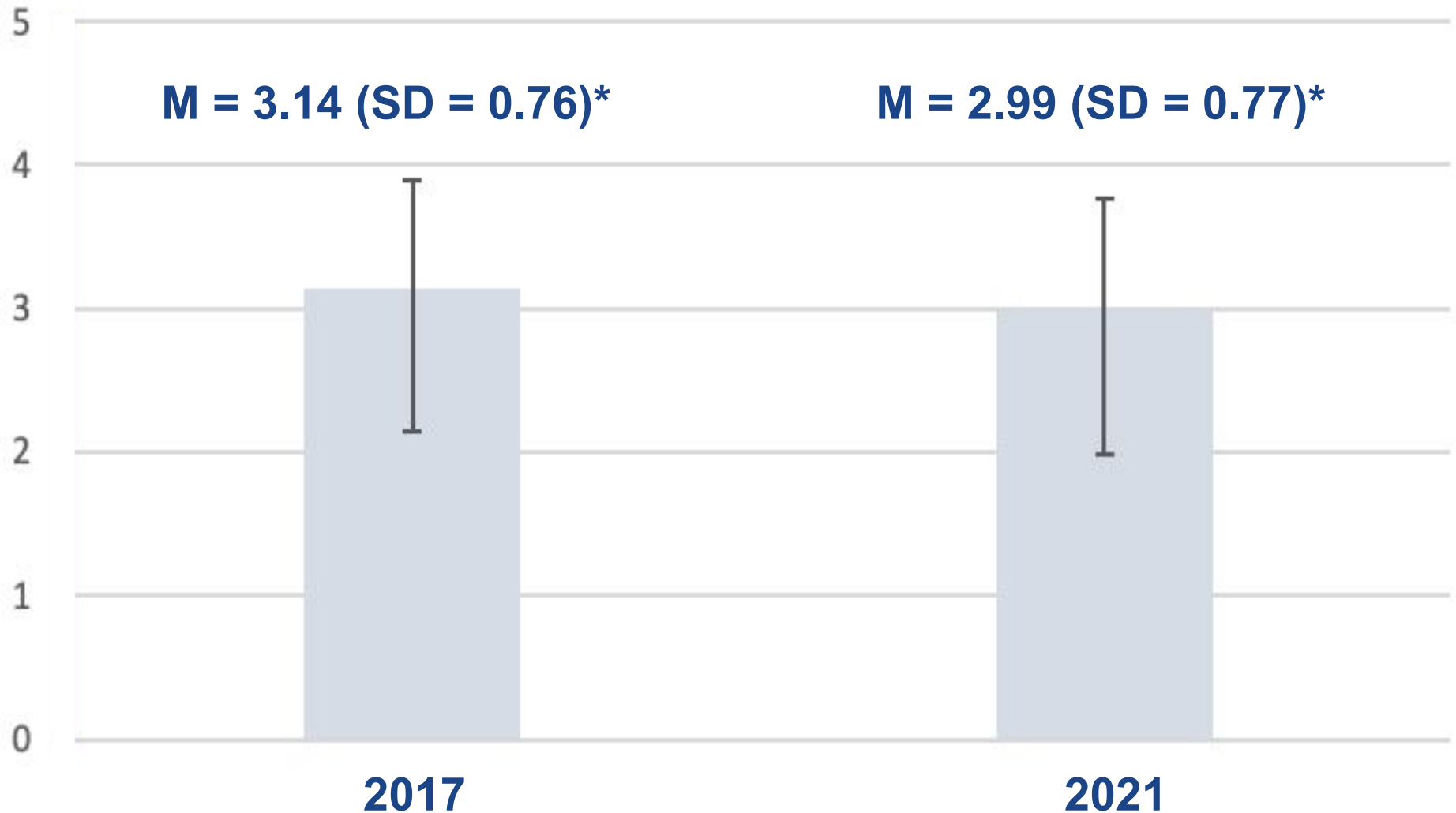
Results - Quality of Life (QOL) - BOTH



2017 vs 2021 Mean Quality of Life Score

M = 3.14 (SD = 0.76)*

