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## Proxy-Responses in Research on COVID-19 Among People with Intellectual and Developmental Disabilities

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<b>Abstract:</b>	<p>Researchers and advocates have long called for improved research methods that better include people with intellectual and developmental disabilities (IDD), but challenges to doing so persist. Proxy responses are frequently used to circumvent some of these challenges, but may not fully capture the perspectives of people with IDD. The COVID-19 pandemic highlighted the possibility of consequences due to a lack of research about health outcomes for people with IDD, with documented disproportionate impact, but little understanding about specific experiences for people with IDD. Using exploratory graph analysis (EGA) we explored the use of proxy responses on the COVID-19 Supplement of the National Core Indicators In-Person Survey. Findings suggest significant differences in response patterns between people who answered independently, via proxy, and with a mix of response types beyond what would be expected due to demographic differences in participants.</p>

## Abstract

Researchers and advocates have long called for improved research methods that better include people with intellectual and developmental disabilities (IDD), but challenges to doing so persist. Proxy responses are frequently used to circumvent some of these challenges, but may not fully capture the perspectives of people with IDD. The COVID-19 pandemic highlighted the possibility of consequences due to a lack of research about health outcomes for people with IDD, with documented disproportionate impact, but little understanding about specific experiences for people with IDD. Using exploratory graph analysis (EGA) we explored the use of proxy responses on the COVID-19 Supplement of the National Core Indicators In-Person Survey. Findings suggest significant differences in response patterns between people who answered independently, via proxy, and with a mix of response types beyond what would be expected due to demographic differences in participants.

**Keywords:** Intellectual and developmental disabilities, proxy response, COVID-19

## **Proxy-Responses in Research on COVID-19 Among People with Intellectual and Developmental Disabilities**

Researchers and advocates in the field of intellectual and developmental disabilities (IDD) have long called for improved data and more inclusive research practices to improve outcomes for people with IDD (Doody, 2018; Krahn, 2019; Krahn et al., 2023; McDonald, 2016). Additionally, Doody (2018) argues that academic researchers cannot fully understand concepts like health and wellness without integrating the voices of people with IDD.

Additionally, excluding people with IDD from research perpetuates existing power imbalances that give people with IDD little control over their lives (McDonald, 2016).

Despite the established need for equitable and inclusive research, there are challenges to doing research with people with IDD. People with IDD are often viewed as a vulnerable population subject to increased protection and oversight from ethics boards (Doody, 2018; McDonald et al., 2016). Many of these policies arose in response to a history of harmful and unethical research performed on people with disabilities, but have often led to people with IDD being fully excluded from research (Doody, 2018; McDonald et al., 2016). Ethics committees and Institutional Review Boards (IRBs) are often unfamiliar with intellectual and developmental disabilities and may believe that all people with IDD are unable to provide consent (Doody, 2018). Additionally, McDonald and colleagues (2016) suggest that researchers may underestimate the interest people with IDD have in participating in research and so do not even consider the possibility of including them.

Beyond the ethical challenges of including people with IDD in research, there are practical difficulties to making research accessible. Compared to more traditional academic research, conducting research with people with IDD costs more, takes more time, and requires a

larger team of people, all of which can present a challenge for academic researchers (Walmsley et al., 2018). Creating accessible research materials is challenging, especially for people who do not communicate verbally (Scott and Havercamp, 2018).

Because of these difficulties, research with people with IDD frequently allows people who know the individual well, including family (Claes et al., 2012; Graves et al., 2016; Scott & Havercamp, 2018), friends (Graves et al., 2016), or staff (Claes et al., 2012; Koch et al., 2015; Scott & Havercamp, 2018; Tourneur et al., 2020), to respond to survey questions. However, literature suggests that proxy responses may not be valid substitutes for self-report, particularly for more subjective measures (Claes et al., 2012; Scott & Havercamp, 2018; Tourneur et al., 2020). For example, in their analysis of self- and proxy responses on measures of health, stress, and social support, Scott and Havercamp (2018) found that correlations between respondents were lower for subjective measures (ex. rating of overall health) compared with objective measures (ex. counts of physical activity). Similarly, in their study of the quantity and quality of family networks of people with IDD, Tourneur and colleagues (2020) found significant differences between self-reports and reports from staff-proxies.

In advocating for inclusive research methods, Hollomotz (2018) argued that for more subjective questions, proxy respondents may not be able to fully separate their own views, so that their answers may be more reflective of their own values and ideas. In support of this claim, Tournier and colleagues (2020) found that self- and proxy-perceptions of family networks differed more when the person with IDD had more externalizing behavior. The authors suggest that staff members' feelings towards the person with IDD may influence the ways that they answer questions on their behalf (Tournier et al., 2020). These concerns have been echoed by

people with IDD, who suggest that parents and support people may have different views and priorities than their own (Krahn et al., 2023).

### **People with IDD and COVID-19**

While the need for improved data about people with IDD predates the COVID-19 pandemic, the global health emergency has highlighted the implications of being excluded from research. The research that does exist suggests that people with intellectual and developmental disabilities (IDD) may have been at a heightened risk for poor outcomes from COVID-19, including high rates of hospitalization and death (Clarke et al., 2022; Gleason et al., 2021). In addition to the impacts of the COVID-19 virus itself, people with IDD faced major disruptions to their daily lives due to the public health response to slow the spread of the virus. Many people with IDD stopped working in the community (Carey et al., 2022; Fisher et al., 2022; Linehan et al., 2022), participated in fewer social activities and community events (Carey et al., 2022; Friedman, 2021), and had changes in their services and supports (Linehan et al., 2022; Rosencrans et al., 2022) compared to before the COVID-19 pandemic. Several studies also found that people with IDD had increased stress, anxiety, and depression since the pandemic began (Carey et al., 2022; Fisher et al., 2022; Hartley et al., 2022; Linehan et al., 2022; Rosencrans et al., 2021). Notably, most research on the experiences of people with IDD in the COVID-19 pandemic utilized proxy responses or secondary data analysis. While the COVID-19 pandemic resulted in additional challenges with conducting research, more work is needed to explore whether these methods accurately reflect the voices of people with IDD.

