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# Exploring Proxy Response Bias in a Large-Scale Survey of People with Disabilities

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# Overview

- **Health surveys often allow proxies to respond for people with disabilities who cannot respond for themselves**
- **Proxy response bias occurs when the responses provided by proxies are systematically different than those given by self-respondents**
- **Researchers should be concerned about the impact of proxy response bias on the validity of estimates of health and functional status**

# What do we know about proxy reporting?

- **Proxy response more likely among older people, those with limited education, and with poorer physical and mental health**
- **Compared to self-response, proxy ratings of health status and functioning have been shown to be biased in different directions in different studies**
- **The relationship between the proxy and the person they answer for could affect the accuracy of proxy responses**

# Limitations to the existing research

- **Few studies examined proxy response bias in surveys of people with disabilities**
- **Most were conducted with small convenience samples of people with specific health care needs**
- **Those sample members who actually needed a proxy because they could not respond for themselves are often not represented**

# National Beneficiary Survey (NBS)

- **Sponsored by the Social Security Administration**
- **Sample of working age people who receive Supplemental Security Income (SSI) and/or Social Security Disability Insurance (SSDI)**
- **Seven rounds of data collection (we will be looking at two)**
  - Seven independent cross-sectional samples of beneficiaries
  - Round 5—4000 completes, 2015, population as of 6/30/14
  - Round 6—4000 completes, 2017, population as of 6/30/16

# Proxies in the NBS

- **Interviews in the NBS were completed by proxy for the following reasons:**
  - The sample member did not pass a standardized cognitive screener
  - A knowledgeable informant expressed that a proxy would be necessary
  - The sample member needed to switch to a proxy during the course of the interview
- **26.5 percent of interviews in Rounds 5 and 6 of the NBS were completed by proxy**
  - 26 percent in Round 5
  - 27 percent in Round 6

# Key research questions

1. **Is the use of proxy respondents in the NBS related to the demographic characteristics of the sample members?**
2. **What is the size and direction of the differences between proxy and self-reported responses to questions on health status and functional limitations?**
3. **To what extent does the proxy-sample member relationship affect the differences between proxy and self-reported responses?**

# Outline

- **Address research question 1**
  - Round 5 and Round 6 separately
- **Address research question 2**
  - Round 5 and Round 6 separately
  - Cognitive and noncognitive disabilities separately
- **Address research question 3**
  - Round 5 and Round 6 separately
  - Cognitive and noncognitive disabilities separately
  - Parent and non-parent proxies separately

# Research Question #1:

## Is the use of proxy respondents in the NBS related to demographic characteristics of the sample members?

# Analysis plan

- **Fit logistic models predicting the likelihood of proxy use accounting for the sample design**
- **Identify characteristics for which proxy and self-reporting sample members differ**

# List of potential confounders

| Variable | |
|---|---|
| Gender of sample member | Disability type (cognitive, mental illness, physical) |
| Race (black, white, other) | Age of disability (<18, 18-29, 30+) |
| Age (18-29, 30-39, 40-49, 50+) | Has children (yes, no) |
| Employment status (working or not) | Beneficiary status (SSI only, SSDI only, concurrent) |
| Education level (HS dropout, HS/GED, certificate/spec ed, some post-secondary | Living arrangement (live alone, with family, with friends/roommates, in group home) |
| Marital status (ever married, never married) | Cohabitation status (living with someone or not) |
| Ethnicity | BMI category |

# Finding

- **Biggest difference is with disability type**
  - Sample members with cognitive disabilities are much more likely to require proxies than those with physical disabilities or mental illness
  - The cognitive and noncognitive disability groups are very different, so it may be difficult to interpret results if the populations are combined
  - Proceed by analyzing cognitive and noncognitive populations separately

# Comparing characteristics of proxy users by disability type

- **For sample members with either cognitive disabilities or noncognitive disabilities, proxy use was related to several demographic characteristics:**
  - Gender, education, living situation, marital status, number of children, and age of disability onset
- **For those with only noncognitive disabilities, proxy use was also related to:**
  - Disability type, benefit type, age

## Research Question #2:

# What is the size and direction of the differences between proxy and self-reported responses to questions on health status and functional limitations?

