

Brief Report

Supporting individuals with intellectual and developmental disability during the first 100 days of the COVID-19 outbreak in the USA

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Abstract

Background It is unknown how the novel Coronavirus SARS-CoV-2, the cause of the current acute respiratory illness COVID-19 pandemic that has infected millions of people, affects people with intellectual and developmental disability (IDD). The aim of this study is to describe how individuals with IDD have been affected in the first 100 days of the COVID-19 pandemic.

Methods Shortly after the first COVID-19 case was reported in the USA, our organisation, which provides continuous support for over 11 000 individuals with IDD, assembled an outbreak committee composed of senior leaders from across the health care organisation. The committee led the development and deployment of a comprehensive COVID-19 prevention and suppression strategy, utilising current evidence-based practice, while surveilling the global and local situation daily. We implemented enhanced infection control procedures across 2400 homes, which were communicated to our

employees using multi-faceted channels including an electronic resource library, mobile and web applications, paper postings in locations, live webinars and direct mail. Using custom-built software applications enabling us to track patient, client and employee cases and exposures, we leveraged current public health recommendations to identify cases and to suppress transmission, which included the use of personal protective equipment. A COVID-19 case was defined as a positive nucleic acid test for SARS-CoV-2 RNA.

Results In the 100-day period between 20 January 2020 and 30 April 2020, we provided continuous support for 11 540 individuals with IDD. Sixty-four per cent of the individuals were in residential, community settings, and 36% were in intermediate care facilities. The average age of the cohort was 46 ± 12 years, and 60% were male. One hundred twenty-two individuals with IDD were placed in quarantine for exhibiting symptoms and signs of acute infection such as fever or cough. Sixty-six individuals tested positive for SARS-CoV-2, and their average age was 50. The positive individuals were located in 30 different homes (1.3% of total) across 14 states. Fifteen homes have had single cases, and 15 have had more than one case. Fifteen COVID-19-positive

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individuals were hospitalised. As of 30 April, seven of the individuals hospitalised have been discharged back to home and are recovering. Five remain hospitalised, with three improving and two remaining in intensive care and on mechanical ventilation. There have been three deaths. We found that among COVID-19-positive individuals with IDD, a higher number of chronic medical conditions and male sex were characteristics associated with a greater likelihood of hospitalisation.

Conclusions In the first 100 days of the COVID-19 outbreak in the USA, we observed that people with IDD living in congregate care settings can benefit from a coordinated approach to infection control, case identification and cohorting, as evidenced by the low relative case rate reported. Male individuals with higher numbers of chronic medical conditions were more likely to be hospitalised, while most younger, less chronically ill individuals recovered spontaneously at home.

Keywords Coronavirus, COVID-19, IDD, intellectual and developmental disability, outbreak

Background

The current pandemic involving the novel Coronavirus SARS-CoV-2, which causes the acute respiratory disease COVID-19, is a serious health threat to millions of people across the globe. Since first being identified in late 2019 in Wuhan, China (Zhu *et al.* 2020), the virus has spread rapidly and has caused over 3 million infections and a quarter of a million deaths (Dong *et al.* 2020). It is unknown how the virus may affect people with intellectual and developmental disability (IDD). Our organisation (BrightSpring Health Services, Louisville, KY) provides continuous support to over 11 000 individuals with IDD in the USA. To address the new threat posed by COVID-19, we developed and deployed a comprehensive outbreak preparedness and suppression strategy, with a primary objective of protecting the over 11 000 individuals with IDD that we support. In this report, we present the preparedness and mitigation methods our organisation has utilised in the 100 days since the first case of COVID-19 was confirmed in the USA on 20 January 2020. We report a COVID-19-positive case series of people with IDD

that summarises our initial experience in supporting individuals during the pandemic, and we identify predictors of hospitalisation. The aim of this paper is to describe how individuals with IDD have been affected in the first 100 days of the COVID-19 pandemic.

Methods

Outbreak management approach

Shortly after the first case of COVID-19 was confirmed in the USA, our health care organisation assembled a cross-functional team of medical, clinical, compliance, risk management, human resources, legal, communications and operations leaders throughout our organisation and formed an Outbreak Preparedness and Action Committee. The mission of the committee was to prepare for potential outbreaks and to act when necessary to protect, support and serve individuals with IDD as well as our employees. The committee worked to develop a comprehensive preparedness plan and served as a means of consolidating internal and external communications regarding COVID-19 questions, planning and response.