M = 2.99 (SD = 0.77)*



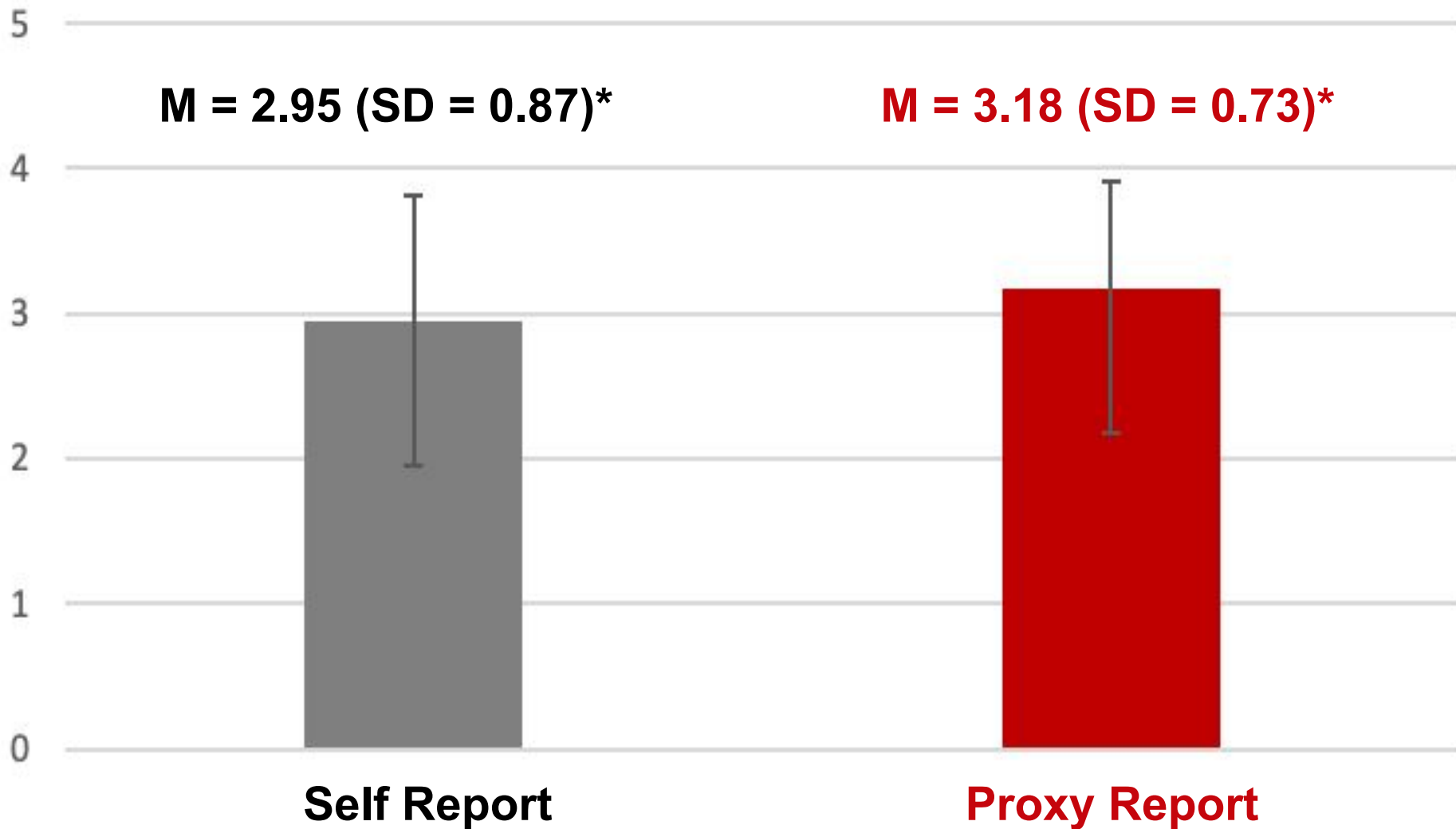
Results - Quality of Life (QOL) - 2017



2017 Mean QOL Scores by Reporter Status