# NBS measures of health status and functioning

- **Measures of physical and mental health status**
  - Eight self reported measures on a Likert scale, converted to binary for analysis
- **Measures of activities of daily living (ADL), instrumental activities of daily living (IADL), and functional limitations assess difficulty with:**
  - Eight self-reported measures on a binary scale

# Matching treatment and comparison groups to minimize bias

- **Sample members with and without proxy responses differ on a lot of characteristics**
- **Estimating the proxy "effect" is potentially biased if not adjusted appropriately for these characteristics**
- **Propensity scoring aligns the distributions of those with and without proxies, reducing the propensity for bias due to observed confounders**

# Analysis plan

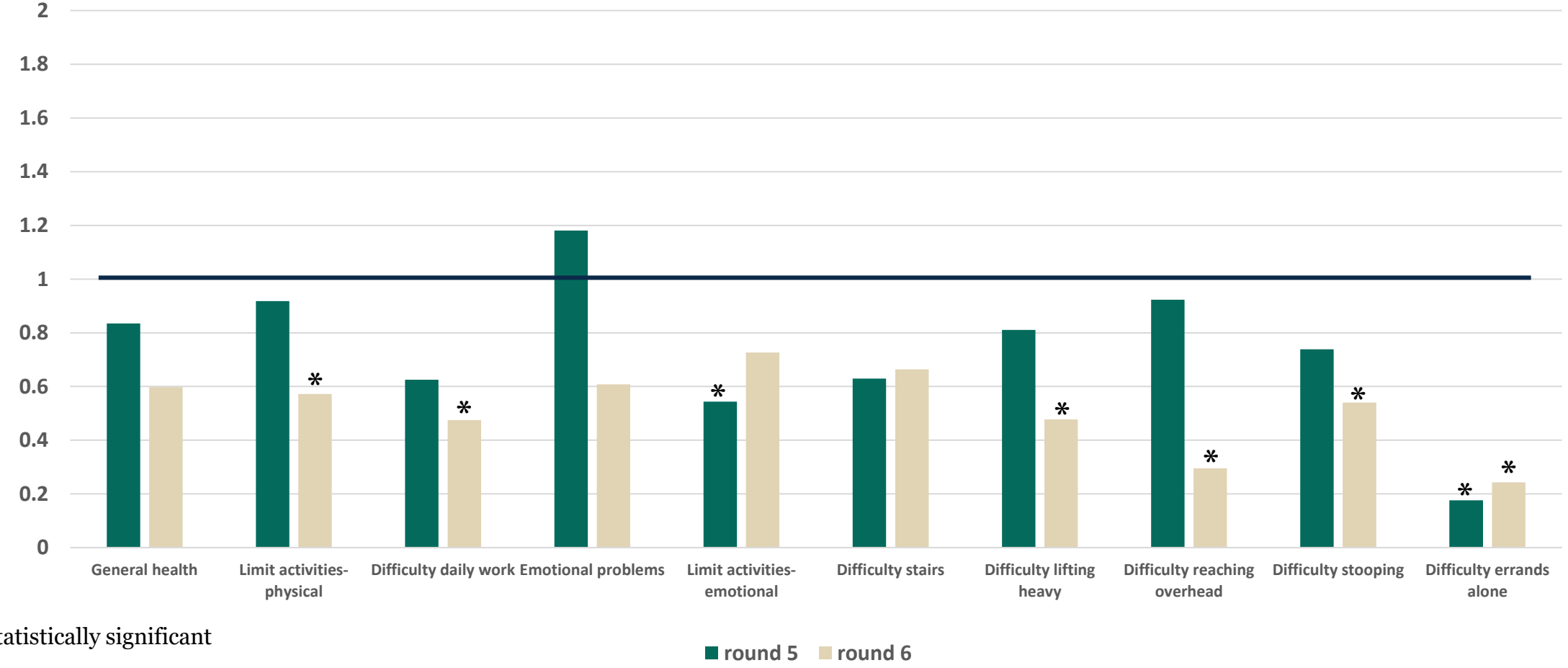
- **Estimate propensity score weights separately for each of the two disability group types, and each of the two rounds**
- **Assess the effect of the "treatment" on the selected outcomes using propensity score weighted logistic regression**
- **Analyze two rounds separately, assess commonalities and differences between rounds**

