Inclusion

The Impact of State COVID-19 Responses on People with Intellectual and Developmental Disabilities

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Abstract:	Evidence suggests that the public health response to the COVID-19 pandemic exacerbated existing inequities, including for people with intellectual and developmental disabilities (IDD). While people with IDD may have been at a higher risk for poor outcomes from COVID-19 than people without disabilities, they were rarely prioritized in the public health response. Using multilevel modeling, we explored the impact of individual-level differences in combination with state-level policies on the likelihood of contracting COVID-19. Findings suggest that the ways people with IDD interact with their community, including where they live, impacted their risk during the COVID-19 pandemic, supporting calls to more actively consider people with IDD in future public health emergencies.

Abstract

Evidence suggests that the public health response to the COVID-19 pandemic exacerbated existing inequities, including for people with intellectual and developmental disabilities (IDD). While people with IDD may have been at a higher risk for poor outcomes from COVID-19 than people without disabilities, they were rarely prioritized in the public health response. Using multilevel modeling, we explored the impact of individual-level differences in combination with state-level policies on the likelihood of contracting COVID-19. Findings suggest that the ways people with IDD interact with their community, including where they live, impacted their risk during the COVID-19 pandemic, supporting calls to more actively consider people with IDD in future public health emergencies.

The Impact of State COVID-19 Responses on People with Intellectual and Developmental Disabilities

In the United States, the COVID-19 pandemic and resulting public health response has exposed longstanding inadequacies in the healthcare and emergency response systems (Gusmano et al., 2020). Like other disasters, the impact of the pandemic has not been felt equally, but rather disproportionately by disadvantaged people from historically marginalized backgrounds, including people with intellectual and developmental disabilities (IDD; Gusmano et al., 2020).

People with Intellectual and Developmental Disabilities and COVID-19

Multiple studies have reported that people with IDD were more likely than the general population to be hospitalized or die from COVID-19 (Gleason et al., 2021; Lunsky et al., 2022). Less is known about whether people with IDD are at increased risk of becoming infected with COVID-19 to begin with, with some studies reporting a higher prevalence (Lunksy et al., 2022; Schott et al., 2022) and other studies reporting lower rates of infection compared to people without disabilities (Landes et al., 2021).

Differences in infection may be partly related to how people with IDD live in the community. For instance, in New York state, the incidence proportion of COVID-19, case fatality rates, and mortality rates for people living in state-run residential centers were significantly higher than for people without disabilities living in the community (Landes et al., 2020). Additionally, while Landes et al. (2021) found lower overall rates of COVID-19 diagnosis among service users with IDD compared to people without disabilities, case rates were highest in congregate settings with more residents.

High rates of chronic health conditions (Gleason et al., 2021; Lunsky et al., 2022; Schott et al., 2022) among people with IDD is also a complicated factor in relation to the risk of COVID-19 infection. Some studies suggest that mental health conditions (Schott et al., 2022;

Wang et al., 2021), some chronic health conditions (Rozenfeld et al., 2020), and specific disabilities (Altable & de la Serna, 2020; Schott et al., 2022) may increase a person's likelihood of contracting COVID-19. In contrast, other health conditions associated with severe outcomes from COVID-19 have been associated with a lower likelihood of infection, possibly due to an increase in health risk reduction behavior (Rozenfeld et al., 2020).

Federal and State COVID-19 Response

In the United States, the official response to the COVID-19 pandemic varied widely between states (Bergquist et al., 2020; Gusmano et al., 2020; Holtz et al., 2020; Xu & Basu, 2020). While some variation in responses is necessary to account for state-level differences, the lack of a coordinated national response limited the effectiveness of local interventions and contributed to the politicization of public health decisions (Gusmano et al., 2020; Holtz et al., 2020; Xu & Basu, 2020). For example, Holtz and colleagues (2020) found that county-level stay-at-home mandates were most effective at decreasing mobility when surrounding counties issued similar guidelines and least effective when surrounding localities did not have policies in place, suggesting the importance of federal oversight and coordination.

The US response to the COVID-19 pandemic was also limited by inadequate testing and reporting, in part due to unclear federal policies (Bergquist et al., 2020; Xu & Basu, 2020). Disease surveillance and control depend on large-scale testing, with established containment measures for high case rates and exit measures when cases drop (Bergquist et al., 2020; Xu & Basu, 2020). As with stay-at-home policies, decisions about testing and reporting strategies were left to individual states, without federal coordination or adequate funding (Bergquist et al., 2020; Xu & Basu, 2020).

