



Center for Studying Disability Policy

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**

Exploring proxy response bias in the 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)**
- **About 28% of all interviews (1,126 out of 4,002) 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

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?**

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:**
 - Being male
 - Living in a group home setting
 - Never being married
 - Never having children
 - Disability onset before age 18
- **For those with only noncognitive disabilities, proxy use was also related to:**
 - Having mental illness
 - Not working
 - Being under 30 years old

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**
 - Domains include general health, physical functioning, role limitations due to physical health problems, bodily pain, vitality (energy/fatigue), social functioning, mental health, and role limitations due to emotional problems
- **Measures of activities of daily living (ADL), instrumental activities of daily living (IADL), and functional limitations assess difficulty with:**
 - Walking or climbing stairs
 - Carrying items as heavy as 10 pounds
 - Using hands and fingers to pick up pencil or grasping a pencil
 - Reaching over your head
 - Standing or being on feet for 1 hour
 - Stooping, crouching or kneeling
 - Getting around inside the home
 - Doing errands alone (such as going to doctor's office or shopping)

Matching treatment and comparison groups to minimize bias

- **Sample members with and without proxy responses differ on a lot of characteristics—people don't always “choose” whether to use a proxy**
- **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**
 - We reweighted the sample members' characteristics among those without proxies to match those with proxies (“propensity score weighting”)

Analysis plan

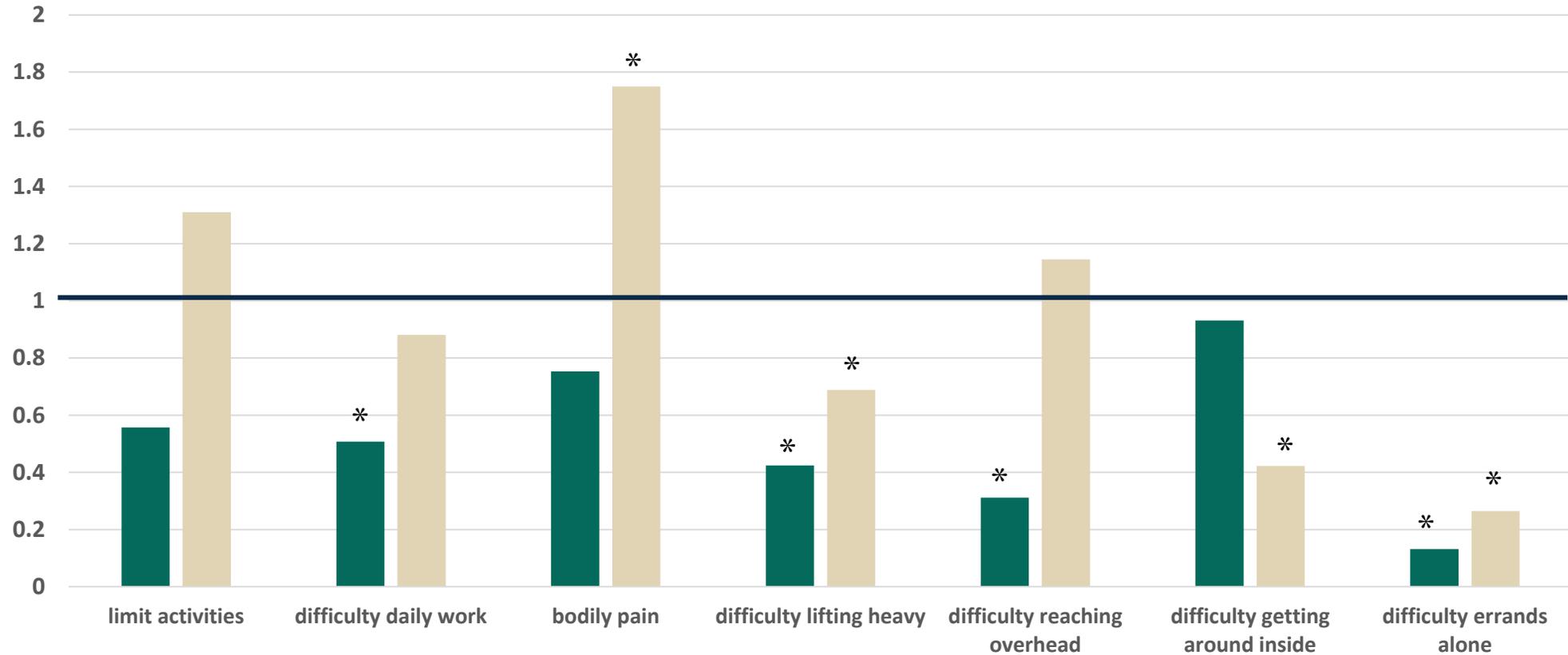
- **Estimate propensity score weights separately for each of the two disability group types**
- **Assess the effect of the “treatment” on the selected outcomes using propensity score weighted logistic regression**
 - Response variable corresponds to the outcome of interest
 - Include dummy variable for “treatment” (proxy)
 - Include propensity score weights that incorporate sampling weights
 - Include terms to account for sample design (clustering and stratification)
 - Include extra covariates corresponding to confounders that had the largest effect sizes after propensity score weighting