# Findings

- **We obtained good covariate balance between the proxy respondents and self respondents with propensity score weights for both disability groups and both rounds**
- **Results between rounds were consistent for noncognitive disabilities, not so for cognitive disabilities**
  - The strongest result was for the outcome "difficulties doing errands alone" in both rounds
  - Cognitive: proxies indicated more health problems in Round 6 only
  - Noncognitive: proxies indicated less bodily pain, more problems lifting heavy objects or getting around home

# Proxy vs. self-report odds ratios for those with cognitive disabilities

[>1: proxies indicate better health/fewer difficulties]




* Statistically significant

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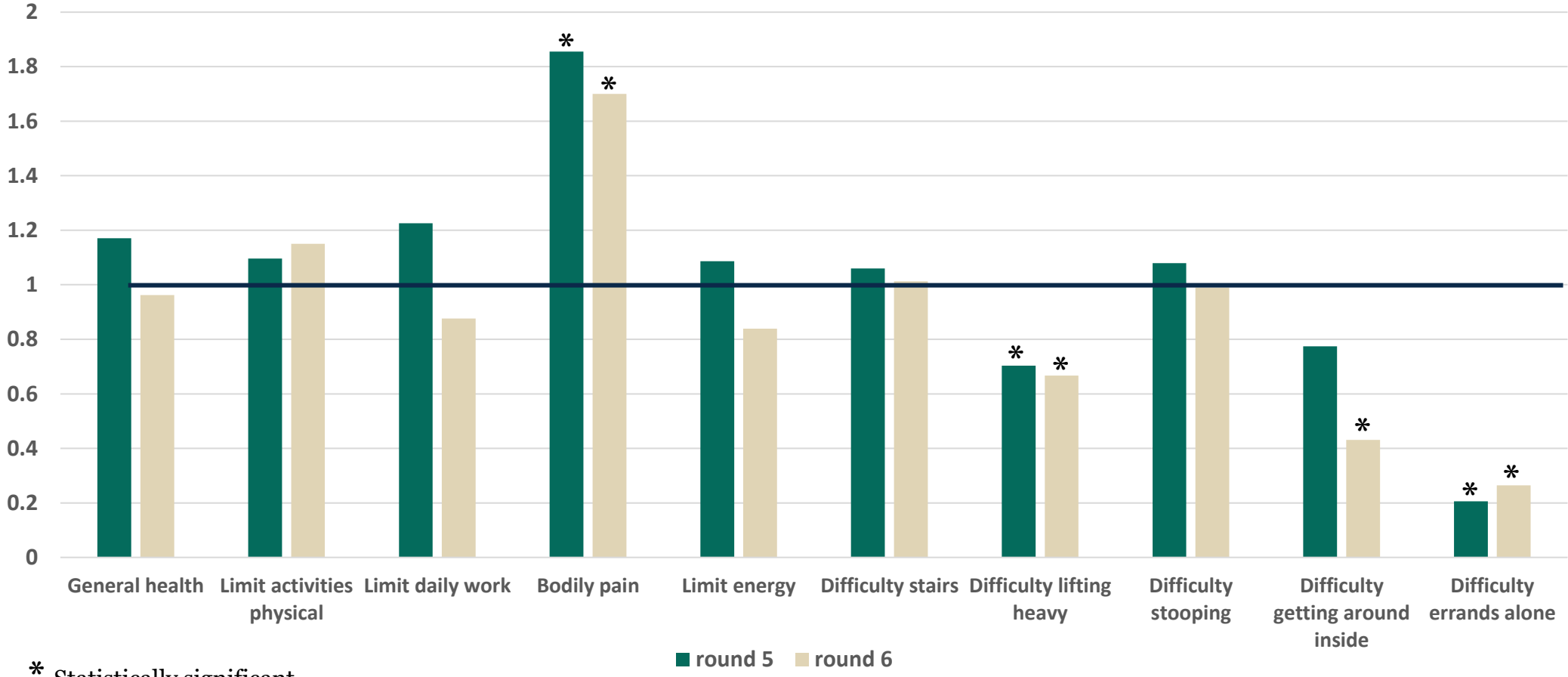
# Proxy vs. self-report odds ratios for those with noncognitive disabilities

[>1: proxies indicate better health/fewer difficulties]




* Statistically significant

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# Research Question #3:

## To what extent does the proxy-sample member relationship affect the differences between proxy and self-reported responses?