Challenges with coordination and data were exacerbated for people with disabilities. Guidance on reporting cases among residents and staff in nursing homes and other long term care facilities was not issued until April of 2020, well after the virus was present in the United States (Bergquist et al., 2020). Many people with disabilities, including IDD, had difficulties accessing community testing events due to a lack of accessible information, challenges with transportation, especially at drive-through events, and difficulty tolerating the nasal swabs needed for a COVID-19 test (Taggart et al., 2022). For people with disabilities who were able to access COVID-19 tests, community events rarely included disability identifiers to track case rates and outcomes compared to people without disabilities, or to understand the impact of COVID-19 on people with specific conditions (Bergquist et al., 2020; Boyle et al., 2020). Later, the lack of disability identifiers in testing data limited the ability to link other system-level data, including mortality data, to understand the impact of COVID-19 on people with disabilities (Bergquist et al., 2020).

Beyond the limitations from poor quality data, pervasive ableism in the healthcare system further impacted the degree to which the public health response to COVID-19 protected people with disabilities, including IDD (Landes et al., 2020; Ne'eman et al., 2021). Despite high rates of people with IDD living in group homes and congregate settings and evidence that these settings placed people at increased risk from COVID-19 (Shapiro, 2020) official guidance was not issued for nursing homes until April 2020 (Bergquist et al., 2020) or for group homes until May 2020 (Landes et al., 2020).

Research Questions

This study aims to better understand the impact of COVID-19 and of varying state responses to the pandemic on people with IDD using publicly available public health data and a representative sample of state-funded service users with IDD. Specifically, the paper seeks to answer the following questions:

1). To what extent did states explicitly protect people with IDD in their COVID-19 response, including emergency response and treatment rationing plans?

2). How did differences in state responses to the pandemic impact reported COVID-19 diagnosis for people with IDD?

Methods

Ethical Oversight

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

Data

NCI-IDD IPS

The National Core Indicators – Intellectual and Developmental Disabilities (NCI-IDD) is a collaboration between the National Association of State Directors of Developmental Disability Services (NASDDDS), the Human Services Research Institute (HSRI), and participating states to measure a variety of outcomes for people with IDD who use state funded service (NASDDDS & HSRI, n.d.). The project is intended to track these performance and outcome measures over time, make comparisons between states, and establish national benchmarks for tracking service quality (NASDDDS & HSRI, n.d.).

The NCI-IDD In-Person Survey (NCI-IDD IPS) is a direct conversation between a trained interviewer and an adult who uses at least one service from the state developmental disabilities service system in addition to case management, which may be held in person or via videoconferencing. Participants are randomly selected from each state's population of IDD service users. Participating states must achieve a sufficient sample to allow for comparisons between states with at least a 95% confidence level and 5% margin of error. Generally, a sample of 400 people meets this threshold, though many states oversample for a variety of reasons. States with smaller service populations need fewer surveys to meet the 95% confidence level and 5% margin of error threshold.

The NCI-IDD IPS consists of three sections. The background section contains information regarding the participant's disability diagnosis, health conditions, service usage, and support needs. This section is completed by a case manager or other knowledgeable person prior to the interview, using data from sources such as service records, billing records, provider records and/or case management records. Section I of the survey is a series of subjective questions including questions addressing a participant's quality of life and satisfaction with services which can only be answered directly by the participant. Finally, Section II consists of objective questions about the participant's rights, choice-making, and community participation. Section II may be completed by the participant or by someone who knows them well.

Data for this paper came from the national 2020-2021 NCI-IDD IPS survey, which was administered from July 2020 through June 2021. All variables for this paper came from the background section of the NCI-IDD IPS and were selected for their potential relationship with a person's susceptibility to COVID-19 exposure and infection. The outcome of interest for this analysis was COVID-19 diagnosis. Specifically, this item asked whether the participant had ever been "diagnosed or presumed diagnosed with COVID-19," defined as having received a positive test result for COVID-19, been told by a physician that they had COVID-19, or shown signs and symptoms consistent with COVID-19. Only affirmative ("yes") and negative ("no") responses were included in the analysis; “don’t know” responses were counted as missing data for the purposes of our analyses.

State COVID-19 Response

Federal guidance from the Centers for Disease Control and Prevention (CDC) and the White House COVID-19 response team was used to evaluate state responses to the COVID-19 pandemic in early 2020. This paper focused on guidelines issued between January and July 2020 to align with data collection for the NCI-IDD IPS 2020-21 data cycle, which ran from July 1, 2020 to June 30, 2021 and on state crisis standards of care (CSOC) plans, described in the next section.

