

SPECIAL ISSUE ARTICLE

Supporting the needs of people with intellectual and developmental disabilities 1 year into the COVID-19 pandemic: An international, mixed methods study of nurses' perspectives

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Abstract

As the largest public health crisis within a century, the COVID-19 pandemic has caused long-term disruption in the support systems of people with intellectual and developmental disabilities (IDD) across the globe. The purpose of this study was to investigate challenges and ameliorative strategies to supporting the basic care needs of people with IDD 1 year into the pandemic, as experienced by nurses who specialize in IDD nursing. We surveyed a convenience sample of 369 nurses from across North America, Europe, and Australasia using a 52-item online questionnaire. Descriptive statistics were used to rank the greatest challenges and the degree of support available to nurses, and manifest content analysis was used to analyze open-ended responses related to ongoing challenges and ameliorative strategies. Results of descriptive analyses revealed consistent findings across global regions in terms of the challenges faced by nurses; the greatest challenges related to supporting or enabling socialization with family/friends, ensuring adequate day programming or educational services, identifying/planning alternative entertainment activities, ensuring adequate staffing of familiar support workers and caregivers, and managing challenging behaviors related to change in daily routine and activities. Nurses described a considerable degree of support offered by their organizations in terms of flexibility in scheduling related to family obligations and paid time off for COVID-19-related isolation and quarantine. Content analysis of open-ended survey responses revealed numerous challenges related to: (1) client socialization, meaningful activity, and mental/behavioral health; (2) interpreting, keeping up with, and helping others to understand COVID-19 guidelines; (3) access to, quality of, and continuity of care; and (4) COVID-19 fatigue and the influence of time. Overall, our study highlights ongoing issues

Abbreviations: DSP, direct support professional; IDD, intellectual and developmental disabilities; UK, United Kingdom; UN, United Nations; USA, United States of America.

with access to care and support, exacerbated by the pandemic, and the importance of having meaningful activity and socialization for overall well-being of people with IDD during a long-term public health crisis.

KEYWORDS

COVID-19, intellectual disability, nursing, policy

INTRODUCTION

The COVID-19 pandemic has highlighted the physical, mental, and social vulnerabilities of people with IDD and their carers (Doody & Keenan, 2021).¹ Data from the United States and the United Kingdom reveal that people with IDD have faced higher mortality rates from COVID-19 than their counterparts without disability (FAIR Health, 2020; Gleason et al., 2021; Spreat et al., 2020; Williamson et al., 2021). People with IDD are at greater risk for serious illness from COVID-19 due to underlying health conditions, limitations in understanding the disease and risk minimization strategies, and decreased ability to social distance for those living in congregate care settings and/or those who are reliant on a professional carer for their daily needs (Doody & Keenan, 2021). High rates of social isolation and loneliness exacerbate existing health disparities for a large proportion of people with IDD (McVilly et al., 2006). Government mandates, often overnight, that stop all social contacts unduly affect the health and well-being of people with IDD who are less likely than others to be able to understand and process rationales that suddenly alter their usual rhythm of life (Desroches et al., 2021). Longstanding socioeconomic and political conditions that produce obstacles for people with IDD to receive equitable, appropriate, and effective physical and mental health care further contribute to poor outcomes (Gleason et al., 2021).

Nurses are an important member of the support team for people with IDD. Due to disparate nonmodifiable genetic and metabolic factors, fully modifiable chronic illnesses, and poor access to and uptake of health prevention (Cooper et al., 2015), people with IDD have a higher rate of multiple chronic and complex health conditions than people without IDD, which often require nursing support (Wilson et al., 2020). While historically most care of people with IDD took place in the family home, IDD nursing, as a nursing specialty, arose with the institutionalization movement of the first half of the 20th century, as many people with developmental disabilities were segregated away from society in large institutions with nurses delivering and overseeing care (Auberry, 2018; Boschma, 2020; O'Reilly et al., 2018). With the deinstitutionalization movement of the 1960s, most IDD nurses