### **Network Analysis**

Exploratory Graph Analysis (EGA) is an emerging tool in the field of network psychometrics that can be used to estimate the dimensional structure of instruments or constructs

(Golino & Epskamp, 2017; Peralta et al., 2020). Golino and Epskamp (2017) suggested that EGA may be the preferred method of estimating dimensions compared to more widely used methods like exploratory factor analysis (EFA) or principal component analysis (PCA), especially when factors are highly correlated, the sample size is small, and each factor has a small number of indicators. EGA is based in network theory and so has less stringent assumptions than EFA. Furthermore, EGA uses a machine learning algorithm to estimate both the number and composition of dimensions (Kyriazos et al., 2021). Finally, EGA allows for multiple connections among variables, so that variables may be associated with more than one cluster (Golino & Epskamp, 2017).

EGA has been used in psychology research to model the relationships of symptoms of mental health conditions (Bos et al., 2018). Bos and colleagues (2018) suggest that focusing on the relationships of symptoms allows for a more nuanced understanding of mental health conditions than a more traditional measurement approach of using the sum-score of an individual's symptoms. Additionally, EGA allows researchers to identify highly influential symptoms that may be critical for understanding the etiology and treatment of a mental health condition (Bos et al., 2018; Robinaugh et al., 2016).

Outside of psychology, EGA has been used to understand a range of phenomena, including the impacts of COVID-19 (Kyriazos et al., 2021). EGA is a particularly useful tool for exploring people's experiences with the pandemic because of its ability to model complex connections between personal characteristics and global health trends (Kyriazos et al., 2021). Furthermore, given this paper's focus on examining how current COVID-19 research has captured the experiences of people with IDD, EGA allows analysis to be data-driven, without influence from prior assumptions (Kyriazos et al., 2021).

## Research Questions

This paper aims to investigate methodological and ethical implications of proxy responses in research with people with IDD with a particular focus on understanding the experiences of people with IDD during the COVID-19 pandemic and associated shutdowns.

Specifically, this paper will address the following questions:

- 1). What are the differences in demographic, disability, and systemic factors between people who respond independently, via proxy, or with a mix of response types?
- 2). Does the COVID-19 Supplement of the NCI-IDD support prior research about the experiences of people with IDD in the COVID-19 pandemic?
- 3). Does the dimensional network structure of COVID-19-related variables differ based on whether a participant responds independently, via proxy, or with a mix of both response types?

## Methods

### Ethical Oversight

This study was reviewed and approved by the institutional review board at the authors' affiliated university.

### Data

**National Core Indicators-Intellectual and Developmental Disabilities.** Data for this paper came from the 2020-2021 National Core Indicators-Intellectual and Developmental Disabilities (NCI-IDD). NCI-IDD is a collaborative effort between participating states, the National Association of State Directors of Developmental Disability Services (NASDDDS), and the Human Services Research Institute (HSRI) and participating state developmental disabilities service systems. NCI-IDD measures outcomes for people with IDD who use state funded services in a variety of domains, including self-determination, relationships and community

inclusion, health and wellness, and rights, choice, and decision making (NASDDDS & HSRI, n.d.). It is designed to track these outcomes over time and between states, as well as to establish national benchmarks for service quality (NASDDDS & HSRI, n.d.). To meet these aims, participating states must achieve a sufficient random sample of people who use state-funded IDD services to allow for comparisons between states with at least a 95% confidence level. For most states a sample of about 400 people meets this requirement, though some states choose to oversample for a variety of reasons.

Most years, the NCI-IDD consists of three sections. The background information section collects data from existing records such as state data systems, case management records and/or provider records. The Background Information section contains information about the participant's demographics, diagnoses, and support needs. Section I may only be answered directly by the participant and contains subjective questions about their quality of life and satisfaction with services. Finally, Section II asks more objective questions about the participant's rights, choice, and community participation which may be answered either by the participant or by someone who knows them well. Each item in this section is preceded by a question that asks who responded. Surveyors receive standardized training to identify when a proxy response is appropriate and to determine who may serve as a proxy.

In the 2020-2021 and 2021-2022 data collection cycles the NCI-IDD included a fourth section about the impact of COVID-19. The COVID-19 Supplement could be answered by either the participant or a proxy. Like Section II, items in the supplement are preceded by a question that asks who responded. The variables of interest in this analysis came from the 2020-2021 COVID-19 supplement and are presented in Table 1. Variables related to individual-level (demographics, diagnoses, etc.) and system-level (residential placement, guardianship, etc) came



from the background section of the 2020-2021 survey and were used to compare the composition of response groups.

### **Analyses**

Analyses were conducted using R (R Core Team, 2017). First, the response variables in the COVID-19 Supplement were used to classify each case as “independent”, “proxy,” or “mixed” response type, where independent indicates that a person responded to every question themselves, proxy indicates that another person answered every question on behalf of the respondent, and mixed indicates that a person answered some questions independently and a proxy answered some questions on their behalf. Chi-squared tests were then used to examine univariate differences in response frequencies and patterns between response types. Exploratory graph analysis (EGA) was then used to estimate a multivariate graphical model of the selected variables to visually represent the impacts of COVID-19 for each response category (Bos et al., 2018; Golino & Epskamp, 2017).