The CDC first issued advice against gatherings of 50 or more people on March 12, 2020 (CDC.org, 2020a). This guidance was immediately followed by The “30 Days to Slow the Spread" campaign ON March 16, 2020, which recommended that people work or attend school from home when possible and avoid gatherings of more than 10 people, unnecessary travel and social visits, eating at bars and restaurants, and visiting nursing homes and other long-term care facilities (trumpwhitehouse.archives.org, 2020).

Some states and territories responded by issuing stay-at-home orders to enforce these guidelines, beginning with Puerto Rico on March 15 and California on March 19, 2020 (Moreland et al., 2020). These policies were evaluated based on their timing and concordance with federal recommendations, based on the data gathered by Moreland and colleagues (2020). States that issued a universal, mandatory stay-at-home order were scored as 2, those that issued an advisory or a mandate that only applied to some people were scored as 1, and those that did not issue guidance were scored as 0. States where some counties issued stay-at-home orders were still scored as 0, reflecting the lack of state-wide guidance.

The CDC first officially recommended that all Americans wear a cloth face mask “in public settings where other social distancing measures are difficult to maintain” on April 3, 2020 (cdc.org, 2020b). This recommendation was followed by state mandates beginning with New Jersey on April 10, 2020, and New York on April 15, 2020 (ballotpedia.org, 2022). The CDC issued a stronger call for Americans to wear a face mask outside of their home on July 14, 2020, based on emerging evidence for masking as an important tool in preventing the spread of COVID-19 (cdc.org, 2020c). State mask policies were compiled by Ballotopedia (2022). States that implemented a mask mandate in the first half of 2020 (prior to June 1) were scored as 2, those that implemented a mandate after June 1, 2020 were scored as 1, and states that never issued guidance on masking were scored as 0. Again, only state-wide policies, not county-level guidance, were considered in this scoring.

State Disability Response

In addition to states’ overall response to the COVID-19 pandemic, this paper also measured the extent to which these responses explicitly protected people with IDD. CSOC plans are guidelines for alterations to usual healthcare that may be made during emergency situations in which resources are limited (Institute of Medicine [IOM], 2009). In the United States, many of these plans were developed in response to the 2009 H1N1 pandemic and have come under increased scrutiny during the COVID-19 pandemic (Cleveland Manchada et al., 2021; Ne’eman et al., 2021). While CSOC plans are intended to outline an equitable distribution of resources, many plans discriminated against people with disabilities and other chronic health conditions in their prioritization guidelines, especially early in the COVID-19 pandemic (CPR, 2020a; Guidry-Grimes et al., 2020; Ne’eman et al., 2021).

This paper evaluated CSOC plans based on guidelines suggested by the Center for Public Representation (2020b) in collaboration with partner organizations. CSOC plans were identified from a dashboard compiled by the Center for Public Representation (2020a), and through reviews by Cleveland Manchada and colleagues (2021) and Ne'eman and colleagues (2021). When none of these sources had a link to a state's plan we searched for "[state name] crisis standards of care plan" or "[state name] COVID-19 allocation plan" on Google and on the state's health department website. Finally, as some states had updated their CSOC plan during the COVID-19 pandemic, we utilized the Internet Archive (archive.org, n.d.) to identify the plan on record in early 2020 to coincide with the timeframe of the NCI-IDD IPS data.

The evaluation criteria and scoring criteria are presented in Table 1. Author 1 completed the initial data extraction and evaluation. Author 2 audited 25% of the plans to check for agreement in ratings. Any discrepancies were discussed until the authors reached 100% agreement on scoring. Scores were then calculated by totaling a state's points for each criterion. States without a CSOC plan were not included in the analysis.

COVID-19 Impact

Cumulative COVID-19 case and death rates for each state as of August 1, 2020 were used as a measure of the impact of the pandemic. Daily case and death counts for each state were compiled by the CDC (data.cdc.gov, n.d.); each state's census data (United States Census Bureau, 2022) were used to calculate rates per 100,000.

Analysis

Bivariate analyses were used to examine the relationship between each variable of interest and COVID-19 diagnosis. All variables from the NCI-IDD were categorical and were analyzed using chi-squared tests. State-response and impact data were continuous and were examined using independent samples T-tests. Bivariate analyses were also used to test for relationships between state-level responses to COVID-19 (stay-at-home orders and masking mandates) with state-level impacts (case-rates and death-rates).

Following the bivariate analysis, multilevel modeling was used to account for clustering of individuals within states to explore inter-state variability in COVID-19 diagnosis. Specifically, generalized linear mixed modeling was used as all variables were categorical. Analysis was conducted in R (R Core Team, 2017) using the lme4 package (Bates et al., 2015). The null model consisted of the outcome variable (COVID-19 diagnosis) and the cluster variable (state). Model 1 added individual level predictors and Model 2 added the state level predictor. Because not every state had a CSOC plan on file, Model 2 was run both with and without CSOC scores as a predictor.