# Analysis plan

- **Review proxy relationships to sample members and their response patterns on outcome variables**
- **Use similar regression model setup as for Q2**
- **Assess the effect of the "treatments" on the selected outcomes**
- **Analyze two rounds separately, assess commonalities and differences between rounds**

# Proxy relationships in the NBS data, round 5

| Proxy relationship | Number in NBS | Cognitive disabilities | Noncognitive disabilities |
|---|---|---|---|
| Total proxies | 1,043 (26%) | 477 (58%) | 561 (18%) |
| Parent (mother or father) | 635 | 283 | 350 |
| Other proxies | 410 | 194 | 211 |
| Self-respondents | 3,019 (74%) | 340 (42%) | 2,630 (82%) |
| **Total** | **4,062** | **817** | **3,191** |

# Proxy relationships in the NBS data, round 6

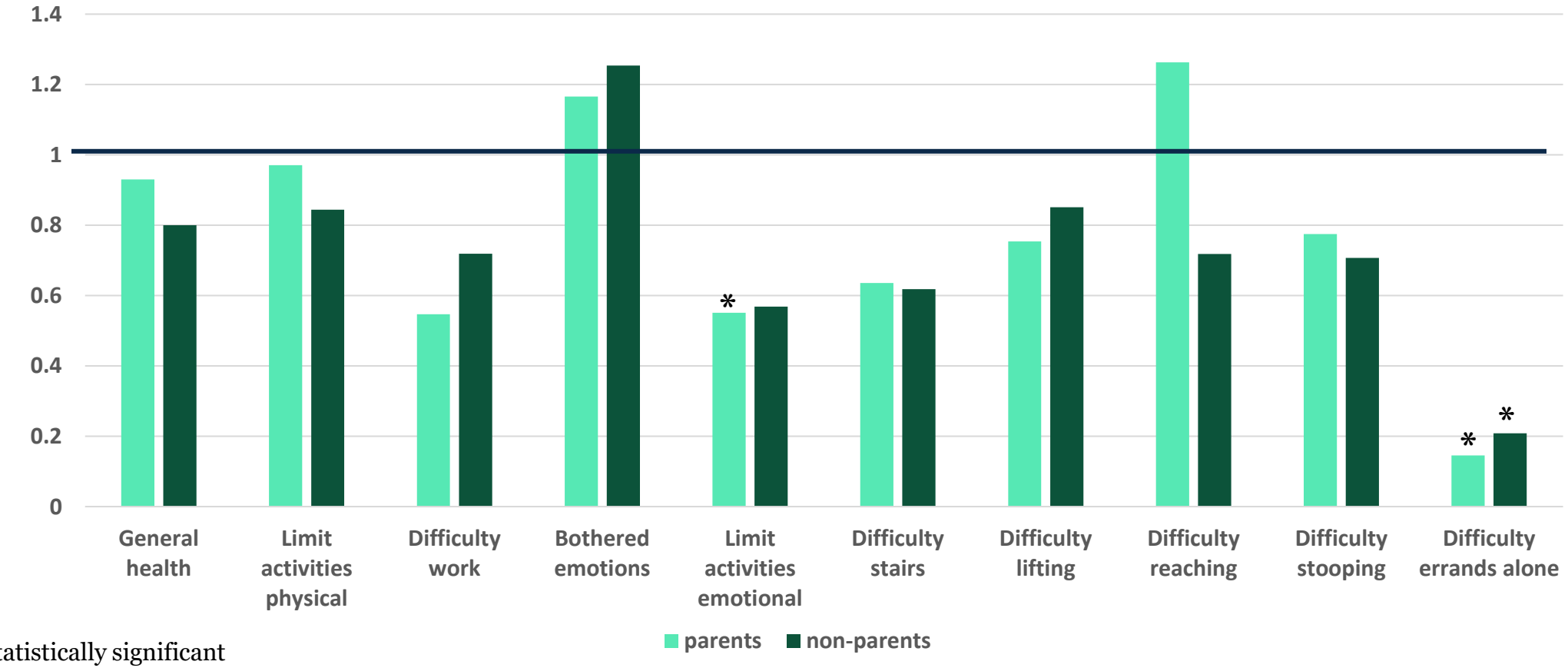
| Proxy relationship | Number in NBS | Cognitive disabilities | Noncognitive disabilities |
|---|---|---|---|
| Total proxies | 1,091 (27%) | 525 (64%) | 552 (18%) |
| Parent (mother or father) | 661 | 325 | 331 |
| Other proxies | 465 | 207 | 221 |
| Self-respondents | 2,911 (72%) | 295 (36%) | 2,575 (82%) |
| **Total** | **4,002** | **820** | **3,127** |