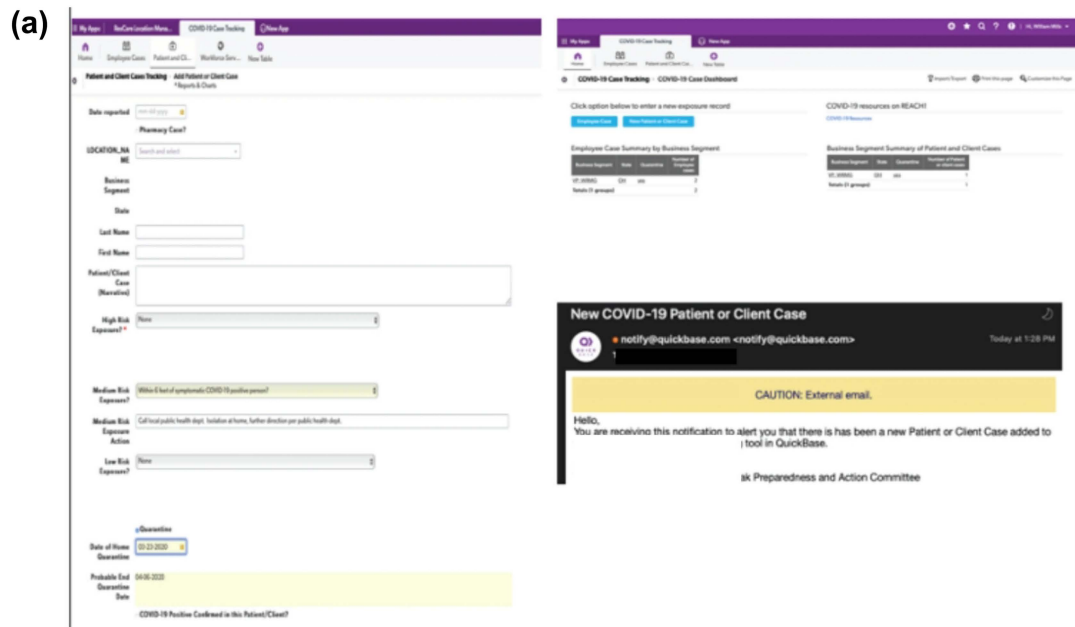
Beginning in early February 2020, we began monitoring the global situation daily, in order to understand transmission patterns, rate of spread and potential mitigation tactics and to highlight geographies that represent risk. Our primary monitoring source was the Johns Hopkins University Coronavirus Resource Center (Dong *et al.* 2020), in addition to the Centers for Disease Control and Prevention (CDC) and World Health Organization's COVID-19 situation rooms.

When assessing individuals with a fever and lower respiratory symptoms, such as coughing or shortness of breath, or potential exposures, we utilised the CDC's infection control guidance for health care professionals about Coronavirus (Centers for Disease Control and Prevention 2020b). A COVID-19 case was defined as a positive nucleic acid test for SARS-CoV-2 RNA.

In order to streamline COVID-19 case and exposure triage and reporting, we built a secure, cloud-based web application. The application leverages a QuickBase (QuickBase, Inc., Cambridge, MA) data structure to quickly capture confirmed

cases as well as potential exposures from our F1 operations sites across the USA (Fig. 1a). Entry of new patient cases auto-notified of our team of nurses. The nurses then advised the operations team at our local and regional sites to assist with triage and

planning. The clinical and operational plan included reinforcement and training on necessary quarantine and isolation procedures, as well as ordering additional personal protective equipment (PPE) supply. Entry of new employee cases or exposures



(b)