The level two (state-level) predictor variable was the state COVID-19 response score. The COVID-19 response score includes both the state’s disability response and their general response to the pandemic. As described previously, the disability response score includes elements of state CSOC plans scored using an evaluation framework suggested by disability advocacy organizations (CPR, 2020b). The general response score includes state closing, stay at home, and masking mandates, analyzed based on their concordance with federal guidelines.

Results

Participants

Sample characteristics are presented in Table 1. Respondents came from 26 states, with a total sample of 19,991. However, rates of missingness for COVID-19 diagnosis were very high, with only 10,093 valid responses after excluding missing data and “don’t know” responses. Additionally, these patterns of missingness were not spread equally among the states, with four states accounting for 9,095 of the missing or "don't know" responses. Based on these findings, we removed the four states with highest missingness from future stages of analysis, leaving us with a sample of 9, 936 from 22 states, of whom 10.76% (1008) had been diagnosed with COVID-19. Missingness in this sample was much lower, with 5.71% (567) missing or "don't know" responses.

State Responses

State COVID-19 Policies.

Masking and stay-at-home guidelines were identified for all 50 states and ranged from 0 to 2, with higher scores indicating stricter COVID-19 policies. The average score for masking policies was 1.06, while the average score for stay-at-home policies was 1.56.

CSOC Plans.

CSOC plans with specific allocation criteria published prior to June 1, 2020, were identified for 24 states. Ten states both participated in the NCI-IDD in 2020-2021 and had a CSOC plan on record. Of these states, scores ranged from 3 to 14 with an average score of 6.80. Nationally, scores ranged from 3 to 14 with an average score of 7.86. Higher scores indicated closer compliance with the CPR evaluation framework.

State COVID-19 Impact.

According to data from the CDC, of the states that participated in the NCI-IDD data collection and were included in this analysis, reported cases per 100,000 ranged from 15.12 to 2,213.75, with an average of 978.41. Nationally, cases rates ranged from 15.12 to 14,132.56 and averaged 1,528.05. Among states who participated in the NCI IDD data collection and included in this analysis, deaths per 100,000 ranged from .66 to 170.59 and averaged 30.63. Comparatively, death rates in all states ranged from .66 to 344.75 and averaged 47.46.

Bivariate Relationships

Significant associations of being diagnosed with COVID-19 were found at the individual and state levels and are presented in Table 3.

Individual Level

Significantly fewer respondents in the youngest age category (18-29) had been diagnosed with COVID-19, while significantly more respondents in the oldest categories (50-64 and 65+) had contracted COVID-19 than would be expected due to chance alone; $X^2(4) = 31.03$, $p < .001$). Several chronic health conditions were significantly associated with an increased likelihood of being diagnosed with COVID-19, including having a cardiovascular condition ($X^2(1)$, 5.29, $p = .02$), high cholesterol ($X^2(1) = 13.15$, $p < .001$), high blood pressure ($X^2(1) = 6.16$, $p = .01$), and mental health conditions ($X^2(1) = 23.12$, $p < .001$). Significantly fewer people with autism had been diagnosed with COVID-19 compared to people without autism ($X^2(1) = 6.62$, $p = .01$). Notably, while Down Syndrome was often prioritized as a high-risk condition, it was not significantly associated with having a diagnosis of COVID-19.

Residence was significantly associated with diagnosis; a higher percentage of people who lived in an Intermediate Care Facility (ICF), nursing home, or other institution or group home setting had been diagnosed with COVID-19 compared with people who lived with family or in host homes/adult foster care ($X^2(7) = 315.49$, $p < .001$) Additionally, a higher percentage of people who had a day activity in the community had been diagnosed with COVID-19 compared to people who did not report having a day activity ($X^2(1) = 30.39$, $p < .001$). Having a job was not significantly associated with COVID-19 diagnosis in the bivariate analysis, but became significant in the regression models.

State Level

At the state level, the degree to which a state responded to the COVID-19 pandemic was significantly associated with COVID-19 diagnosis. There was a significant difference in state masking ($t(9367) = 4.47$, $p < .001$) and stay at home guidelines ($t(9367) = 3.24$, $p = .001$) by COVID-19 diagnosis. Having been diagnosed with COVID-19 was associated with living in a state with less strict policies. There was a significant difference in case rates ($t(9367) = -7.23$, $p < .001$)) and death rates ($t(9367) = -2.19$, $p = .028$), with higher rates associated with a COVID-19 diagnosis. The degree to which states issued explicit protections for people with disabilities in their CSOC plans was also significant ($t(4185) = 2.14$, $p = .03$). Having been diagnosed with COVID-19 was associated with living in a state with fewer protections codified into policy.

