Since January 2020 Elsevier has created a COVID-19 resource centre with free information in English and Mandarin on the novel coronavirus COVID-19. The COVID-19 resource centre is hosted on Elsevier Connect, the company's public news and information website.

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Brief Report

COVID-19 outcomes among people with intellectual and developmental disability in California: The importance of type of residence and skilled nursing care needs

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ABSTRACT

Background: People with intellectual and developmental disabilities (IDD) appear to be at greater risk for severe outcomes from COVID-19. The roles of congregate living and skilled nursing care needs in this disparity are unclear.
Objective: To determine the impact of residential setting and level of skilled nursing care on COVID-19 outcomes for people receiving IDD services, compared to those not receiving IDD services.
Methods: Utilizing publicly available California data on COVID-19 outcomes for people receiving IDD services (early May through October 2, 2020), we report outcomes based on seven types of residence, differentiated by number of residents and level of skilled nursing care provided. We compared these results to the larger California published outcomes.
Results: Compared to Californians not receiving IDD services, in general, those receiving IDD services had a 60% lower case rate, but 2.8 times higher case-fatality rate. COVID-19 outcomes varied significantly among Californians receiving IDD services by type of residence and skilled nursing care needs: higher rates of diagnosis in settings with larger number of residents, higher case-fatality and mortality rates in settings that provided 24-h skilled nursing care.
Conclusions: Diagnosis with COVID-19 among Californians receiving IDD services appears to be related to the number of individuals within the residence, while adverse COVID-19 outcomes were associated with level of skilled nursing care. When data is available, future research should examine whether these relationships persist even when controlling for age and pre-existing conditions.

Introduction

Due to a lack of health surveillance,[1] attempting to understand COVID-19 outcomes among people with intellectual and developmental disabilities (IDD) in the US is similar to piecing together a complex puzzle. Despite the challenge, it is essential to investigate the effects of the pandemic on this vulnerable health population,[2] as people with IDD have higher prevalence of chronic health conditions,[3,4] and a disproportionate percentage of the population resides in congregate settings.[5] Two early studies provide critical baseline information.

An initial study analyzed comorbidity trends and case-fatality rates among people with and without IDD through May 14, 2020 utilizing the TriNetX global health research network composed of real-time electronic medical records.[6] Among those with COVID-19, people with IDD had higher prevalence of cardiovascular disease, respiratory diseases, diabetes or other metabolic and endocrinologic disorders than those without IDD. In addition, COVID-19 case-fatality rates were higher among people with than without IDD at ages 0–17 and 18–74, but similar at ages 75 and over. A second study focused on COVID-19 outcomes among adults with IDD living in residential group homes in New York State through May 28, 2020.[7] People with IDD living in residential group homes, compared to New York state overall, had a higher case rate (7841 per 100,000, 95% CI 7480–8,218, compared to 1910 per 100,000, 95% CI 1910–1916), case-fatality rate (15.0, 95% CI 13.3–16.8, compared to 7.9, 95% CI 7.8–8.0), and mortality rate (1175 per 100,000, 95% CI 1036–1,332, compared to 151 per 100,000, 95% CI 150–153). A recent report from the authors of the New York study detailed that, as of July 10, the case rate and case-fatality rate

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remained higher for people with IDD living in residential group homes.[8]

These studies provided initial empirical evidence that people with IDD may be at greater risk during the pandemic, but they were not able to differentiate COVID-19 outcomes among people with IDD by residential setting. Compared to the general population, a disproportionate percentage of people with IDD live in congregate setting, such as residential group homes.[5] Beyond the fact that people with IDD, in general, are a vulnerable health population,[2] individuals with IDD living in congregate settings typically have more intensive care needs and poorer health outcomes than those living at home.[9–12] In addition, living in a congregate setting may increase the risk of COVID-19 transmission due to limitations on physical distancing.[13–15]

While true that a disproportionate percentage of people with IDD live in congregate settings, an estimated 77% of people with IDD who receive long-term supports and services reside in non-congregate settings, such as their own home, in the home of a family member, or in the home of a host or foster family.[16] Distancing concerns may not be as pressing for people with IDD living in their own or a family home, although there may still be a need for personal and/or skilled nursing care, which could increase the number of people that come in/out of the home. The current study utilized data from one US state to compare COVID-19 outcomes among people who were/were not receiving IDD services, then to examine whether differentials in outcomes varied by type of residence for people who were receiving IDD services. Our hypothesis was that COVID-19 outcomes for people receiving IDD services would be more severe for those living in settings that have more residents and/or provide more intensive skilled nursing care.