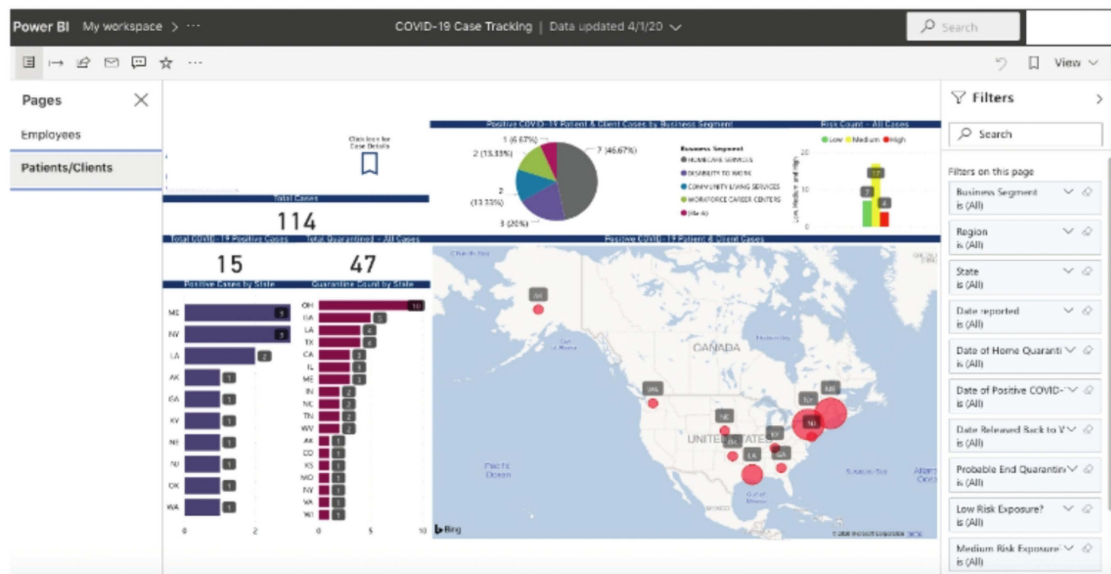


Figure 1. COVID-19 case tracking and data visualisation application. (a) COVID-19 tracking application that stratifies risk using CDC guidance. (b) COVID-19 case visualisation application. [Colour figure can be viewed at [wileyonlinelibrary.com](https://onlinelibrary.wiley.com)]

triggered an auto-notification to that location's human resources partner, who then worked with the clinical team and the employee to support triage and assessment. To optimise our ability to visualise COVID-19-positive individuals by business segment and geography, we also developed a business intelligence application, leveraging Power BI (Microsoft Corp, Redmond, WA) (Fig. 1b). The clinical, operations, human resources and executive teams used the visualisation tool throughout the day as a 'situation room' that enabled us to deploy specific mitigation tactics as cases emerged.

Comprehensive training on infection control policies and procedures was deployed through a combination of intranet resources as well as on-site and web-based live meetings. The infection control measures were adapted from the US Centers for Disease Control and Prevention, and the educational training enabling appropriate implementation of these measures was developed by our nursing quality team through a variety of live and recorded web meetings and slide presentations, videos and written policy and instructional documents. In order to streamline the procurement and distribution of PPE to our 2400 community living sites, we formed a new central supply function. Full PPE kits were assembled and shipped to all locations, in addition to extra allotments of surgical masks, hand sanitiser, cleaning materials and other items required to effectuate optimal infection control. As evidence suggests that COVID-19 may remain viable for hours to days on surfaces (Doremalen *et al.* 2020), we implemented additional cleaning and disinfection protocols in our IDD community living homes and offices.

To limit visitors as a potential vector of SARS-CoV-2 transmission, we enacted a policy that limited visits by people who are sick and posted signs near the entrance of our sites to remind visitors that if they are sick they should not visit until they are free of fever, cough and shortness of breath for at least 48 h. Shortly thereafter, we restricted all non-essential, non-health care provider visitors. Letters were sent to inform individuals and guardians of the visitor management policy, and we initiated mandatory visitor logs. In order to prevent employees from coming to work sick, we initially used a paper screening tool, followed by a cloud-based symptom screening application. For self-screening, all employees were asked to record their temperature

daily and answer simple screening questions as shown (Fig. 2). Symptomatic employees were isolated at home and tested for COVID-19 where testing was available. Where testing was not available, employees were prohibited from working until they met return to work requirements. For any COVID-19-positive employees, we isolated the employee at home until they met the CDC's return to work criteria for health care workers (Centers for Disease Control and Prevention 2020a).

To enable employees across all locations to have access to the most current information, policies and training materials, we developed and deployed over 100 COVID-19 and outbreak prevention and action resource materials for employee use. This resource library was posted to our organisational intranet (Fig. 3), and updates were also communicated by email to the organisation three times per week. The infection control resource library and trainings are available here.