There were also significant relationships between the state-level variables included in this analysis. Case-rates in particular were related to a state's response to the COVID-19 pandemic, with higher reported cases in states without a stay-at-home order ($F(2) = 812.82$, $p < .001$) or masking mandates ($F(2) = 1175.32$, $p < .001$). Death-rates were also related to stay-at-home orders ($F(2) = 116.91$m $p < .001$) and mask mandates ($F(2) = 818.90$, $p < .001$), though the direction of these relationships was less clear. Finally, protections in CSOC plans were significantly, though moderately, related to a state's death rates ($r = .51$, $p < .001$).

Multilevel Model

Intraclass Correlation (ICC) and Model Fit

To assess the appropriateness of multilevel modeling, the intraclass correlation (ICC) was calculated by dividing the group variance (Level 2) by the total variance (Levels 1 and 2). An ICC of .05 or greater suggests that multilevel models should be used (Garson, 2019). In the Null Model the ICC was .11, indicating that approximately 11% of the variance in COVID-19 diagnosis occurred at the state level.

A two-level logistic regression was fitted with COVID-19 diagnosis as the dependent variable. The Null Model only included the cluster variable, state, as a predictor. Model 1 included all individual predictors and Model 2 added the state-level predictors. These results are presented in Table 4.

Two measures of model fit--the Akaike Information Criterion (AIC) and the Bayesian Information Criterion (BIC)--were used to assess the predictive power of more complex models (Garson, 2019). Both the AIC and BIC in each model decreased with the addition of predictors, indicating that variables at the individual and state levels added significant predictive power to the model. Of the 22 states with NCI-IDD IPS data included in this analysis, 10 states had CSOC plans. The state-level model was therefore run with and without this variable. The state-level model with CSOC included had higher predictive power and so was retained as the final model.

In the final model, a person's residence remained the strongest predictor of their likelihood of being diagnosed with COVID-19. Compared to people who lived in their own home, people who lived in large group homes with 7-11 residents (OR 1.22, $p = .002$) or in an ICF or institutional setting (OR 1.46, $p = .02$) had higher odds of being diagnosed with COVID-19, while people who lived with family had lower odd (OR = -.99, $p < .001$). At the state level, people who lived in states with higher rates of COVID-19 had higher odds of diagnosis (OR .81, $p = .001$) while people who lived in states with higher death rates had lower odds of diagnosis (OR -.52, $p = .01$). State masking guidelines approached significance in the final model, though not in the expected direction. People who lived in states with stricter masking guidelines had somewhat higher odds of being diagnosed with COVID-19 (OR = .49, $p =.10$).

Discussion

This paper offers important insight into the potential vulnerability of people with IDD in a public health emergency like the COVID-19 pandemic and underscored the ways in which individual-, system-, and state-level policies interact to impact a person's risk during such an event. This analysis supports the literature that suggests that more people with IDD contracted COVID-19 during the NCI-IDD data collection period than people without IDD (Gleason et al., 2021; Lunksy et al., 2022; Schott et al., 2022). While cases per 100,000 as of August 1, 2020 averaged 1,053.73 (1.05%) in states that participated in this NCI-IDD IPS (data.cdc.gov, n.d.), approximately 11% of the sample reported being diagnosed with COVID-19 during the same timeframe. Given the evidence that people with IDD who contract COVID-19 are at an increased risk of severe outcomes compared to people without IDD, understanding these risks is imperative to develop an equitable response to future public health emergencies.

Implications for the Disability Service System

Like previous research, this study suggests that where people with IDD lived significantly impacted their risk of contracting COVID-19. In the final model, people who lived in group homes with 7-11 residents, intermediate care facilities, nursing homes, or other institutional settings had significantly higher odds of being diagnosed with COVID-19 compared to people who lived independently or with family. In the bivariate analysis, all congregate settings were associated with higher than expected rates of COVID-19 diagnosis, while living with family or in a host home was associated with lower than expected rates of being diagnosed with the virus.

Given the history of institutionalization for people with IDD, understanding the risks associated with living in congregate settings is particularly important. In 2019, approximately 19% of people with IDD in the US received Long Term Supports and Services (LTSS; Larson et al., 2022). Of these people, about 20% lived in a group setting (Larson et al., 2022). In contrast, only about 6% of people over 65 live in congregate settings (Shapiro, 2020). People who live in group settings face a number of factors that increase their risk of being exposed to COVID-19. Sharing a home with multiple people may make physical distancing difficult or impossible (Landes et al., 2021).