Methods

The most populous US state, California, provides services for more people with IDD than any other US state, accounting for 18.3% of all people with IDD receiving long term supports and services in the US.[16] The California Department of Developmental Disabilities Services (DDS) has provided publicly available data on COVID-19 for people with IDD served by the state since early May 2020.[17] For this study, we utilized the publicly available California DDS data on COVID-19 outcomes for people with IDD receiving services from the state as of October 2, 2020, inclusive of number served, number of cases, and number of deaths, reported overall and by type of service received. COVID-19 data for the state of California overall is from the California Open Data Portal,[18] providing the number of cases and deaths for the entire state as of October 2, 2020. Estimates of the population of California are from the US Census 2019 population estimates. The population and COVID-19 outcomes for Californians not receiving IDD services were calculated by subtracting the number of people receiving IDD services from the overall California population data.

COVID-19 outcomes analyzed included case rate per 100,000 (cases/population*100,000), case-fatality rate (deaths/cases), and mortality rate per 100,000 (deaths/population*100,000).

COVID-19 outcomes for Californians receiving IDD services are reported overall and by type of services received. We identified seven distinct categories of residence type based on the types of services provided as reported by the California DDS: family or own home; Community Care Facility (CCF); Intermediate Care Facility for the Developmentally Disabled-Habilitative (ICF/DD-H); Intermediate Care Facility for the Developmentally Disabled-Nursing (ICF/DD-N); Intermediate Care Facility for the Developmentally Disabled (ICF-DD); Skilled Nursing Facility (SNF); and other type of residence (not specified in California DDS data). Table 1 provides details for each category, inclusive of the type of service received, type of residence, number of residents, and whether skilled nursing care is/is not provided and the intensity of that care in the residence.[19–22]

We first compared COVID-19 outcomes for Californians who were/were not receiving IDD services overall. We then examined differences in COVID-19 outcomes among Californians receiving IDD services by type of residence. Confidence intervals for point estimates were calculated assuming a standard normal distribution for Californians not receiving IDD services and using Wilson's score method for Californians receiving IDD services due to the smaller sample size. In instances when confidence intervals overlapped,[23] we utilized *t*-test to determine whether difference in point estimates were statistically significant. All analysis was conducted utilizing STATA 16.0 (College Station, TX).

Results

Differences between Californians who were/were not receiving IDD services

All results are reported in Table 2. Among Californians not receiving IDD services, the COVID-19 case rate was 2085 cases per 100,000 people, the case-fatality rate was 1.9%, and the mortality rate was 41 deaths per 100,000 people. Among all Californians receiving IDD services, the case rate was 831 cases per 100,000 people, the case-fatality rate was 5.5%, and the mortality rate was 46 deaths per 100,000. Thus, compared to Californians not receiving IDD services, the risk ratios for Californians receiving IDD services were: 60% lower for case rate (95% CI 0.38–0.41); 2.8 times higher for case-fatality rate (2.43–3.28); and 1.1 times higher, but not statistically significant, for mortality rate (0.96–1.31).

Differences among Californians receiving IDD services by type of residence and skilled nursing care

The majority of Californians receiving IDD services, 89%, lived in their own or a family home. The remaining 11% lived in a CCF (6.7%), some type of ICF (1.9%), a SNF (0.3%), or other type of residence (2.2%).

COVID-19 outcomes varied considerably for Californians receiving IDD services by type of residence and level of skilled nursing care. The group with the least severe COVID-19 outcomes across the board were people with IDD living in their own or a family home. This group had a case rate of 523 cases per 100,000 people, a case-fatality rate of 2.8%, and a mortality rate of 15 deaths per 100,000 people.

Case rates varied across the other IDD settings and were notably higher in the two settings with the largest number of residents. Outside of those living in their own or a family home, the case rate was lowest, 2268 per 100,000, for those living in a CCF, which typically have between 4 and 16 residents. The mid-range case rate, from 4392 to 5590 per 100,000, was among those living in an ICF/DD-N or ICF/DD-H setting, both which have between 4 and 15 residents. Case rates were highest in the types of facilities with more residents: 19,031 per 100,000 for those living in an ICF-DD, a health care facility with 15 or more residents; and 27,546 per 100,000 for those living in a SNF, which are extended care facilities with 80 or more residents. Differences observed in the point estimates between ICD/DD-N and ICF/DD-H were not statistically significant.