**Network Estimation using EGA.** The R package EGAnet (Golino & Christensen, 2020) was used to estimate network models and visually present the relationship between variables for each response category. EGA applies a Gaussian graphical model, estimated using the graphical least absolute shrinkage and selection operator (GLASSO). GLASSO is a regularization technique that sets small partial correlation coefficients to zero to avoid overfitting (when a statistical model fits the data so exactly that it cannot be used to generalize; Golino & Epskamp, 2017). This process establishes a baseline of connections, or ties, between related items.

Next, the walktrap algorithm identifies communities--clusters of closely connected variables--based on “random walks” or steps between variables in the network (Golino & Epskamp, 2017). Distance is computed as the number of “steps” between nodes. Communities

are groups of nodes with small distances between them and larger distances to nodes in other communities. Golino and Epskamp (2017) argue that these communities can be interpreted as similar to latent constructs in structural equation modeling (SEM). EGA then produces a visual representation of the network structure, in which each node represents a variable. Nodes are connected by edges, which represent partial Pearson's correlations between two variables, controlling for all other variables in the network.

In addition to a visual comparison of network structures, networks for each of the three categories were also compared using centrality estimation and network comparison tests, which are described in more detail below.

**Centrality Estimation.** Centrality is a measure of the amount of influence that each node exerts on the other variables in the network. Nodes that are more “central” to a network in turn exert more influence on other nodes. Based on the recommendations of previous researchers (Peralta et al., 2020; Robinaugh et al., 2016), this paper uses expected influence (EI) as the main centrality measure. EI is the sum of a node's connections (edges) in a network and accounts for the impact of negative edge weights (Robinaugh et al., 2016). In other words, the most connected nodes in a network have the highest EI. The qgraph package (Epskamp et al., 2012) was used to calculate the EI for each node.

**Network Comparison.** The Network Comparison Test (NCT) package was used to compare networks (van Borkulo et al., 2017). The NCT is a permutation-based test which repeatedly measures network connectivity on randomly re-grouped participants. The NCT assesses differences in global strength (the overall connectivity of a network) and network structure (a measure of the distribution of edge weights in a network). Statistically significant differences in tests suggest that differences between networks are meaningful and are unlikely to

occur due to chance alone. Stated a different way, the NCT allows us to say with confidence that there are differences in response patterns and in connections between variables based on group membership

## Results

### Response Categories

Sample characteristics are presented for the full sample and by response category in Table 2. Data came from respondents in 26 states, for a total sample of 19,991. Of this, 235 cases were missing a designation for respondent for at least one variable, leaving a sample of 19,756 for the remaining analysis. Respondents were most likely to answer via proxy (40.87%), followed by independently (33.25%) and with a mix of respondents (25.38%). Respondents were mostly male (59.0%) and White (60.6%). Smaller percentages of respondents identified as Black (14.3%) and Latinx (16.8%). Eight participants identified as a gender identity other than male or female. Most respondents had a mild (34.00%) or moderate (24.71%) intellectual disability, communicated verbally (73.12%), and were their own legal guardian (58.26%).

### Bivariate Analysis

Significant differences between the response categories in demographic, disability, and system characteristics are presented in Table 2. People who were younger ( $F(1) = 65.94, p < .001$ ), Black ( $X^2(2) = 16.63, p < .001$ ), and who had a mild intellectual disability ( $X^2(8) = 4293.09, p < .001$ ) were more likely to answer the survey independently. People who were older ( $F(1) = 65.94, p < .001$ ), Latino ( $X^2(2) = 34.84, p < .001$ ), and who had a severe or profound intellectual disability ( $X^2(8) = 4293.09, p < .001$ ) were more likely to participate via proxy response. Unsurprisingly, people who answered via proxy were more likely to communicate nonverbally ( $X^2(2) = 4169.49, p < .001$ ), and to have a legal guardian ( $X^2(2) = 887.66, p < .001$ ).

Differences in the variables related to COVID-19 are highlighted in Table 3. With the exception of stopping going to school and having time when help was not available, all of the variables related to COVID-19 differed significantly between participants who answered independently, via proxy, or with a mix of response types. Important differences were seen in participants reporting stopping paid work in the community: 20.34% of people who responded independently reported this change, compared to 4.51% of people who responded via proxy, and 16.83% of people who answered using a mix of response types ( $X^2(2) = 805.82, p < .001$ ). People who answered independently and with a mix of response types were also more likely than people who answered via proxy that they felt more worried, scared, or anxious since the start of the COVID-19 pandemic ( $X^2(2) = 484.44, p < .001$ ). Proxy respondents were significantly more likely to report needing reminders to wash hands ( $X^2(2) = 3364.81, p < .001$ ), wear a mask ( $X^2(2) = 3033.65, p < .001$ ), and social distance ( $X^2(2) = 2988.56$ ) compared to people who answered independently, with those who used a mix of response types falling in between.

### **Network Structure**

Models for the self-response, proxy-response, and mixed-response categories are presented in Figures 1, 2, and 3 respectively.

Five communities emerged for the proxy- and mixed-response samples, compared to seven communities for the self-report sample. While the specific clusters varied, some similarities were seen across models. Three variables related to changes in one's housing, changes in daily supports, and needing additional help clustered together in all three networks. Feeling increased anxiety clustered with these variables for participants who answered the survey independently. The three variables related to health reminders (reminders to mask, wash hands, and social distance) also clustered together in all three networks. Variables related to changes in

social connections and community participation clustered together in all groups, though the exact combination of variables differed somewhat between groups. Similarly, the importance of a technology as a means to facilitate connection during COVID-19 emerged as a cluster for all groups, though the exact clusters varied.