Additionally, especially in the first months of the COVID-19 pandemic, direct support professionals (DSPs) who worked in group homes often lacked appropriate personal protective equipment (PPE; Shapiro, 2020). DSPs may also have been likely to contract and spread COVID-19: low wages mean that many DSPs work in multiple settings and often rely on public transportation (Pettingell et al., 2023; Shapiro, 2020). This risk was reflected by other studies on inequities in the COVID-19 response, which suggest that social distancing was weaker and risk of exposure to COVID-19 was higher in areas with higher concentrations of poverty and essential workers compared to more affluent areas where more people were able to work from home (Garnier et al., 2021).

It is also possible, however, that after the initial delay in guidance, people who lived in congregate care settings were tested for COVID-19 more frequently than people who lived on their own or with family. Guidance issued by the CDC in May 2020 recommended regular screening of group home staff and residences for any symptoms of COVID-19, monitoring people who had been in contact with someone with COVID-19, and reporting cases or suspected cases of COVID-19 to the local health department for testing, if necessary (CDC, 2020d). While the NCI-IDD IPS included symptoms associated with COVID-19 in their question about diagnosis, asymptomatic or mild cases may have been missed in people who lived at home or with family and identified in people who lived in settings with stricter guidelines around testing.

Findings from this study support prior research that congregate care settings, including group homes, may put people with IDD at an increased risk of contracting COVID-19 (Landes et al., 2021). Given these findings, responses to a future public health emergency should explicitly consider people with IDD who live in congregate care settings.

The Role of State Responses to COVID-19

Geographically, where people lived was also significantly associated with their risk of being diagnosed with COVID-19. As expected, people who lived in states with higher case rates of COVID-19 were significantly more likely to have been diagnosed with the virus. Living in a state with a higher death rate was also associated with participants' odds of being diagnosed with COVID-19, but not in the expected direction; higher state death rates were significantly related to lower odds of being diagnosed. Given prior research that a high perceived risk from COVID-19 was associated with more protective health behaviors, it is possible that people who lived in states with higher death rates were more worried about the virus and took more precautions (Bruine de Bruin & Bennett, 2020).

Furthermore, while masking and stay-at-home mandates were not significant in the final model, other analyses in this study suggest that the way a state responded to the COVID-19 pandemic may still be important. At the bivariate level, masking and stay-at-home guidelines were associated with case-rates. Case rates were lowest in states that issued a mask mandate before June 1, 2020, and in states that issued a universal stay-at-home mandate. In the final model, living in a state with higher case rates was associated with increased odds of COVID-19 diagnosis, suggesting a possible relationship between public health policy and population-level impacts with individual behaviors and outcomes.

Implications for Health Equity

This study also underscores the importance of quality data for an equitable public health response, as well as how a lack of data can perpetuate inequity. Monitoring of the incidence and outcomes of COVID-19 for people with IDD was limited by a lack of health data that long predated the pandemic (Havercamp et al., 2019). This absence of baseline knowledge was then compounded by insufficient testing (Bergquist et al., 2020; Xu & Basu, 2020) that did not collect disability data (Bergquist et al., 2020), and was often inaccessible to people with disabilities (Taggart et al., 2022). Research on outcomes for patients who contracted COVID-19 was similarly limited, as most secondary data analysis relied on diagnostic codes in a patient's medical chart to identify an intellectual and/or developmental disability (Gleason et al., 2021). Combined, these persistent exclusions from research and knowledge creation culminated in a situation in which the needs of people with IDD were often overlooked.

The consequences of the lack of data about people with IDD continued past the initial wave of COVID-19 in the US. Vaccination against COVID-19 was not considered in this study because vaccines were only beginning to be authorized at the time of the NCI-IDD IPS survey. However, the COVID-19 vaccine rollout in the US is a key example of why disability data is necessary for an equitable public health response. While people living in congregate care settings, including group homes for people with IDD, and people with some specific conditions, including Down Syndrome, were prioritized early (Hotez et al., 2021), a review conducted in early 2021 found that only 10 states prioritized people with other physical, intellectual, and/or developmental disabilities (Jain et al., 2021). This deprioritization can be partially attributed to the lack of data about health outcomes for people with IDD and other disabilities (Hotez et al., 2021; Lunsky et al., 2022).

In planning for future public health emergencies like the COVID-19 pandemic, efforts must be made to include disability identifiers in existing population surveys and on any future testing and surveillance efforts (Bergquist et al., 2020; Boyle et al., 2020; Havercamp et al., 2019). Federal guidance and oversight regarding testing may help to ensure consistency in these data collection and reporting methods, allowing for a better understanding of the impact of an emerging disease as a whole and on specific populations (Gusmano et al., 2020; Holtz et al., 2020; Xu & Basu, 2020).