Case-fatality rates also varied across settings, but were highest in the settings in which people with IDD received a comparatively higher intensity of skilled nursing care. Apart from Californians receiving IDD services in their own or a family home, the case-fatality rate was lowest among those living in CCF (4.3%) and ICF-

Table 1
Types of residence for Californians receiving IDD services.

Type of service	Type of residence	Number of residents	Skilled nursing care provided as part of services
Family or Own Home* • *Family or Own Home* • *Supported Living Services (SLS)* • *Independent Living Services (ILS)* • *Family Home Agency (FHA)*	Residential	Based upon size of family	No
Community Care Facility (CCF)	Residential group home	Typically 4 to 16, but may at times exceed 16	No, only limited medical services allowed (gastrostomy, catheter, colostomy, and ileostomy care)
Intermediate Care Facility for the Developmentally Disabled-Habilitative (ICF/DD-H)	Residential group home	4 to 15	Yes, but intermittent
Intermediate Care Facility for the Developmentally Disabled-Nursing (ICF/DD-N)	Residential group home for the medically fragile	4 to 15	Yes, 24-h nursing supervision, with up to 8 h per day on-site direct nursing care
Intermediate Care Facility for the Developmentally Disabled (ICF-DD)	Health care facility	15 or more	Yes, but intermittent
Skilled Nursing Facility (SNF)	In-patient medical facility	80 or more	Yes, 24-h on-site direct care availability
Other	Not specified	Not specified	Not specified

Note: *Composite category inclusive of services that are provide in the family home or the individual's residence.

DD (4.7%) settings, which provide either no or intermittent skilled nursing care. The mid-range case rate was in the ICF/DD-H setting (6.2%), which provides intermittent skilled nursing care. Higher case-fatality rates were apparent for Californians with IDD receiving services in facilities that provided 24-h skilled nursing supervision or care (ICF/DD-N – 15.8%; SNF – 20.4%). Differences in points estimates of the case-fatality rate between own or family home, CCF, and ICF-DD were not statistically significant. Neither were differences in the case-fatality rate between ICF/DD-N and SNF.

Mortality rates varied across settings as well, but were highest in the setting with the largest number of residents and most intense levels of skilled nursing. Beyond those living in their own or a family home, the lowest mortality rate, 97 per 100,000, was among those living in a CCF, a setting with 4 to 16 residents that does not provide skilled nursing care. The mid-range mortality rate was among those living in ICFs: ICF/DD-H (348 per 100,000), a setting with 4 to 15 residents that provides intermittent skilled nursing care; ICF/DD-N (693 per 100,000), a setting with 4 to 15 residents that provides 24-h skilled nursing supervision; and the ICF-DD setting (898 per 100,000), a setting with 15 or more residents that provides intermittent skilled nursing care. The highest mortality rate, 5626 per 100,000, was for those living in SNFs, a setting with 80 or more residents that provides 24-h skilled nursing and supportive care. Differences in points estimates of the mortality rates for ICF/DD-H, ICF/DD-N, and ICF-DD were not statistically significant.

Discussion

Results from this study provide evidence that COVID-19 outcomes varied among Californians receiving IDD services by type of residence and skilled nursing care needs. The least severe COVID-19 outcomes were among Californians with IDD who lived in their own or a family home, a group that accounted for 89% of those receiving IDD services. Californians with IDD who lived in their own or a family home had a case rate and mortality rate lower than that for Californians not receiving IDD services, and only a slightly higher case-fatality rate. COVID-19 outcomes were more severe for Californians receiving IDD services who lived in congregate settings with varying degrees of skilled nursing care needs. For these individuals, the highest case rates were among those living in settings

Table 2
Distribution of COVID-19 outcomes for Californians who were/were not receiving IDD services as of October 2, 2020.