now practice in community settings, where the majority of people with IDD now reside (Auberry, 2018; Emerson & Hatton, 2008; O'Reilly et al., 2018). IDD nurses are now more dispersed and employed in a wide variety of settings, including the private homes of people with IDD and their families, schools, group homes, intermediate care facilities, day habilitation centers, community-based support centers, the remaining large institutions, etc. Although the discipline of nursing has received increased attention during the COVID-19 pandemic in terms of media attention, research, and support initiatives for nurses, nurses who specialize in IDD nursing have not received the same level of attention. This is even though IDD nurses support a population who is devastatingly impacted by COVID-19. Sensing this gap, in April of 2020, we surveyed 556 IDD nurses in the United States about their challenges in meeting the care needs of people with IDD during the pandemic (Desroches et al., 2021). Our findings revealed myriad challenges across socioecological levels, with the greatest challenges related to personal protective equipment (PPE), environments and conditions engendering challenging behaviors, and helping people to understand COVID-19 guidelines and mandates (Desroches et al., 2021). Expert commentary from England and Scotland about nursing support to people with IDD during the early COVID-19 pandemic highlights these same challenges (Dean, 2020; Middleton et al., 2021).

Given the fact that our study was conducted during the initial COVID-19 surge in the United States in Spring of 2020, we sought to better understand whether our findings would be generalizable to 1 year later into the pandemic and to other English-speaking countries where the IDD nursing specialty exists, because as of Spring 2021, our study was the only empirical research study that we were aware of in the world that represented the perspectives of the IDD nurse during the pandemic.

Research exploring the differences in social policy and COVID-19 responses related to people with IDD across countries is lacking. Pincombe et al., (2021) summarized general COVID policy responses across 113 countries and found that comprehensive containment policies, including travel restrictions and school and workplace closures, were implemented in a standardized



fashion across most countries. However, COVID-19 response related to disability has varied across countries. The United Nations' (UN) published guidance related to COVID-19 and the human rights of people with disabilities and identified countries with promising practices (United Nations, 2021). In the United States, the Office of Civil Rights issued a bulletin to prohibit discrimination based on disability in medical care and to ensure outreach and accessibility of information to people with disabilities. In Canada, a COVID-19 Disability Advocacy Group was formed with participation of people with disabilities and advocacy organizations to address disability specific issues and strategies. In the United Kingdom, a program of support for parents and caregivers of people with disabilities was implemented, and exceptions were made for people with autism and other disabilities to go outside when strict confinement rules were in place. In New Zealand, the Ministry of Health has dedicated space on its website to provide accessible information, including in sign language and easy to read format.

The purpose of our study was to assess the experiences of nurses supporting people with IDD 1 year into the COVID-19 pandemic and to compare IDD nurses' experiences across six English-speaking countries with differing disability nursing care systems and responses to COVID-19, to guide collaborative recommendations for policymaking and nursing practice for future public health crises. Our research questions were as follows:

- What are the greatest challenges to IDD nurses across the globe in meeting the care needs of people with IDD 1 year into the COVID-19 pandemic?
- How much and what types of support are nurses receiving within their organizations?
- What challenges and strategies employed to overcome these challenges are reported by nurses related to enacting COVID-19 guidelines during the pandemic?

METHODS

To examine the perceptions and experiences of IDD nurses 1 year into the pandemic, a convergent mixed methods design was utilized, where qualitative and quantitative data were collected simultaneously (Creswell & Plano Clark, 2017). Data analysis occurred of two parts. For the first part, the quantitative data were analyzed and "integrated" with statements from the qualitative data that exemplified findings from the quantitative data. We provide a joint display table, which is the visual representation of the integration of the two data sets (Creswell & Plano Clark, 2017). In the second part, manifest content analysis was applied to the qualitative data to

capture challenges and ameliorative strategies not identified in the quantitative survey.

Sample and setting

Research team members in the countries of the United States, Canada, Ireland, the United Kingdom, New Zealand, and Australia, recruited licensed or registered nurses currently providing, directing, consulting, or managing the care of people with IDD in their respective countries. Excluded from participation in this study were retired nurses, unlicensed student nurses or caregivers, and those not currently practising IDD nursing. Nurses were recruited via emails sent by the research team members through their respective IDD national or regional nursing networks. Snowball sampling was also employed as the email requested that the recipient share the study invitation with other IDD nurses in their personal or professional networks. This request served to reduce bias associated with belonging to a professional nursing organization.