Results

In the 100-day period between 20 January 2020 and 30 April 2020, we provided continuous support for 11 540 individuals with IDD. Sixty-four per cent of individuals were in residential, community settings, and 36% were in intermediate care facilities. The average age of the cohort was 46 ± 12 years, and 60% were male. One hundred twenty-two individuals with IDD were placed in quarantine for exhibiting symptoms and signs of acute infection such as fever or cough. In each case, a nurse, after assessing the individual's clinical stability, worked with regional and local operational leadership to evaluate the individual's likelihood of being able to maintain isolation protocol, as well as weighing practical considerations such as whether a given home could provide adequate physical separation between the quarantined individual and others living in the home. Sixty-six individuals tested positive for SARS-CoV-2 by nucleic acid test (Table 1), with an average age of 50. The positive individuals were located in 30 different homes across 14 states, which represents 1.3% of our total number of IDD homes. Fifteen homes have had single cases, and 15 have had more than one case. One home has had six cases, and two homes have had five cases. For each positive case, the

Employee ID
1234567

Email
User.name@

First Name
User

Last Name
Name

Please let us know if you have any of the following (Check all that apply)

- Fever greater than or equal to 100.4° F(37.8° C), and a cough or shortness of breath?
- Have you traveled internationally or on a cruise ship within the last 14 days ?
- Have you or anyone in your immediate household had close (within 6 feet) contact with someone who is under investigation for, or has laboratory-confirmed COVID19 within the last 14 days

What was your temperature(F) today?

If you have any of the above symptoms or exposures, we ask that you contact your supervisor or HR representative immediately and prior to going to work.

Thank you for your understanding and cooperation in helping us keep everyone safe.

I certify that this information is accurate to the best of my knowledge and that I will report any changes in these conditions immediately.

Submit **Log out**

Figure 2. Employee symptom screening application. [Colour figure can be viewed at wileyonlinelibrary.com]

local and/or state health department was notified, and any additional guidance was implemented.

Fifteen COVID-19-positive individuals were hospitalised. As of 30 April, seven of the individuals hospitalised have been discharged back to home and are recovering. Five remain hospitalised, with three improving and two remaining in intensive care and on mechanical ventilation. There have been three deaths.

One individual with IDD who died was an 80-year-old male with multiple chronic medical and mental health conditions, including anaemia, diabetes mellitus, dysphagia, constipation, hypertension, dementia and schizophrenia. He was admitted to the hospital's COVID-19 isolation unit with altered mental status and fever, tested positive for COVID-19 and died 1 day later. The second individual who died

Preview	File Name	Category	Last Modified	Format
	Daily_Infection_Control_Update	Isolation Procedure	April 24, 2020	PDF
	Guidance_for_Large_or_Extended_Families_Living_in_the_Same_Household	Employee Reference	April 21, 2020	PDF
	What_to_Do_if_You_Are_Sick_With_COVID-19	Employee Reference	April 21, 2020	PDF
	Isolation_of_Client_or_Patient_Presentation	Isolation Procedure	April 17, 2020	PDF
	Coronavirus_and_Infection_Control_PowerPoint_Presentation	Isolation Procedure	April 17, 2020	PDF
	Employee_Quarantine_Presentation	Isolation Procedure	April 16, 2020	PDF
	PPE_Request_Form	Employee Reference	April 15, 2020	PDF
	Using_Respirator_Masks_Without_Fit-Testing_Availability	Employee Reference	April 13, 2020	PDF
	PPE_Donning_and_Doffing_Instructions	Employee Reference	April 10, 2020	PDF
	COVID-19_and_Adult_CPR	Employee Reference	April 10, 2020	PDF
	Post-Isolation_Cleaning_Checklist	Isolation Procedure	April 9, 2020	PDF

Figure 3. COVID-19 educational and practical resource hub. [Colour figure can be viewed at wileyonlinelibrary.com]

was a 74-year-old male, hospitalised after developing fever and cough. He had chronic kidney disease, hypertension, gout, hyperlipidaemia, osteoarthritis and hyperthyroidism. He died 5 days into the admission of respiratory failure. The third individual who died was a 59-year-old female with a history of

hypertension, chronic constipation and anxiety disorder who developed fever and cough. She was hospitalised and died during the hospitalisation of respiratory failure. Overall, we found that those individuals who were hospitalised had a higher number of chronic medical conditions, were more