Findings

- **We obtained good covariate balance between the proxy respondents and self respondents with propensity score weights for both disability groups**
- **Proxies for those with cognitive and noncognitive disabilities generally indicated more health problems and functional limitations than self-respondents**
 - The strongest result was for the outcome “difficulties doing errands alone;” proxies were much more likely to indicate difficulty with this task than comparable self-respondents
- **There was one exception to this general finding...**
 - Proxies for those with noncognitive disabilities indicated less bodily pain than comparable self-respondents

Proxy vs. self-report odds ratios

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



* Statistically significant

■ cognitive ■ noncognitive

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 (with same propensity score weights), but instead of a single dummy for proxy cases, include dummy variables for types of proxies (new “treatment” variables)**
- **Assess the effect of the “treatments” on the selected outcomes**

Proxy relationships in the NBS data

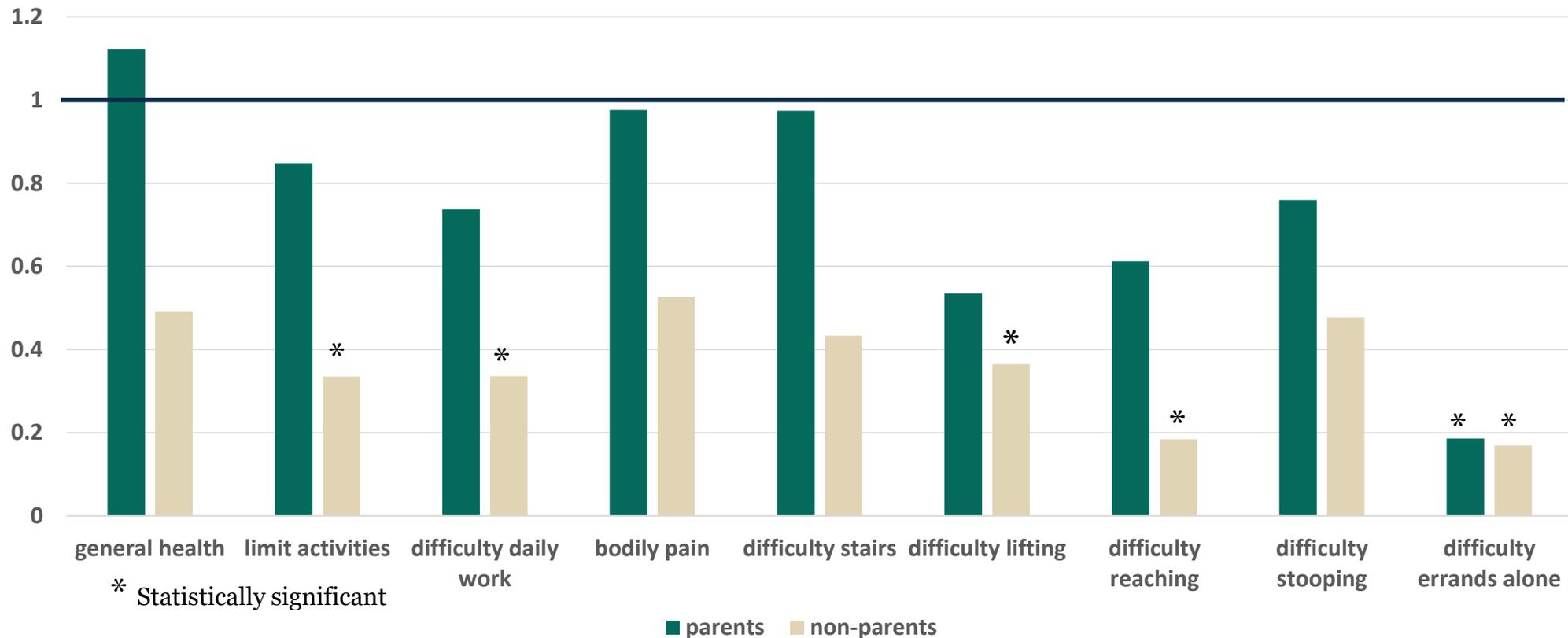
Proxy relationship	Number in NBS	Cognitive disabilities	Noncognitive disabilities
Total proxies	1,126 (28%)	532 (65%)	594 (19%)
Parent (mother or father)	661	325	336
Other proxies	465	207	258
Self-respondents	2,876 (72%)	288 (35%)	2,588 (81%)
Total	4,002	820	3,182