M = 2.95 (SD = 0.87)*

M = 3.18 (SD = 0.73)*



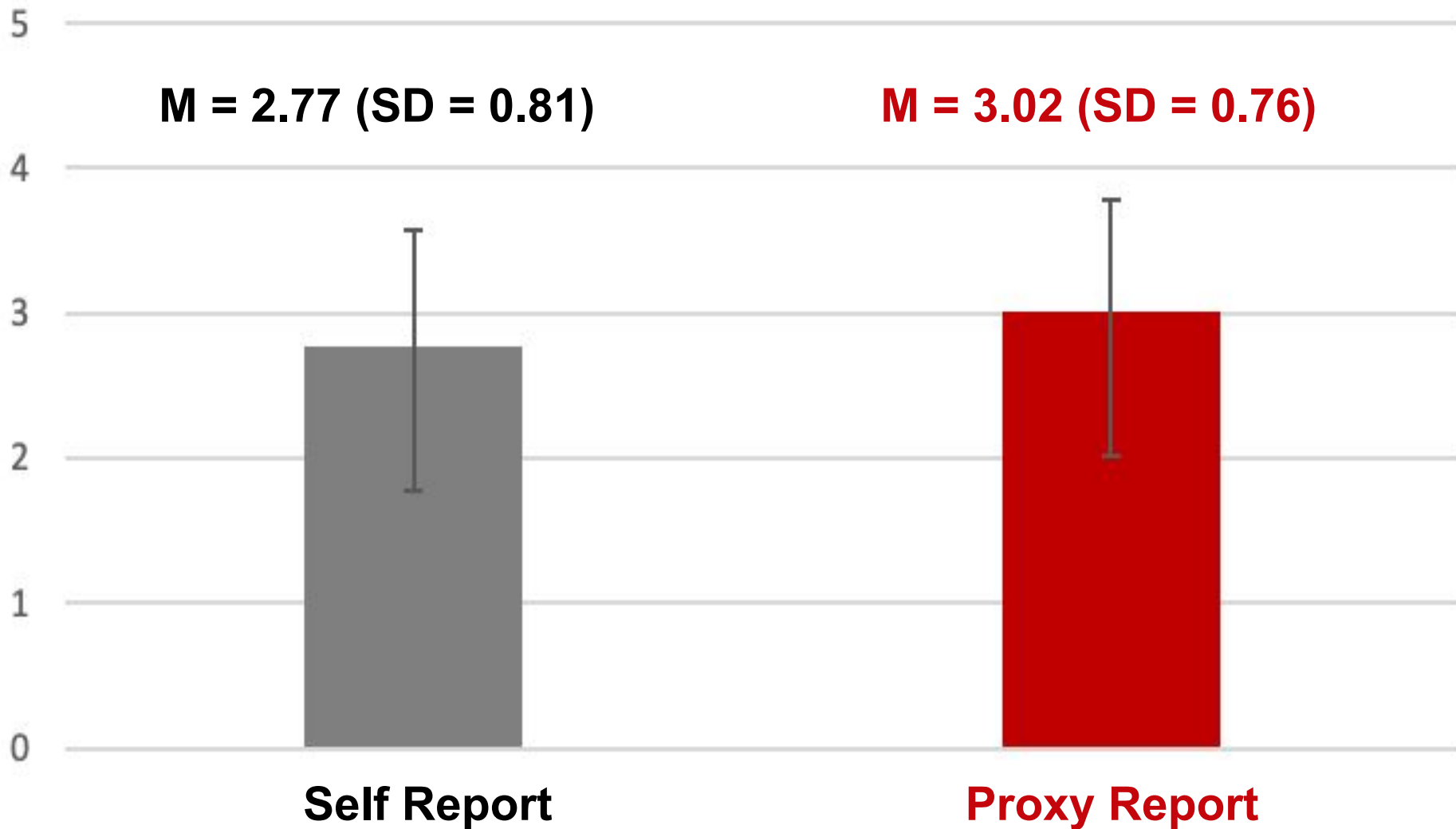
Results - Quality of Life (QOL) - 2021