Other variables behaved differently across groups. For example, changes to one's day program and job clustered together for the full sample and mixed-response group, but formed separate clusters in the group that answered the survey independently or via proxy.

### **Centrality Estimation**

EI centrality estimates differed between variables, but were fairly consistent across groups. Table 4 presents the EI for each node across the three networks. A similar pattern of EI was observed across networks. While the order differed, variables related to health reminders (washing hands, wearing a mask, and social distancing) and participating in the community less were the most influential in networks for all three response types. Notably, stopping one's job was only highly influential in the proxy-response category.

### **Network Comparison**

The mixed-response group differed from both the self-response and proxy-response groups in network strength ( $p < .05$ ). All three groups varied significantly in network structure ( $p < .05$ ), though the difference between the proxy- and mixed-response groups had borderline significance ( $p = .055$ ). These findings suggest that group membership significantly impacted the network of variables related to COVID-19.

## **Discussion**

The findings from this study support prior literature that the COVID-19 pandemic had a substantial impact on the lives of people with IDD as well as research that suggests differences in

self- and proxy-responses to surveys. Taken together, these findings can be used to inform policy, practice, and research moving forward in regards to support for people with IDD as the United States emerges from the COVID-19 pandemic, preparedness for future public health emergencies, and equitable research practices.

This study identifies several important areas of impact for people with IDD regardless of the way they responded to the survey. The networks for all response categories had clusters of variables related to social relationships and community participation, which also supports previous research on the impact of COVID-19 (Carey et al., 2022; Fisher et al., 2022). These variables were also highly influential in all four networks—a finding which, as described previously, can be used to understand a phenomenon and intervene to improve outcomes (Bos et al., 2018). While the experience of going into the community less during the COVID-19 pandemic is not unique to people with IDD, studies of social isolation and a lack of community belonging for people with IDD long predate the pandemic, making it an important area of consideration moving forward (Carey et al., 2021; Fisher et al., 2022; Friedman, 2021).

The need for additional support to stay healthy (reminders to wash one's hands, wear a mask, and practice social distancing) were highly influential across response types. Given the ongoing shortage of DSPs (Friedman, 2021), particularly during the COVID-19 pandemic, this finding is particularly noteworthy. This finding also supports calls for accessible information about COVID-19 for people with IDD, who may need additional support in understanding and following public health restrictions (AUTHORS et al, 2023).

Using technology to connect with friends and family, case managers, and medical providers, emerged as a pattern in all four networks, though the exact relationships and variables differed. Associations were generally small, but positive: people who had a smartphone, tablet,

or computer and who had reliable internet were more likely to talk to family and friends and their case manager as often as they wanted and were more likely to have used video conferencing to talk to a healthcare provider. For the proxy- and self-response networks, feeling more anxious, sad, scared or worried since the start of COVID-19 clustered with variables related to technology; people who had reliable internet were less likely to report these feelings.

The importance of connecting virtually in this study echoes previous suggestions that the quality of social interactions matters more than the number of activities (Spassiani et al., 2022). Moving activities online may have made community spaces more accessible for some people with disabilities (Shew, 2020). In this study, the majority of people reported that their internet worked well (82.27%) and that they had a smartphone, tablet, or other device that they could use to communicate with people who did not live with them. Families, support workers, and case managers should consider, however, that people with IDD may need support and instruction to learn how to use these devices (Spassiani et al., 2022).

### **Differences Between Response Types**

Within the broad themes, important differences in the networks suggest ways in which people with IDD who responded to the NCI-IDD independently, via proxy, or with a mix of response types may have experienced the COVID-19 pandemic differently, with implications for interventions and for future research. The differences observed through visually examining the network structures for people who responded to the COVID-19 Supplement independently, via proxy, or with a mix of responses were also reflected in the statistical comparison networks.

Results from the NCT support the claim that network structures differ significantly based on response type beyond what would be expected from chance alone. This finding is particularly important given the variation in personal characteristics between response categories. People

who answered the survey via proxy- or mixed-response were more likely than people who answered independently to have more significant levels of intellectual disability, to communicate using methods other than speech, and to have a legal guardian. However, these characteristics alone cannot explain the differences in networks between people who answered independently, via proxy, or with a mix of responses. That is, while the differences in demographic and disability characteristics between groups offer important insights into how people with IDD respond to survey questions and may inform strategies for making survey research more accessible, the NCT suggests that these factors cannot fully account for the variation in network structure between response types.

For example, the end of paid community employment was only highly influential in the proxy-response group. While more research is needed to understand this difference, it is possible that proxy respondents overestimated the importance of paid work and that other ways of interacting with the community may be equally or more valuable to people with IDD. For example, Lysaght and colleagues (2016) found that social connection was a primary motivator of employment for people with IDD. Feeling included may matter more than the work itself, as evidenced by the importance of community participation in all response categories (Lysaght et al., 2016). Understanding what makes work meaningful may be important in supporting people with IDD to re-engage with the community, including paid employment, post-pandemic.

### **Implications for Research**

While similar clusters emerged in each of the four networks, differences in network strength and structure suggest that there are differences between self-, proxy-, and mixed-responses to the NCI-IDD COVID-19 supplement. This finding supports previous researchers



who reported limitations to the validity of proxy responses in research with people with IDD (Claes et al., 2012; Graves, 2012; Scott & Havercamp, 2018).