Table 1 Population with intellectual and developmental disability in 24/7 support programs and COVID-19 cases in the first 100 days of the COVID-19 pandemic (20 January 2020 to 30 April 2020)

	<i>n</i>	Male <i>n</i> (%)	Age in years Mean (SD); min–max	Number of chronic medical conditions Mean (SD); min–max
COVID-19 positive	66	45 (68%)	50 (14); 18–80	5.8 (4.5); 0–21
Not hospitalised	51	35 (69%)	48 (14); 18–74	4.9 (2.8); 1–14
Hospitalised	15	12 (80%)	55 (14); 31–80	7.9 (6.5); 0–21
Deceased	3	2 (67%)	71 (8.8); 59–80	7.3 (2.9); 4–11

often male and were older than those not requiring hospitalisation.

Discussion

While emerging SARS-CoV-2 antibody testing is indicating a prevalence in some areas between 5% and 14.9% (County of Los Angeles Public Health 2020; New York State Department of Health 2020), the actual prevalence of infection in the general US population, as well as how many individuals with IDD are affected, remains unclear. In the USA, at least 5700 (12.8%) of the approximately 44 500 nursing homes and assisted living facilities have reported a COVID-19 case (Nadolny & Kwiatkowski 2020). To date, 1.3% of our IDD homes have had at least one COVID-19-positive case. We report 66 positive cases in the first 100 days of the USA. COVID-19 outbreak in our IDD population of 11 540. Less than one quarter required hospitalisation, and those who did were more likely to have a higher chronic number of chronic medical conditions and were more often male. COVID-19-positive individuals with IDD share similar risks for increased disease severity requiring hospitalisation as the general population (Wu & McGoogan 2020), with older individuals with higher numbers of chronic medical conditions at risk for being most severely ill, while most younger, less chronically ill individuals recover spontaneously.

Overall, we found that a highly coordinated and frequently communicated approach to infection control, employee screening and visitor management facilitated the relatively low prevalence of COVID-19 in our congregate settings. Within our homes, we were able to readily isolate in place higher functioning individuals with IDD. Isolating infected individuals with significant behavioural conditions was more

difficult, requiring frequent staff redirection to their room, and additional assistance with hand hygiene, cleaning and mask replacement. COVID-19-positive individuals with IDD who did not require hospitalisation were able to wear a mask, isolate in their room and recover with symptomatic support, without utilisation of acute care. In a home with five positive individuals, four staff members also tested positive. In this home, after consulting with the Department of Health, asymptomatic, COVID-19-positive direct support personnel elected to shelter in place along with the affected individuals with IDD to provide needed support, as well as to avoid potential broader transmission to other homes, and into the community. The authors found it heartening that employees of the organisation donated additional food, activities, games and additional recreational supplies to help morale in the quarantined home. More generally, when a home had more than one case, efforts were made to cohort the positive individuals together, and to have the cases supported by any asymptomatic COVID-19-positive staff who donned appropriate PPE, and to create physical separation between affected and non-affected individuals within a home.

In the next phase of our response to COVID-19, we plan to utilise diagnostic testing to enable a more precise approach to identification of cases, assessment of exposure risk and triage. We are currently procuring SARS-CoV-2 diagnostic testing capabilities to enable rapid point of care (POC) testing for individuals served and employees. Overall, we expect the POC testing capabilities to provide more rapid access to accurate diagnosis – enhancing safety – while decreasing unnecessary isolation for non-infected individuals with IDD and employees. We are pursuing a ‘two-pronged’ approach to testing

that includes nasopharyngeal swab for SARS-CoV-2 nucleic acid to diagnose acute infection for those who are acutely symptomatic and a rapid POC test for IgM and IgG antibodies against SARS-CoV-2 to determine recent or past infection by demonstrated immune response.

In the first 100 days of the COVID-19 outbreak in the USA, we observed that people with IDD living in congregate care settings can benefit from a coordinated approach to infection control, case identification and cohorting, as evidenced by the low relative case rate reported. While all congregate living settings pose challenges for infection control with a highly contagious pathogen, we believe that vigilant infection control procedures, case and exposure documentation and real-time data analysis can be enablers of optimal, coordinated outbreak response.

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Conflict of Interest

No conflicts of interest have been declared.

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