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

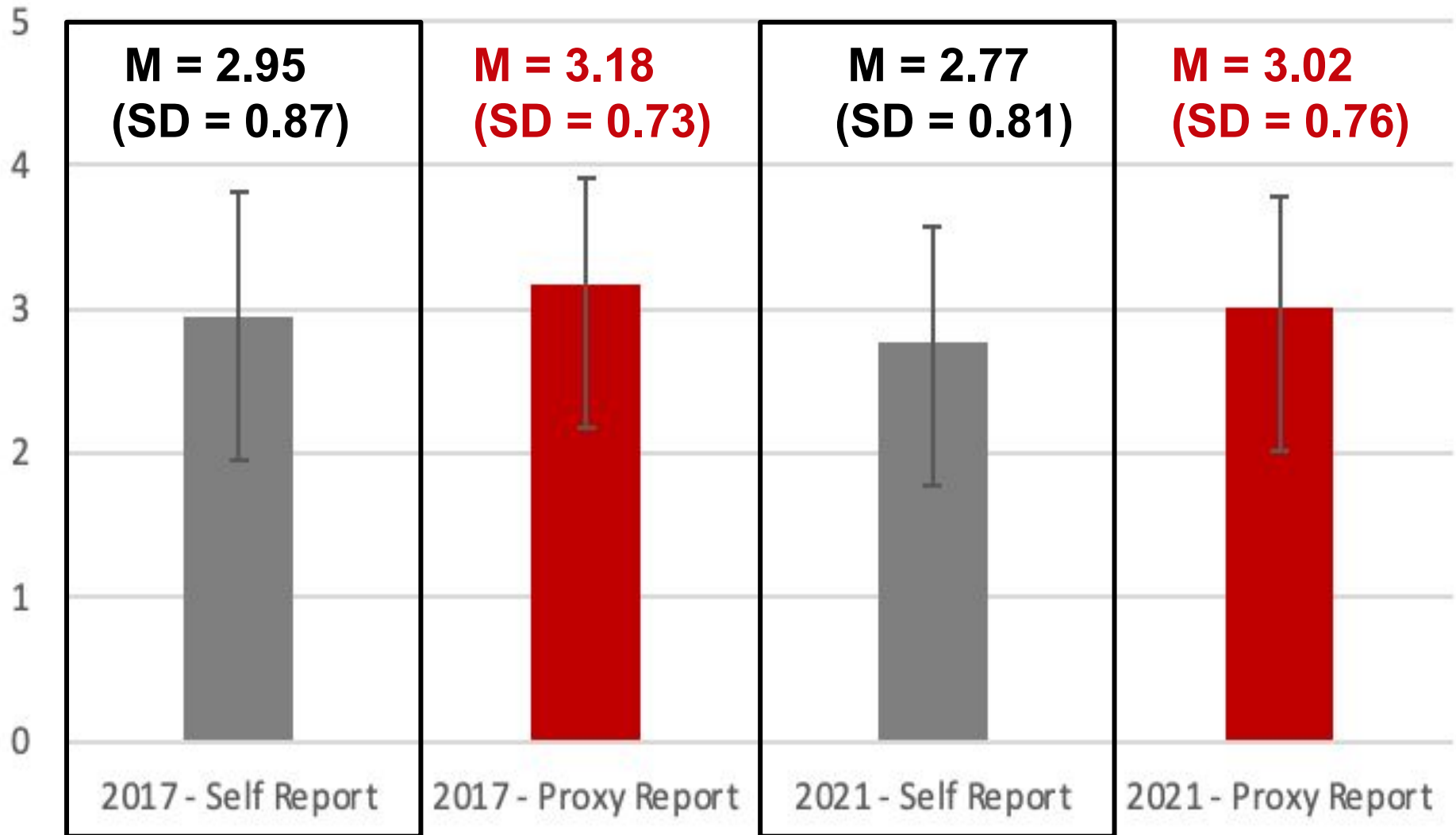
Proxy = ↑ QOL

No significant difference for reporter status in 2021