Findings

- **Non-parent proxies indicated more health problems and functional limitations than comparable self-respondents, regardless of disability type**
- **Parent proxies indicated fewer health problems and functional limitations than comparable self-respondents for noncognitive disability sample members only**
- **Regardless of relationship and disability type, all proxies reported sample members had more difficulty doing errands alone than comparable self-respondents**

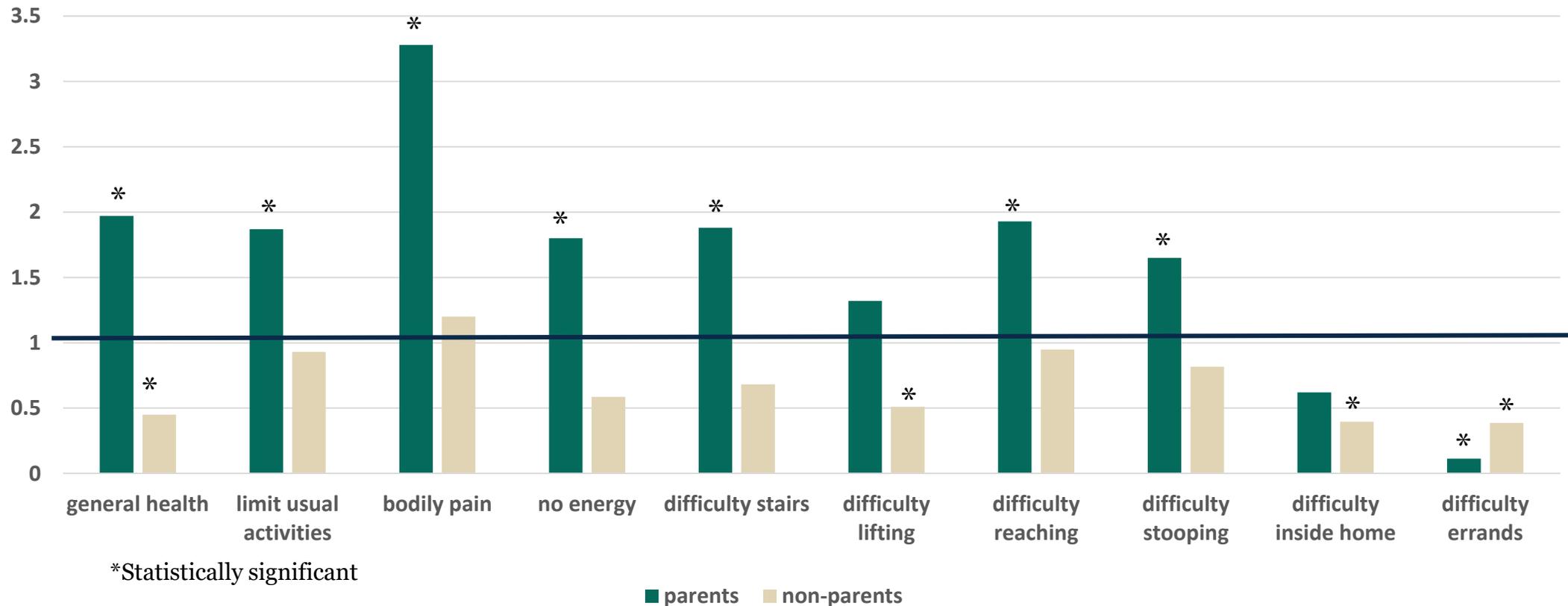
Proxy vs. self-report odds ratios among those with cognitive disabilities

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



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

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



Closing Remarks

Recap

- **Proxy responses were consistently more likely for sample members who were men, living in group homes, unmarried, and younger (particularly those under 30 years old)**
- **In general, where differences existed, proxies tended to report more health and functional limitations for people with cognitive and noncognitive disabilities than self-respondents with these disabilities**

Recap, cont.

- **However, when broken out by relationship type,**
 - Only non-parent proxies reported more functional limitations/poorer health than self-respondents for sample members in both of the two disability groups
 - In contrast, parent proxies reported fewer limitations/better health than self-respondents for sample members with noncognitive disabilities
- **For the outcome “difficulty doing errands alone,” all proxies reported more difficulty than self-respondents regardless of disability group or proxy relationship**

Limitations of research

- **This is not an 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 more health and functional limitations 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

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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)