While there are ethical and practical considerations for including people with IDD in research, promoting equity requires researchers to confront these challenges (Doody, 2018; McDonald et al., 2016). Doing so may improve the validity of research findings by ensuring that the voices and experiences of people with IDD are centered, which may in turn allow for more effective interventions (McDonald et al., 2016). At a higher level of impact, including people with IDD in research can challenge negative assumptions about people with IDD and promote inclusion in other life domains as well (McDonald et al., 2016).

Our findings support those from Claes and colleagues (2012), who argue that proxy responses provide comparable data to self-reports, but that the two sources of data are not interchangeable. While similar clusters of impact emerged for all four response categories in our study, both visual and statistical examination reveal differences in network structure between people who responded independently, via proxy, or with a mix of response types. To account for these differences, Claes and colleagues (2012) recommend that proxy and self-report data should be analyzed and reported separately.

Prior literature is also clear that proxy responses should be limited to objectively observable questions (Claes et al., 2012; Scott & Havercamp, 2018). Many of the variables on the NCI-IDD meet this recommendation—they are about whether or not the participant experienced certain changes during the pandemic. Other questions, however, are far more subjective (reference table of variables). For example, participants were asked if they felt more worried, anxious, or scared since the start of the pandemic and if they were able to talk with friends and family members who didn't live with them “as much as you wanted”.

Supporting previous research, the impact of some subjective variables seems to differ across networks. Instances where needed help was not available was associated with change in residence or in-home supports for the proxy-response sample, but with the community participation cluster in the self-response sample. Similarly, talking with friends and family clustered with community participation in the proxy-response and full sample, but with variables related to technology in the mixed-response sample and in a cluster of participating in the community and seeing family and friends in the self-response sample. However, feeling more worried clustered with community participation variables across response categories.

Additional research should consider the impact of different types of proxy respondents. For purposes of this paper, all proxy responses were grouped into a single category. It is possible, however, that differences exist based on the relationship the respondent had with the person with IDD. For example, while Claes and colleagues (2012) found that no proxy-response perfectly matched self-reported data, responses from family members aligned more closely with self-responses than responses from staff. The NCI-IDD and COVID-19 supplement identifies respondents as friend/family, staff, or other. Future studies may wish to further specify the “proxy” and “mixed” categories to explore these differences.

### **Limitations**

As with any study, this paper has several limitations. First, it must be noted that the term “IDD” refers to a broad range of conditions and describes a heterogeneous population of people with diverse experiences, diagnoses, and support needs (Schalock et al., 2019). Furthermore, the data represents a sample of disability service users from across the United States, another extremely heterogeneous group. Disability service systems differed widely between states, even before COVID-19, as did states’ responses to the pandemic. Future research should further

examine the connections between state-level differences, types of responses to the NCI-IDD, and outcomes related to COVID-19.

There are also limitations with the data used in this analysis. Firstly, rates of missingness were high for the COVID-19 supplement. Any variable that had higher than 20% missing was excluded from the analysis, and rates of missing for the included variables ranged from .24% to 7.80%. This missingness may have been due in part to the nature of the NCI-IDD survey. Previous research on survey administration suggests that survey breakoff (ending the survey early) can be influenced by the length of the survey, with breakoff commonly occurring at the introduction of new survey sections (Hsia et al., 2023; Peytchev, 2009). The COVID-19 supplement was the last section of a long interview and participants may have declined to answer. Future research on the use of proxy responses should also examine whether the factors that predict survey breakoff may also predict whether participants answer independently or designate someone to respond on their behalf.

### **Conclusion**

This paper supports prior research that suggests that people with IDD faced significant disruptions to their everyday lives due to the COVID-19 pandemic. Additionally, this paper supports literature that argues that proxy-responses may differ from self-report, especially for more subjective questions. While challenging, finding ways to include people with IDD in research can improve the validity of findings and outcomes while simultaneously promoting inclusion and challenging injustice.