# Findings

- **Cognitive: In Round 6, non-parent proxies indicated more health problems and functional limitations, not in Round 5**
- **Noncognitive: parent proxies indicated fewer health problems and functional limitations than comparable self-respondents regardless of round—more than just bodily pain that we saw in result from RQ2**
- **Regardless of relationship and disability type, all proxies reported sample members had more difficulty doing errands alone than comparable self-respondents**

# Proxy vs. self-report odds ratios among those with cognitive disabilities, Round 5

[>1: proxies indicate better health/fewer difficulties]

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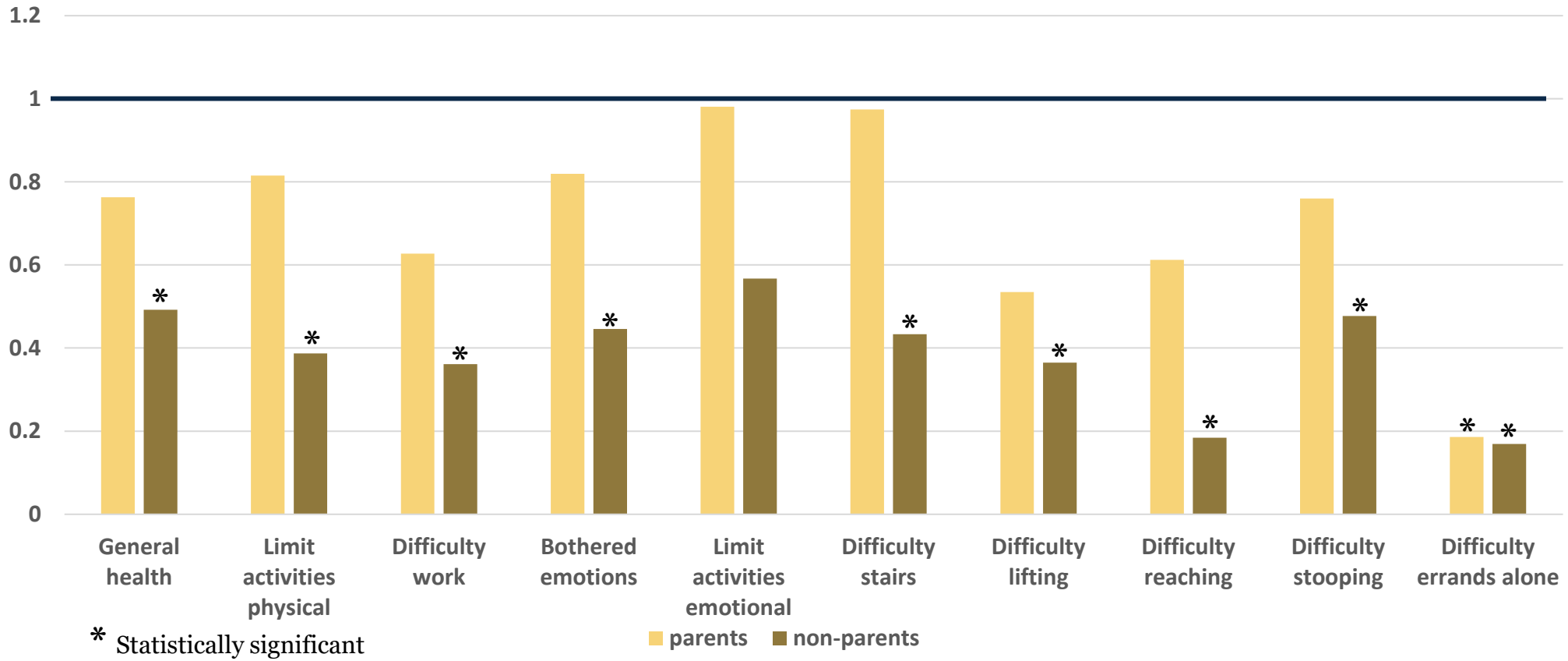
# Proxy vs. self-report odds ratios among those with cognitive disabilities, Round 6