Limitations and Directions for Future Research

Inconsistencies in states' responses to COVID-19 made comparison challenging. Specifically, only about half of the states with NCI-IDD IPS data had a CSOC plan on record. While CSOC scores added predictive power to the model and were retained, additional research is needed to better understand the impacts of having specific, state-level protections for people with disabilities in a public health crisis. Two states added or updated CSOC plans during the NCI-IDD data collection cycle, suggesting that conversations about health equity and resource allocation were ongoing. Furthermore, while data on COVID-19 case rates and death rates were available for each state in this analysis, the validity of this data is dependent on coordinated testing and reporting. Evidence suggests that these numbers may be underreported (Xu & Basu, 2020), especially for nursing homes and congregate care settings (Bergquist et al., 2020).

Missingness in the NCI-IDD also limited analysis, even after removing the four states that accounted for a large proportion of the missing data. The 2020-2021 NCI-IDD survey included questions about COVID-19 outcomes (hospitalization, ICU admission, and intubation), but were only answered by about 13% of respondents. Given the nature of the survey data, it is impossible to know whether respondents skipped these questions because they were not applicable (i.e. the person had never been hospitalized with COVID-19) or if this information was not available at the time of the survey.

These limitations with the data coupled with the timing of the NCI-IDD IPS data meant that the analysis in this paper focused on odds of being diagnosed with COVID-19 as an outcome of interest. As described previously, people with IDD are also at increased risk for severe illness, hospitalization, and death following infection with COVID-19 (Gleason et al., 2021; Lunsky et al., 2022). Future research should consider the range of impacts that the COVID-19 pandemic has had on people with IDD.

Conclusion

These findings suggest that individual-, system-, and state-level factors are all associated with a person's risk of contracting COVID-19, so that a successful public health response must consider the broader context in which a person lives. These factors are particularly important for people with IDD, who interact with the environment in ways that may put them at increased risk from contracting COVID-19 and for poor outcomes compared to people without disabilities. Unfortunately, historic and ongoing hermeneutical injustice means that these factors are not well understood and, as such, not considered in public health decisions. Pursuing health equity and hermeneutical justice requires actively including people with IDD in public health research in preparation for future emergencies and natural disasters.

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Table 1. *CSOC Scoring Criteria*

Variable	Definition	Scoring
Equity	Allocation plan explicitly states and defines equity/fairness as a principle of the framework.	0 = no plan 1 = equity is stated, not defined 2 = equity is stated and defined
Identity Statement	Allocation plan explicitly prohibits discrimination based on race, disability, and other protected classes.	0 = no statement 1 = some classes are stated 2= statement includes disability, race, and other major protected classes
Reasonable Modification	Assessment criteria allows for modification to account for pre-existing disabilities.	0 = no 1 = yes
Eligibility	Plan explicitly states that all patients are eligible for life-saving treatment.	0 = no 1 = yes
Resource Intensity	Plan allows for consideration of expected intensity/continued need for resources (ex. home oxygen use)	0 = considers resource intensity 1 = resource intensity not mentioned 2 = consideration for resource intensity/ongoing need is explicitly prohibited
Categorical Exclusion	Plan explicitly prohibits categorical exclusions based on diagnosis	0 = plan categorically excludes patients with some diagnoses 1 = no categorical exclusions 2 = plan explicitly prohibits categorical exclusions
Survival	Allocation plan explicitly states that treatment decisions should be based on likelihood of surviving the acute illness	0 = long term survival (>2 years) 1 = medium term survival (6 months - 1 year) 2 = short term survival (acute illness period)
Reallocation	Reallocation plan is specified and allows for extended time as reasonable accommodation	0 = no reallocation plan is specified 1 = reallocation plan is defined, no reasonable accommodation 2 = reallocation plan specifies extended time as accommodation
Personal Ventilators	Plan includes protections for personal ventilators	0 = no 1 = yes
Appeals process	Plan includes an appeals process for patients denied treatment	0 = no 1 = yes