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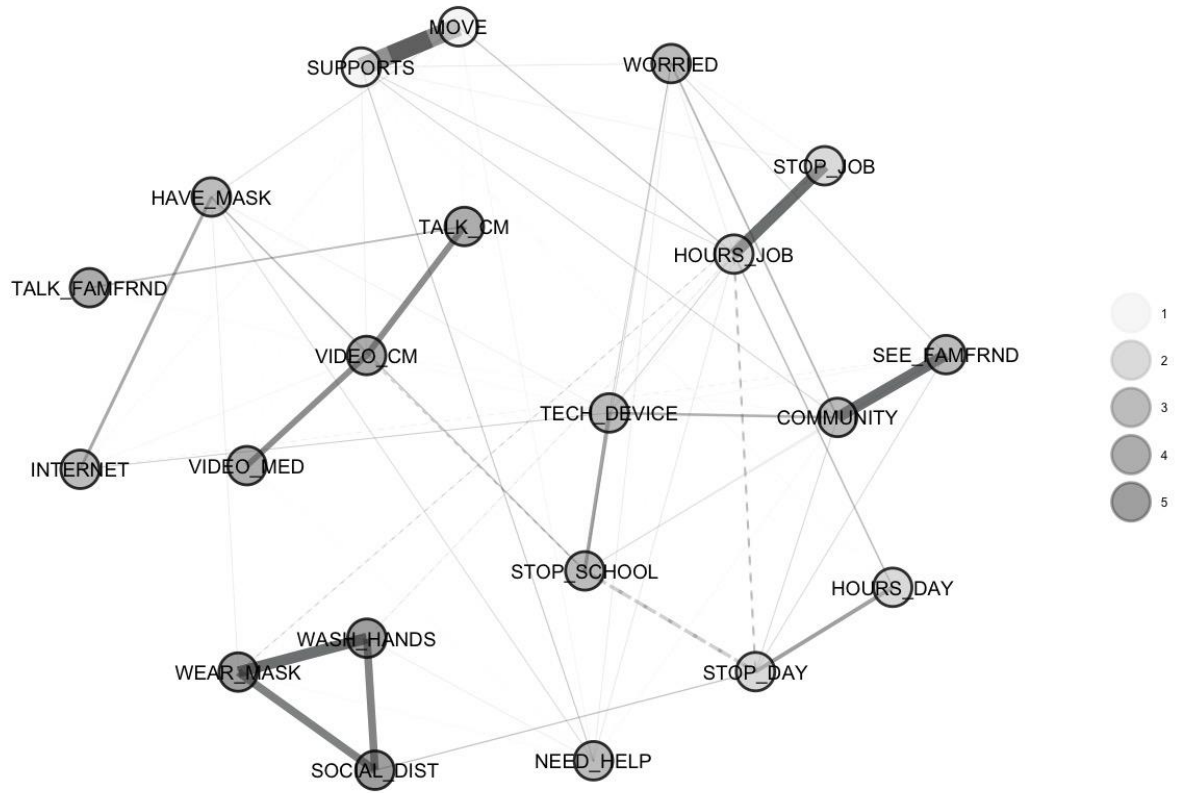
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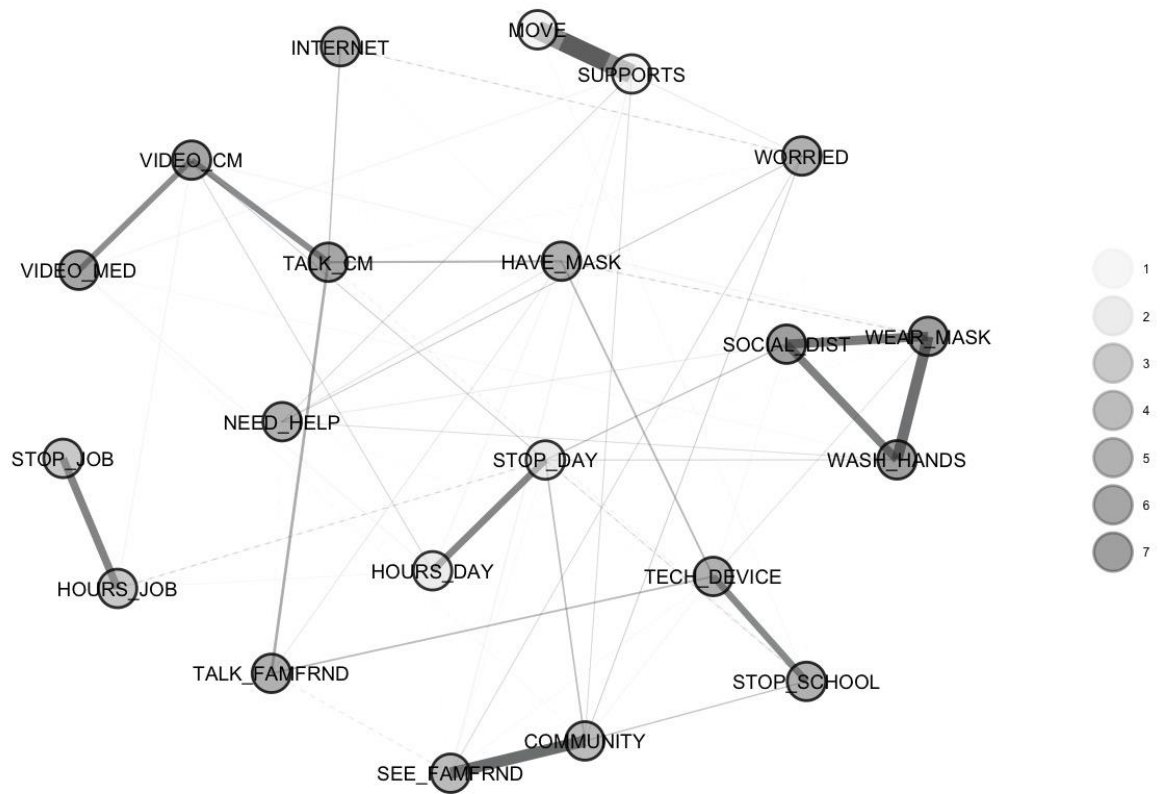
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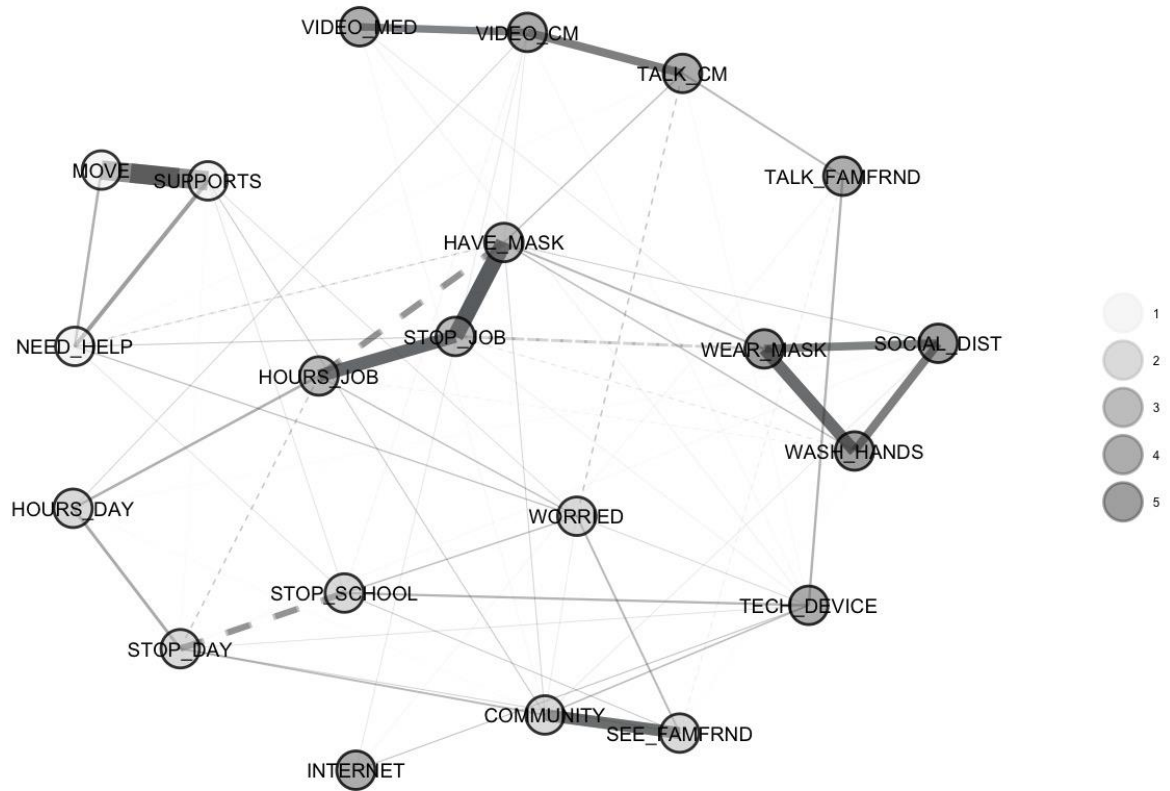
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Figure 3. Mixed-Response Network