[>1: proxies indicate better health/fewer difficulties]




* Statistically significant

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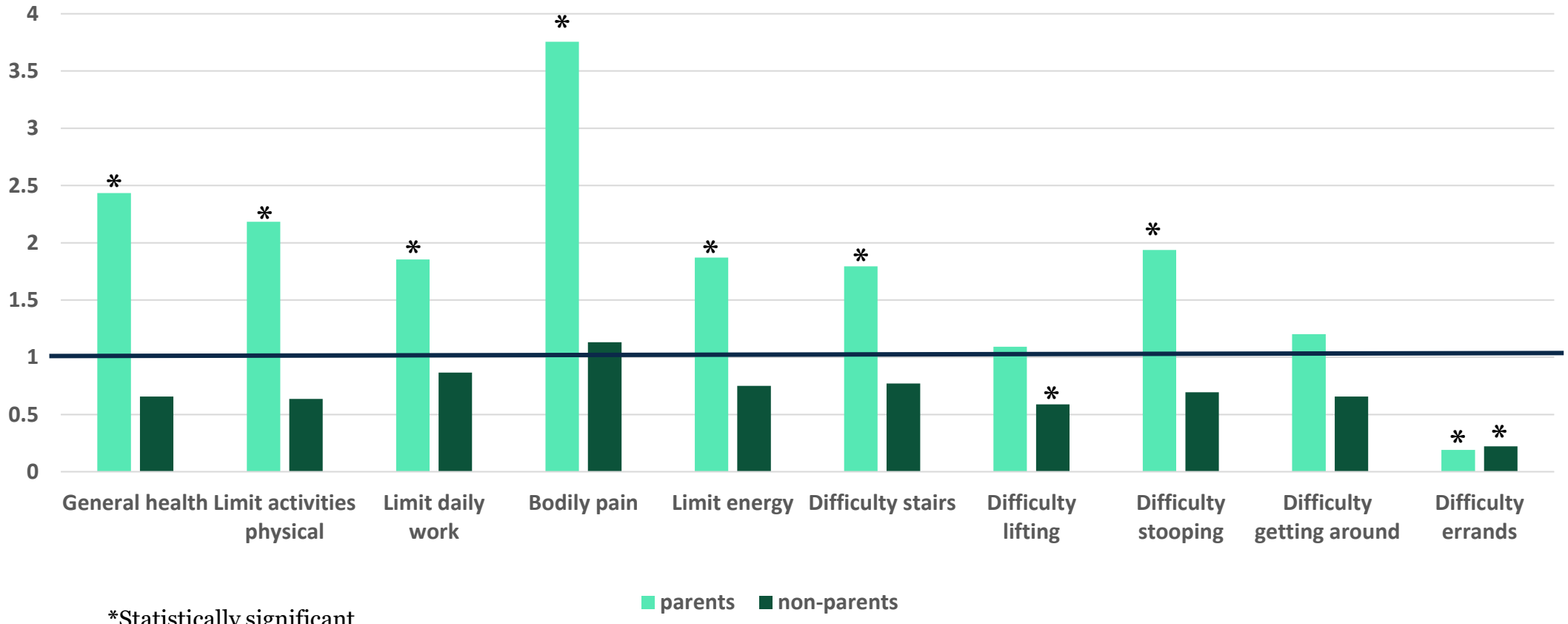
# Proxy vs. self-report odds ratios among those with noncognitive disabilities, Round 5

[>1: proxies indicate better health/fewer difficulties]