Table 2. Predictors of COVID-19 Diagnosis

	Valid %	N
COVID-19 Diagnosis (N =9,369)	10.76	1,008
Age (N = 9,869)		
18-29	27.89	2,752
30-39	25.20	2,487
40-49	15.88	1,567
50-64	22.13	2,184
65+	8.91	879
Race (N = 9467)		
Black	16.58	1,570
Latino	4.23	400
White	71.52	6,771
Other	1.45	137
Gender (N = 9,842)		
Female	41.16	4051
Male	58.84	5791
Health Conditions		
Cardiovascular (N = 9,382)	6.59	618
Diabetes (N = 9,452)	12.78	1208
Cancer (N = 9,445)	2.23	211
High Blood Pressure (N = 9,356)	21.16	1980
High Cholesterol (N = 9,332)	18.20	1698
Level of ID (N = 8,507)		
Mild	37.32	3175
Moderate	32.87	2796
Severe	13.64	1160
Profound	7.21	613
Unspecified	9.00	763
Mental Health Condition (N = 9,713)	53.06	4464
Residence Type (N = 9,739)		
ICF/Nursing Home	1.85	180
Group Home 2-3	14.42	1404
Group Home 4-6	13.86	1350
Group Home 7-11	3.83	373
Own Home	17.75	1729
With Family	37.22	3625
Host Home	10.23	996
Other	.84	82
Day Activity (N = 6,339)	48.41	3069
Job (N=6,369)	25.53	1626
State Level		
	Mean (SD)	N
CSOC	7.28 (3.68)	4,478
Masks	1.04 (.67)	9,936
Stay-at-Home	1.60 (.64)	9,936
Case Rates	978.41 (610.10)	9,936
Death Rates	30.63 (33.66)	9,936

Table 3. Bivariate Associations with COVID-19 Diagnosis

	X^2 (df)
Age	31.04 (4) ***
Black	.22 (1)
Latino	1.22 (1)
White	4.72 (1)*
Other	2.83 (1) #
Gender	.55(1)
Cardiovascular	5.29 (1) *
Diabetes	4.27 (1)*
Cancer	.59 (1)
High Blood Pressure	6.17 (1) *
High Cholesterol	13.15 (1) ***
Mental Health Condition	23.12 (1) ***
Down Syndrome	.04 (1)
Autism	6.62 (1) *
Residence Type	315.49 (7) ***
Day Activity	30.39 (1) ***
Job	.22 (1)
	t (df)
CSOC	2.14 (4185) *
Stay Home	3.24 (9367) **
Masks	4.47 (9367) ***
Cases	-7.23 (9367) ***
Deaths	-2.19 (9367) *

* p < .05 ** p < .005 *** p < .001 # p < .10

Table 4. Multilevel Model

Odds Ratio (Standard Error)	Null Model (N = 9369)	Model 1 (N = 4328)	Model 2 (N = 2041)
Intercept	-2.24 (.14) ***	-2.36 (.20) ***	-3.23 (.89) ***
Age (30-39)		.09 (.15)	.08 (.22)
Age (40-49)		-.17 (.17)	-.56 (.27) *
Age (50-64)		-.15 (.16)	-.27 (.24)
Age (65+)		-.28 (.22)	-.42 (.33)
Race (Black)		-.09 (.14)	-.03 (.20)
Race (Latino)		.001 (.27)	.25 (.36)
Race (Other)		-.32 (.37)	-.81 (1.05)
Cardiovascular disease		.11 (.20)	.09 (.30)
Cancer		-.08 (.32)	.04 (.47)
Diabetes		.12 (.14)	.14 (.20)
High Blood Pressure		-.11 (.13)	-.14 (.20)
High Cholesterol		.09 (.13)	.33 (.20)
Mental Health Condition		.08 (.11)	-.05 (.16)
Moderate ID		.07 (.11)	.13 (.16)
Severe ID		-.72 (.28) *	-.24 (.36)
Profound ID		-.58 (.54)	-.70 (.76)
Unspecified ID		.05 (.22)	.13 (.35)
Down Syndrome		-.06 (.19)	.34 (.29)
Autism		-.10 (.15)	-.27 (.25)
Group Home 2-3		.13 (.17)	.07 (.23)
Group Home 4-6		.49 (.16) **	.35 (.26)
Group Home 7-11		.88 (.22) ***	1.22 (.40) **
With Family		-.66 (.16) ***	-.99 (.27) ***
Host Home		-.16 (.22)	.29 (.33)
ICF/Institution		1.39 (.34) ***	1.46 (.65) *
Other Residence		-1.00 (1.02)	-14.36 (161.91)
Job		.29 (.11) *	.10 (.19)
Day Activity		.29 (.11) **	.08 (.16)
CSOC			-.002 (.04)
Masks			.49 (.29) #
Stay-at-Home			.36 (.30)
Case Rate			.81 (.26) **
Death Rate			-.52 (.20) *
AIC	6,220.0	2,962.0	1,377.2
BIC	6,234.3	3,159.6	1,579.6
X^2	6,216	2,900	1,305.2

* p < .05 ** p < .005 *** p < .001 # p < .10