**Figure 1.** Self-Response Network

**Figure 2.** Proxy-Response Network

**Table 1.** Included Variables

<b>Abbreviation</b>	<b>COVID-19 Supplement Question</b>
MOVE	Did you/this person move, or change where you live?
SUPPORTS	(If you did not move) were there changes in your/this person's in-home supports?
STOP_DAY	Did you/this person stop going in-person to day program, workshop, or other unpaid day/community activity?
HOURS_DAY	Did you/this person go fewer hours to day program, workshop, or other unpaid day/community activity?
STOP_JOB	Did you/this person stop working at a paid job in the community?
HOURS_JOB	Did you/this person work fewer hours at a paid job in the community?
SEE_FAMFRND	Did you/this person see friends and family who don't live with you less often or stop seeing them in person?
COMMUNITY	Did you/this person go into the community (stores, restaurants, theaters, etc.) less often or stop going?
STOP_SCHOOL	Did you/this person stop going to school in-person?
WORRIED	Since COVID time started, have you been more worried, scared, anxious or sad than before?
TECH_DEVICE	Is there a computer, tablet, or smartphone that you can use in your home?
INTERNET	How does your internet work at home?
TALK_FAMFRND	Since COVID time started, have you talked to your friends and family as much as you want?
TALK_CM	Since COVID time started, have you talked to your case manager/service coordinator enough?
VIDEO_CM	Have you ever talked to your case manager/service coordinator using video conference or telehealth like Skype, Zoom or FaceTime?
VIDEO_MED	Have you ever talked to any health professionals using video conference/telehealth like Skype, Zoom, or FaceTime?
WASH_HANDS	Do you need more help or reminders to wash your hands regularly during the day?
WEAR_MASK	Do you need more help or reminders to wear a mask when you go outside or to places where other people are?
HAVE_MASK	Is there always a clean mask for you to use when you want or need one?
SOCIAL_DIST	Do you need more help or reminders to stay far enough away from people when you're out in the community so germs don't spread?
STAFF_PPE	Since COVID time started, have your staff used personal protective equipment (PPE)?
NEED_HELP	Since COVID time started, have there been times when you didn't have the help you needed?



Table 2. Personal Characteristics by Response Category

	Self (N = 6000)	Proxy (N = 7267)	Mix (N = 4513)	Total (N = 17780)	df	F or X2
Age (54)	39.18 (14.12)	41.89 (16.34)	42.17 (15.87)	41.05 (15.58)	1	65.94***
Gender (65)					2	10.27**
Female	2529 (42.29%)	2873 (39.70%)	1880 (41.80%)	7282 (41.11%)		
Male	3451 (57.71%)	4364 (60.30%)	2618 (58.20%)	10433 (58.89%)		
Race						
Black	886 (15.22%)	959 (13.78%)	540 (12.41%)	2385 (13.92%)	2	16.63***
Latino	1019 (17.51%)	1382 (19.86%)	677 (15.56%)	3078 (17.97%)	2	34.84***
White	3496 (60.07%)	3870 (55.61%)	2757 (63.36%)	10123 (59.10%)	2	70.03***
Other	127 (2.16%)	150 (2.13%)	84 (1.91%)	361 (2.08%)	2	.85
Type of home (236)					14	1880.99***
ICF/Nursing home	125 (2.10%)	665 (9.29%)	165 (3.72%)	955 (5.44%)		
Group 2-3	482 (8.11%)	552 (7.71%)	285 (6.42%)	1319 (7.52%)		
Group 4-6	817 (13.75%)	1703 (23.78%)	907 (20.43%)	3427 (19.53%)		
Group 7-15	145 (2.44%)	179 (2.50%)	128 (2.88%)	452 (2.58%)		
Independent	1701 (28.63%)	338 (4.72%)	533 (12.00%)	2572 (14.66%)		
Family	2343 (39.43%)	3272 (45.69%)	2074 (46.71%)	7689 (43.83%)		
Host	300 (5.05%)	426 (5.95%)	326 (7.34%)	1052 (6.00%)		
Other	29 (0.49%)	27 (0.38%)	22 (0.50%)	78 (0.44%)		
Level of ID (3079)					8	4293.09 ***
Mild	3108 (70.81%)	1186 (18.35%)	1826 (47.43%)	6120 (41.63%)		
Moderate	926 (21.10%)	1970 (30.49%)	1356 (35.22%)	4252 (28.92%)		
Severe	73 (1.66%)	1614 (24.98%)	278 (7.22%)	1965 (13.37%)		
Profound	12 (0.27%)	1096 (16.96%)	81 (2.10%)	1189 (8.09%)		
Autism (366)					2	161.16***