	Population	Percent of population	Cases	Deaths	Case rate per 100,000 (95% CI)	Case-fatality rate (95% CI)	Mortality rate per 100,000 (95% CI)
Californians not receiving IDD services	39,157,583	100%	816,488	15,912	2085 (2081–2090)	.019 (.019–.020)	41 (40–41)
Californians receiving IDD services	354,640	100%	2948	162	831 (802–862)	.055 (.047–.064)	46 (39–53)
Californians receiving IDD services by type of residence							
Own home or family home	315,650	89.0%	1651	47	523 (498–549)	.028 (.021–.038)	15 (11–20)
Community Care Facility (CCF)	23,722	6.7%	538	23	2268 (2086–2465)	.043 (.029–.063)	97 (64–145)
ICF/DD-Habilitative (ICF/DD-H)	3739	1.1%	209	13	5590 (4898–6373)	.062 (.037–.103)	348 (203–594)
ICF/DD-Nursing (ICF/DD-N)	2163	0.6%	95	15	4392 (3606–5339)	.158 (.098–.244)	693 (421–1141)
ICF for the Developmentally Disabled (ICF-DD)	557	0.2%	106	5	19,031 (15,987–22,498)	.047 (.020–.106)	898 (384–2084)
Skilled Nursing Facility (SNF)	1031	0.3%	284	58	27,546 (24,906–30,353)	.204 (.161–.255)	5626 (4377–7204)
Other	7778	2.2%	65	1	836 (656–1064)	.015 (.003–.082)	13 (2–73)

with more residents, whereas the highest case-fatality and mortality rates were among those living in settings that provided the most intensive skilled nursing care.

There are few studies that have analyzed data related to outcomes of people with disability and COVID-19. The data that is available often offers limited details of those variables that have been identified as being associated with severe outcomes. The associations of age and pre-existing health conditions with severe outcomes have been confirmed in general populations.[24–26] There has been more specificity identified within specific populations related to health conditions,[27–29] but not for specific disability groups. This study makes the important contribution that for people with IDD, and possibly for other disability groups, an element of underlying health or personal attendant needs may affect COVID-19 outcomes. People with IDD, and with disability in general, have not been identified among the vulnerable health populations who should be considered a priority in emergency preparedness and planning for immunizations.

Strengths and limitations

The data currently available on COVID-19 outcomes among people with IDD in the US is scarce at best.[7,30] Until more thorough data is at hand, efforts to understand and address how the pandemic is affecting this vulnerable population must make use of all available data.[31] This study is now one in a series that has used available data to better define the risks and outcomes for people with IDD, noting some cause for concern.

However, there are limitations. It is possible that the primary characteristics determining COVID-19 outcomes among Californians receiving IDD services are age and pre-existing health conditions, and that type of residence simply appropriates these indicators. Although the California DDS COVID-19 data does provide the age distribution of those served, it does not detail the age distribution by type of service. Thus, we are not able to account for the possible effect of age on COVID-19 outcomes by types of residence. We did compare the overall age distribution of those receiving IDD services to the age distribution for California,[32] and note that when not accounting for possible differences in type of setting, those receiving IDD services were a younger population. This is in line with previous research reporting that people with IDD die ten to twenty years earlier than age-matched peers.[33,34]

In addition, there is no detailed information about people with IDD living in a family home related to intensity of medical and personal services for comparisons to those living in congregate settings, such as pre-existing conditions, numbers of medications prescribed, or specific treatments. It is important to recognize that some individuals with IDD may be receiving intensive skilled nursing care in a family home, depending on the resources available to the family. This is the case for both people with IDD living within a family home or congregate setting. Availability of skilled nursing care is a proxy for significant health care needs and is only available for congregate settings. Due to these limitations, the precise contributions of age and pre-existing health conditions to COVID-19 outcomes within this population remain unanswered. Though not testable with the data at hand, it is feasible to think that the markedly different COVID-19 outcomes among those with IDD living in their own or a family home in this study may be a result of this population being comparatively younger and having fewer medical conditions than people with IDD in other types of settings. This may especially be the case compared to the ICF-DD settings that serves adults who have comparatively higher prevalence of medical conditions.[35]

It also must be emphasized that the data from this study is from California and may not be generalized to other states because of the significant variation in designs of programs, availability of services, and models of service delivery. Among the few states providing information about their citizens with IDD and the pandemic, comparisons are limited by the varied presentations of the data and restricted definitions.

Conclusions

Early studies indicated that COVID-19 may present a greater risk to people with IDD, especially those residing in congregate settings and related to increasing supports and services.[6,7] Results from this study provide additional information related to the combination of residence and the need for skilled nursing care for people with IDD. The risks of COVID-19 outcomes among people with IDD living in congregate settings may be more severe than for the general population – with diagnosis of COVID-19 more common in settings with increased numbers of residents, and case-fatality more common in settings that provide higher levels of skilled nursing care. When data is available, future research should focus on whether these differences in COVID-19 outcomes persist even when controlling for age and pre-existing conditions.

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Declaration of competing interest

To the best of our knowledge, no conflict of interest, financial or other, exists.

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