*Statistically significant

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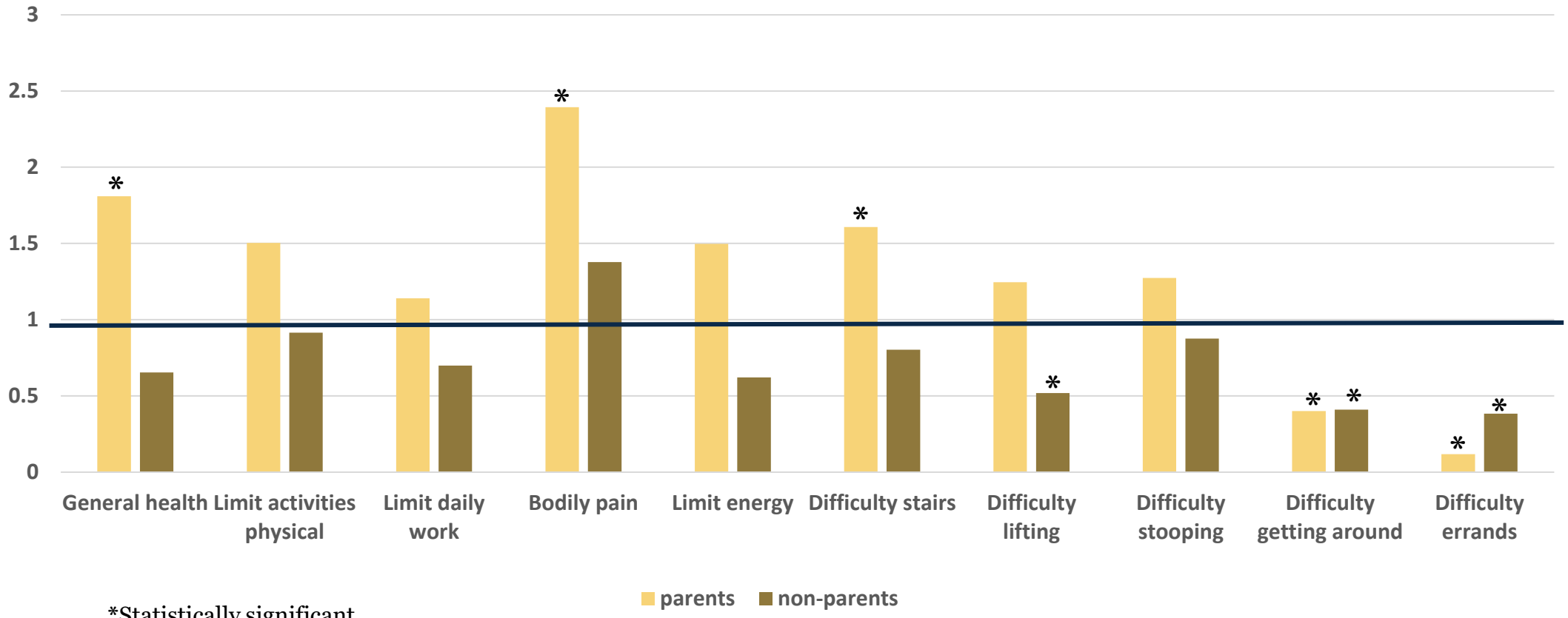
# Proxy vs. self-report odds ratios among those with noncognitive disabilities, Round 6

[>1: proxies indicate better health/fewer difficulties]




*Statistically significant

# Closing Remarks

# Recap

- **Proxy responses were consistently more likely for sample members who were men, living in group homes, unmarried, younger (particularly those under 30 years old), and either had no school, or had a special education certificate of completion**
- **From the analyses of RQ2 and RQ3, across the board, proxies reported more problems with doing errands alone**
- **Other results differed between cognitive and noncognitive disability types**

# Recap, cont.

- **Cognitive:**
  - From RQ2 analysis results, proxies reported were more likely to report functional limitations/poorer health than self-respondents for sample members, but for one round only.
  - From RQ3 we saw that this was only true for non-parent proxies, again for one round only.

# Recap, cont.

- **Noncognitive:**
  - For both RQ2 and RQ3, results were mostly consistent across rounds.
  - From RQ2, proxies were more likely to report less bodily pain than self respondents, and less likely to report difficulty lifting heavy things
  - From RQ3, parent proxies were more likely to report fewer limitations/better health than self-respondents for a number of outcomes, particularly health outcomes, not just bodily pain, but it was non-parent proxies were more likely to report difficulty lifting heavy things

# Limitations of research

- **This is not a randomized control trial**
  - Propensity Score Weights are a vehicle that can be used to ensure proxy respondents and self-respondents are as alike as possible for the given confounders
  - The differences that we observed may not be due to bias, but due to differences between the groups that are not captured by the confounders we have available
- **We considered all proxy types together in the model—we did not break it down by the reason for proxy use**
- **The extent of self-report bias is unknown**