Data collection

Ethics approval was obtained from the Institutional Review Board of the University of Massachusetts Dartmouth. The email invitation included a brief description of the study, inclusion and exclusion criteria, the primary investigator's contact information, and a link to the study. Upon clicking the link, potential participants were presented with the study information sheet. Implied consent was obtained from all participants who clicked "yes" in agreement to participate; those who agreed were then presented with the survey items on subsequent screens. The survey was open from March 4 to May 20, 2021.

Measures

A 52-item online questionnaire was used to collect data from participants. The questionnaire was adapted from our April 2020 31-item questionnaire, whose development we have previously described (Desroches et al., 2021). For this study, we included additional items based on challenges identified in the first study that were not captured in the questionnaire. The resulting questionnaire was comprised of 52 items: 44 quantitative items assessing the degree of challenges faced by nurses in meeting the needs of people with IDD during the COVID-19 pandemic in the domains of health needs, social needs, support needs, and COVID-19 needs,

5 quantitative items assessing the degree of support offered to nurses, and 3 open ended items exploring ongoing challenges and ameliorative strategies related to COVID-19 guidelines, grief, and telehealth. The questionnaire was reviewed by the research team for face and content validity and minor revisions were made to reflect language universally acceptable across countries. The quantitative items were rated using a 5-point Likert scale anchored with the endpoints of 1-“not at all” to 5-“extreme.” The open-ended items elicited the nurses’ first-hand experience of challenges related to the pandemic and strategies used to meet these challenges, using free-text entry boxes.

Data analysis

Descriptive statistics using IBM SPSS software version 27 characterized the degree of challenges faced by nurses and the degree of organizational support offered to nurses during the COVID-19 pandemic. We analyzed all item responses individually as we were interested in the specific results for each item, not an overall level of challenge or support as with a psychometrically tested scale, thus missing data were not a concern. Because we were not able to recruit an adequate number of nurses outside of the United States to power inferential statistical tests, we did not test for statistically significant differences by country. We grouped the countries in pairs by global region (United States/Canada, the United Kingdom/Ireland, and Australia/New Zealand) for ease of comparison. Two research team members identified, by consensus, nurses’ comments from the qualitative data that illustrated each of the five most highly rated challenges faced by nurses of each global region to meeting the support needs of people with IDD.

Manifest content analysis was used to examine nurses’ responses to the following open-ended questions: What ongoing challenges are you facing in enacting COVID-19 pandemic guidelines related to care of people with DD you support? What strategies are you using to meet these challenges?

Manifest content analysis is used to compare and describe what is present or observable in the text and develop conclusions from the collected data, with the following four stages: decontextualization, recontextualization, categorization, and compilation (Bengtsson, 2016). In the decontextualization phase, line by line coding was performed individually by three researchers for the 265 responses to open ended questions from nurse participants. After reading through all the data, the individual researchers identified relevant textual data and inductively derived codes. During the recontextualization phase, the individual researchers reread the data to check that no data

were excluded related to the study aim as captured by their individual list of codes. During categorization, the individual researchers grouped similar codes into sub-categories. Because our aim was to identify common nursing challenges across countries, we compiled codes into sub-categories only if the coded challenge was represented in more than one country. Examples of coding sub-categories included: socialization needs, behavioral concerns, guidelines, access, advocacy, policy, safety, staffing issues, telehealth/online technology, and COVID fatigue. To maximize the identification of strategies to assist nurses to address the challenges of the COVID-19 pandemic, we did not limit sub-categories based on being represented in a single country. During the categorization stage, the three researchers compared their sub-categories and identified, through a consensus-making discussion via videoconferencing software, four major qualitative categories. In the fourth stage, compilation, realistic conclusions were identified, with two of the researchers together selecting appropriate quotations for each qualitative category, and the entire research team reviewing the results to consider the reasonableness and logicity of the results and how the results relate to existing literature. Trustworthiness of the content analysis was promoted by triangulation of the data, with independent analysis of the data by three experienced qualitative researchers, followed by comparison and consensus building, as previously described.

RESULTS

In total, 369 nurses responded to our online survey, 306 of whom responded to the demographic section of the online survey, the results of which are presented in Table 1. The majority of nurses were from the United States ($n = 255, 69.1\%$).

Quantitative results

A joint display of the descriptive analyses of the five most highly rated challenges faced by nurses of each global region to meeting the support needs of people with IDD, with illustrative comments from the qualitative data for each item, is presented in Table 2.