Results - Quality of Life (QOL) - BOTH



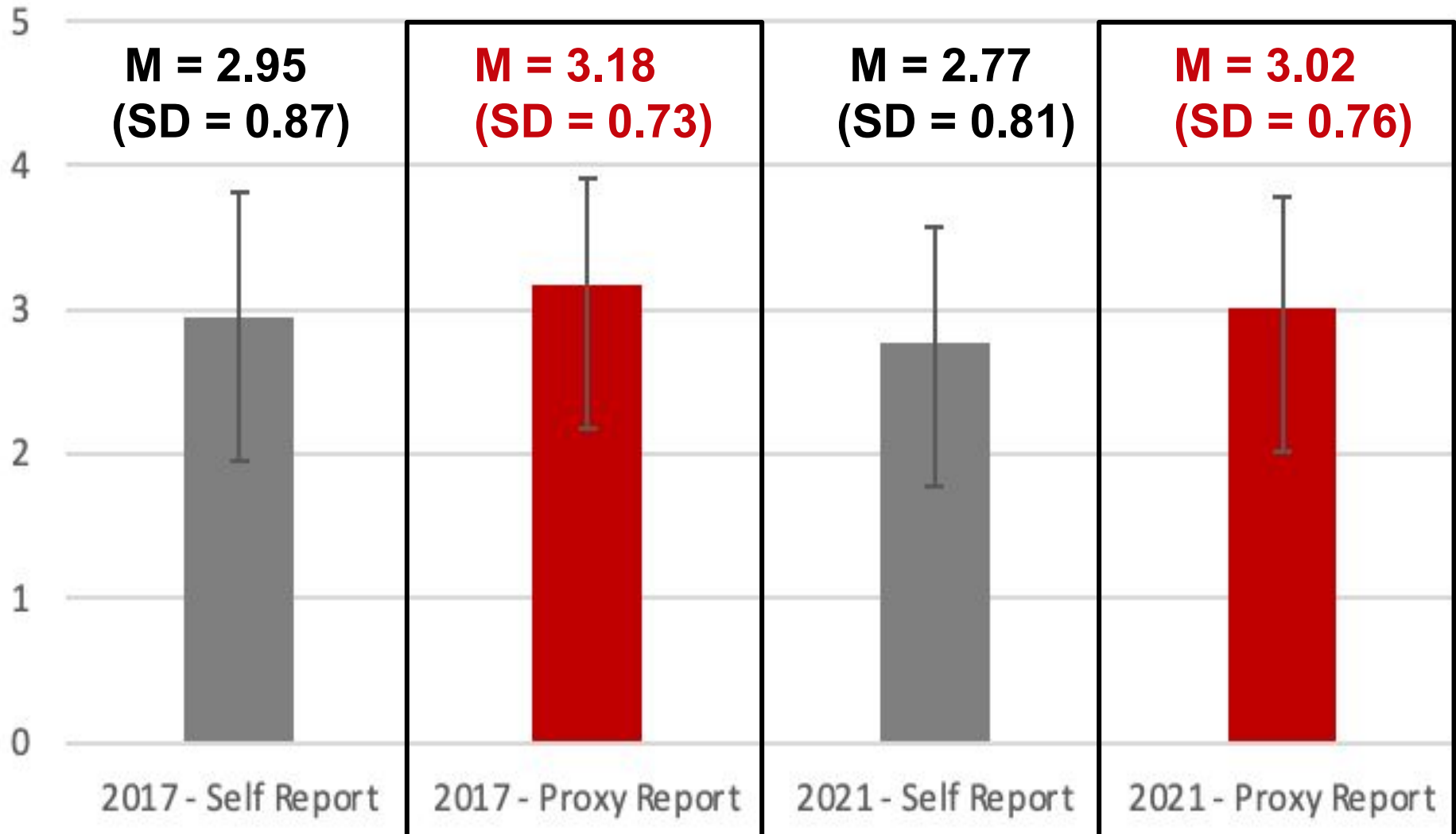
Mean QOL by Year & Reporter Status



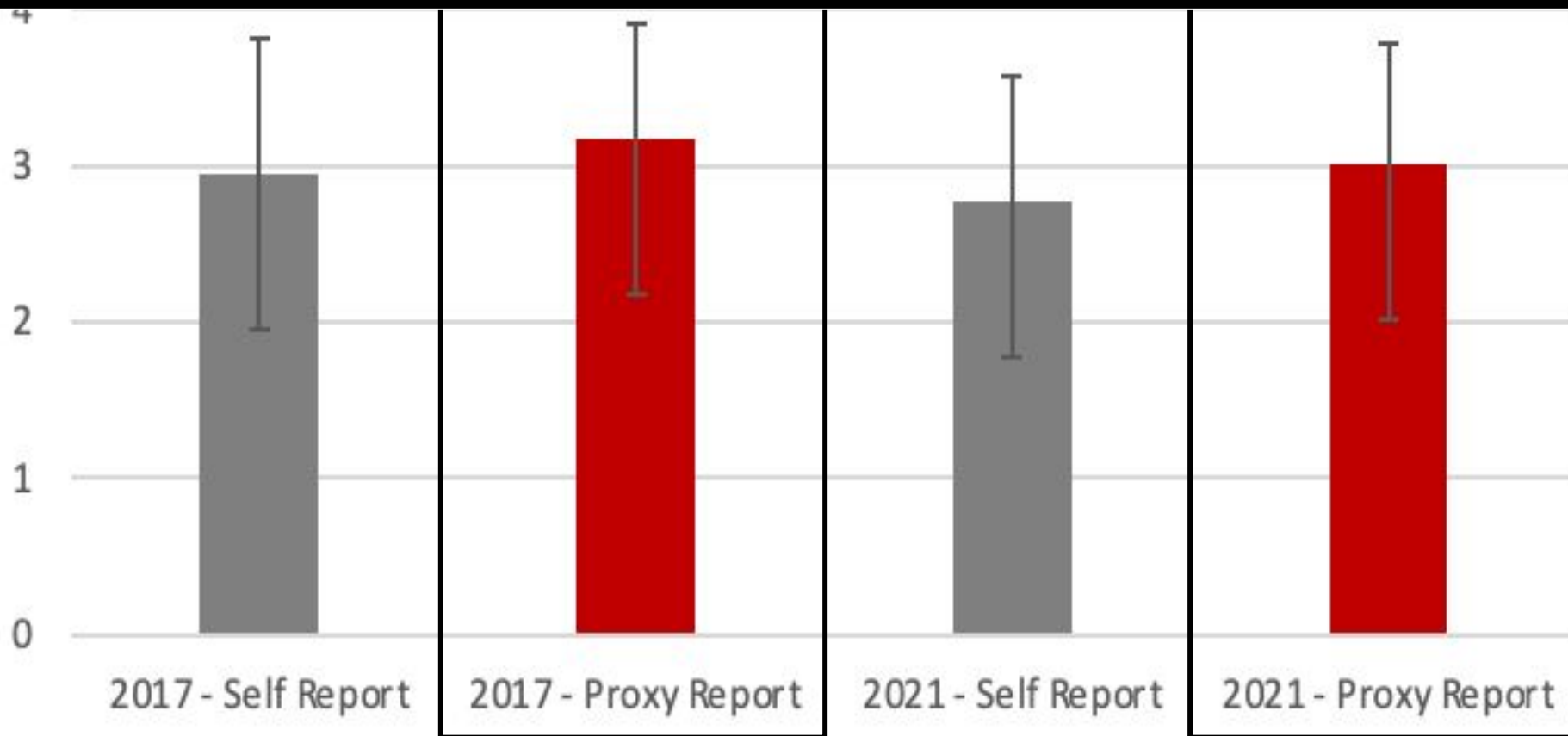
Results - Quality of Life (QOL) - BOTH



Mean QOL by Year & Reporter Status



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.