# Implications for future research

- **Findings that show proxies report differing health and functional limitations than self respondents in populations of people with disabilities should be acknowledged but viewed with caution, as causal factors are not clear**
- **Consider implementing statistical correction procedures that reduce the impact of proxy response bias for estimates of health and functional status of people with disabilities**
  - Such procedures should account for known information about the relationship between the proxy and the sample member

# Acknowledgements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# For more information

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# Appendices

# Odds Ratios (P-values < 0.05)

[>1: proxies indicate better health/fewer difficulties; ns = not significant]

| Variable | Cognitive odds ratio | Noncognitive odds ratio |
|---|---|---|
| **Health Status Variables: In the past 4 weeks…** | | |
| Physical health limited usual activities | 0.75 (ns) | 1.10 (ns) |
| Had difficulty doing daily work due to physical health | 0.71 | 0.92 (ns) |
| Experienced at least moderate bodily pain | 0.87 (ns) | 1.30 |
| **ADL/IADL: Having difficulty with…** | | |
| Lifting or carrying something heavy | 0.65 | 0.82 |
| Reaching over your head | 0.56 | 1.07 (ns) |
| Getting around inside your home | 0.97 (ns) | 0.67 |
| Doing errands alone | 0.43 | 0.50 |

# Odds Ratios for Those with Cognitive Disabilities (P-values<0.05)

[>1: proxies indicate better health/fewer difficulties; ns = not significant]

| Variable | Parents odds ratio | Non-parents odds ratio |
|---|---|---|
| **Health Status Variables: In the past 4 weeks…** | | |
| General health was fair or worse | 1.06 (ns) | 0.70 (ns) |
| Physical health limited usual activities | 0.92 (ns) | 0.58 |
| Had difficulty doing daily work due to physical health | 0.86 (ns) | 0.58 |
| Experienced at least moderate bodily pain | 0.99 (ns) | 0.73 (ns) |
| **ADL/IADL: Having difficulty with…** | | |
| Walking/climbing stairs | 0.99 (ns) | 0.66 (ns) |
| Lifting or carrying something heavy | 0.73 (ns) | 0.60 |
| Reaching over your head | 0.78 (ns) | 0.43 |
| Stooping, crouching, or kneeling | 0.87 (ns) | 0.69 (ns) |
| Doing errands alone | 0.43 | 0.41 |

# Odds Ratios for Those with Noncognitive Disabilities (P-values<0.05)

[>1: proxies indicate better health/fewer difficulties; ns = not significant]

| Variable | Parent odds ratios | Non-parent odds ratios |
|---|---|---|
| **Health Status Variables: In the past 4 weeks…** | | |
| General health was fair or worse | 1.40 | 0.67 |
| Physical health limited usual activities | 1.37 | 0.97 (ns) |
| Experienced at least moderate bodily pain | 1.81 | 1.09 (ns) |
| Had little or no energy | 1.34 | 0.77 (ns) |
| **ADL/IADL: Having difficulty with…** | | |
| Walking/climbing stairs (i29) | 1.37 | 0.83 (ns) |
| Lifting or carrying something heavy (i35) | 1.15 (ns) | 0.71 |
| Reaching over your head (i39) | 1.39 | 0.97 (ns) |
| Stooping, crouching, or kneeling (i43) | 1.28 | 0.90 (ns) |
| Getting around inside your home (i45) | 0.79 (ns) | 0.63 |
| Doing errands alone (i47) | 0.34 | 0.62 |

# Propensity score weighting

- **The nonparametric form of logistic regression is called "boosted logistic regression"**
- **The method puts a penalty on large coefficients**
- **We use a freeware software package developed at RAND called**
  - The Toolkit for Weighting and Analysis of Nonequivalent Groups (TWANG)
- **This package includes the capacity for incorporating sampling weights into the final weights**

# Propensity score weighting

- **There are multiple ways of measuring "distance" between treatment and comparison groups in the algorithm**
- **The algorithm minimizes the distance using these "stopping methods" subject to constraints**
- **We consider two:**
  - Minimize the maximum Kolmogorov-Smirnov statistic across confounders (KS-max)
  - Minimize the absolute standardized mean effect size across confounders (ES-mean)