Table 3. COVID-19 Impact by Response Category

	Self (N = 6000)	Proxy (N = 7267)	Mix (N = 4513)	Total (N = 17780)	df	X2
MOVE (42)	401 (6.70%)	299 (4.13%)	254 (5.64%)	954 (5.38%)	2	43.34***
SUPPORTS (42)	585 (9.77%)	998 (13.78%)	600 (13.32%)	2183 (12.31%)	2	54.36***
STOP_DAY (42)	2505 (41.83%)	4583 (63.26%)	2755 (61.15%)	9843 (55.49%)	2	687.65***
HOURS_DAY (42)	979 (16.35%)	1410 (19.46%)	966 (21.44%)	3355 (18.91%)	2	45.88***
STOP_JOB (42)	1218 (20.34%)	327 (4.51%)	758 (16.83%)	2303 (12.98%)	2	805.82***
HOURS_JOB (42)	507 (8.47%)	108 (1.49%)	238 (5.28%)	853 (4.81%)	2	351.52***
SEE_FAMFRND (42)	3947 (65.92%)	4586 (63.30%)	3187 (70.74%)	11720 (66.07%)	2	68.78***
COMMUNITY (42)	4894 (81.73%)	6277 (86.64%)	3877 (86.06%)	15048 (84.83%)	2	68.45***
STOP_SCHOOL (42)	561 (9.37%)	623 (8.60%)	371 (8.24%)	1555 (8.77%)	2	4.56
WORRIED (698)	2681 (45.88%)	1952 (28.27%)	1881 (43.41%)	6514 (38.13%)	2	484.44***
TECH_DEVICE (226)	5423 (91.20%)	6078 (85.04%)	3946 (88.46%)	15447 (88%)	2	117.85***
INTERNET (1385)	4320 (79.21%)	5747 (84.70%)	3421 (82.31%)	13488 (82.27%)	2	62.56***
TALK_FAMFRND (1285)	4195 (72.13)	5747 (84.70%)	3421 (82.31%)	13488 (82.27%)	2	246.48***
TALK_CM (773)	4310 (74.93%)	5990 (86.19%)	3393 (78.82%)	13693 (80.51%)	2	264.78***
VIDEO_CM (506)	2955 (50.55%)	4125 (58.62%)	2539 (57.82%)	9619 (55.68%)	2	95.21***
VIDEO_MED (400)	2550 (43.40%)	3894 (55.02%)	2176 (49.15%)	8620 (49.60%)	2	174.07***
WASH_HANDS (257)	1167 (19.73%)	5046 (70.58%)	2035 (45.64%)	8248 (47.07%)	2	3364.81***
WEAR_MASK (319)	1209 (20.41%)	4853 (68.43%)	1858 (41.80%)	7920 (45.36%)	2	3033.65***
SOCIAL_DIST (349)	1278 (21.63%)	4940 (69.75%)	2153 (48.49%)	8371 (48.02%)	2	2988.56***
HAVE_MASK (272)	5748 (97.14%)	7053 (98.86%)	4383 (98.34%)	17184 (98.15%)	2	53.92***
NEED_HELP (465)	430 (7.42%)	480 (6.70%)	338 (7.75%)	1248 (7.21%)	2	5.05

\* p < .05 \*\* p < .005 \*\*\*p < .001

<b>Variable</b>	<b>Proxy-Response</b>	<b>Self-Response</b>	<b>Mixed-Response</b>
WASH_HANDS	1.28	1.57	1.29
COMMUNITY	1.27	1.20	1.27
WEAR_MASK	1.12	1.19	1.26
STOP_JOB	.36	-.001	.36
SOCIAL_DIST	1.05	1.28	1.12
VIDEO_CM	1.04	.93	1.04
SEE_FAMFRND	.69	.55	.69
HOURS_JOB	.89	-.12	.89
TECH_DEVICE	.40	.25	.40
TALK_CM	-.28	.43	-.28
HAVE_MASK	-.37	-.73	-.02
VIDEO_MED	-.03	.08	-.19
HOURS_DAY	-.18	.20	-.18
WORRIED	-.26	-.68	-.05
NEED_HELP	-.41	-.72	-.31
TALK_FAMFRND	-.61	-.45	-.75
INTERNET	-.87	-.98	-.46
STOP_DAY	-1.13	.22	-.82
STOP_SCHOOL	-1.13	-.03	-.81
SUPPORTS	-1.44	-1.76	-1.57
MOVE	-2.32	-2.40	-2.51