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

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



- **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

National Institutes of Health (NIH) ✓
September 26 at 10:22 AM · 🌐

Today, Eliseo J. Pérez-Stable, M.D., director of the [National Institute on Minority Health and Health Disparities](#) (NIMHD), designated people with disabilities as a population with health disparities for research supported by NIH in consultation with the [Agency for Healthcare Research and Quality](#) (AHRQ) Director Robert Otto Valdez, Ph.D. The designation is one of many steps NIH is taking to address health disparities faced by people with disabilities and ensure their represent...
[See more](#)

NIH.GOV
NIH designates people with disabilities as a population with health disparities

Link to NIH article about disability as a health disparity:





Thank you!

Allison Caudill, OTR, PhD Candidate

acaudill@wisc.edu

[@allisondcaudill](https://twitter.com/allisondcaudill)

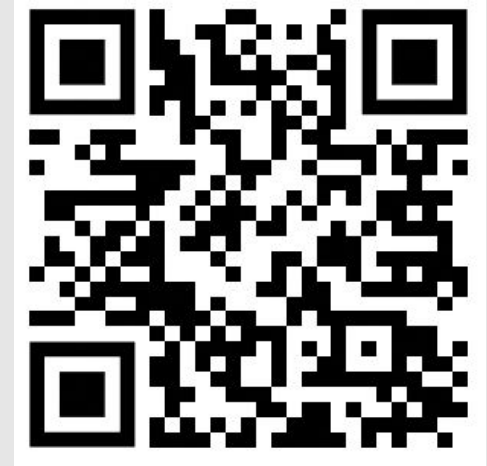


Discussion Questions



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?**

Ausderau Lab Website:



“Opening the door to health research” manuscript:



References



- Carlson L. (2013). Research ethics and intellectual disability: broadening the debates. *The Yale journal of biology and medicine*, 86(3), 303–314.
- DeCormier Plosky, W., Ne'eman, A., Silverman, B. C., Strauss, D. H., Francis, L. P., Stein, M. A., & Bierer, B. E. (2022). Excluding People With Disabilities From Clinical Research: Eligibility Criteria Lack Clarity And Justification. *Health affairs (Project Hope)*, 41(10), 1423–1432. <https://doi.org/10.1377/hlthaff.2022.00520>
- Jacinto, M., Rodrigues, F., Monteiro, D., Antunes, R., Ferreira, J. P., Matos, R., & Campos, M. J. (2023). Quality of Life in Individuals with Intellectual and Developmental Disabilities: The Congruency Effect between Reports. *Healthcare (Basel, Switzerland)*, 11(12), 1748. <https://doi.org/10.3390/healthcare11121748>
- McDonald, K. E., Conroy, N. E., Olick, R. S., & Panel, T. P. (2017). What's the Harm? Harms in Research With Adults With Intellectual Disability. *American journal on intellectual and developmental disabilities*, 122(1), 78–92. <https://doi.org/10.1352/1944-7558-122.1.78>
- McDonald, K. E., Schwartz, A. E., & Sabatello, M. (2022). Eligibility criteria in NIH-funded clinical trials: Can adults with intellectual disability get in?. *Disability and Health Journal*, 15(4), 101368.
- McDonald, K. E., & Stack, E. (2016). You say you want a revolution: An empirical study of community-based participatory research with people with developmental disabilities. *Disability and health journal*, 9(2), 201–207. <https://doi.org/10.1016/j.dhjo.2015.12.006>
- Rios, D., Magasi, S., Novak, C., & Harniss, M. (2016). Conducting Accessible Research: Including People With Disabilities in Public Health, Epidemiological, and Outcomes Studies. *American journal of public health*, 106(12), 2137–2144. <https://doi.org/10.2105/AJPH.2016.303448>
- Sabatello, M., Landes, S. D., & McDonald, K. E. (2020). People with disabilities in COVID-19: fixing our priorities. *The American Journal of Bioethics*, 20(7), 187-190.
- St. John, B. M., Hickey, E., Kastern, E., Russell, C., Russell, T., Mathy, A., ... & Ausderau, K. K. (2022). Opening the door to university health research: recommendations for increasing accessibility for individuals with intellectual disability. *International Journal for Equity in Health*, 21(1), 130.