In Table 3, we present the descriptive analysis of the items related to nurses’ level of support within their organizations. While we were not adequately powered to compare results across countries, the findings reveal that the mean score of the level of support for nurses in terms of hazard pay for COVID-19 exposure was in the “slight to moderate” range in the United States, while nurses in other countries rated hazard pay support between “not at all” and “slight.” In contrast, the mean

TABLE 1 Participant characteristics by country

Practice setting	United States (n = 255)	Canada (n = 5)	United Kingdom (n = 11)	Ireland (n = 14)	Australia (n = 12)	New Zealand (n = 9)
Hospital or medical center	1/0.4%	1/20%	2/18.2%	0	1/8.3%	3/33.3%
Outpatient clinic	3/1.2%	0	1/9.1%	0	2/16.7%	1/11.1%
Public residential institution/agency	27/10.6%	1/20%	0	7/50%	0	1/11.1%
Private residential institution/agency	45/17.6%	0	1/9.1%	1/7.1%	1/8.3%	1/11.1%
Community-based group home	75/29.4%	2/40%	0	5/35.7%	7/58.3%	1/11.1%
Adult foster care/shared living	5/2%	0	0	0	0	0
Private duty	5/2%	0	0	0	0	0
More than one type of setting	36/14.1%	1/20%	2/18.2%	0	1/8.3%	1/11.1%
Other	58/22.8%	0	5/45.5%	1/7.1%	0	1/11.1%
Approximate number of COVID-19 cases at organization						
0	16/6.3%	0	1/9.1%	1/7.1%	6/50%	6/66.7%
1–10	67/26.4%	3/60%	2/18.2%	7/50%	4/33.3%	1/11.1%
11–25	51/20.1%	0	2/18.2%	3/21.4%	0	0
26–50	35/13.8%	1/20%	1/9.1%	0	0	0
More than 50	85/33.5%	1/20%	5/45.5%	3/21.4%	2/16.7%	2/22.2%
Approximate number of COVID-19 deaths at organization						
0	120/47.8%	4/80%	7/63.6%	4/28.6%	12/100%	9/100%
1–10	97/38.7%	1/20%	4/36.7%	10/71.4%	0	0
11–25	19/7.6%	0	0	0	0	0
26–50	7/2.8%	0	0	0	0	0
More than 50	8/3.2%	0	0	0	0	0
Have you tested positive for COVID-19?						
Yes	55/21.8%	0	2/18.2%	2/14.3%	0	0
No	200/78.4%	5/100%	9/81.8%	12/85.7%	12/100%	9/100%
Have you experienced the loss of a family member or close friend from COVID-19?						
Yes	73/28.7%	2/40%	3/27.3%	1/7.1%	1/8.3%	1/11.1%
No	181/71.3%	3/60%	8/72.7%	13/92.9%	11/91.7%	8/88.9%

score of the level of support for nurses in terms of emotional support was in the “moderate” range for Australia/New Zealand and Ireland/United Kingdom, while nurses in the United States/Canada rated emotional support between “slight” and “moderate.”

Qualitative results

Based on the analysis the following four major qualitative categories of challenges nurses faced in meeting the needs of people with IDD during the COVID-19 pandemic were identified: (1) Socialization, meaningful activity, and mental/behavioral health; (2) understanding

and complying with COVID-19 guidelines; (3) access to, quality of, and continuity of care; and (4) COVID fatigue and the influence of time. Twelve nurses (4.5%) reported no challenges or minimal challenges experienced because of the COVID-19 pandemic. Strategies identified by the nurses for each major qualitative category are presented in Table 4.

Socialization, meaningful activity, and mental/behavioral health

Being separated from friends, family members, and familiar paid carers due to social distancing guidelines, with

TABLE 2 Joint display of the five highest ranked challenges of each global region with exemplary qualitative responses

	Mean score/rank		
	USA/Canada	UK/Ireland	Australia/New Zealand
Ensuring appropriate day programming or educational services	3.9 (1)	3.65 (2)	3.76 (1)
Supporting people who cannot be out and about in the community, perhaps must quarantine, and who have had their usual day program disrupted is the biggest challenge (USA) Keeping people occupied when they are unable to attend day activities (Australia)			
Supporting, enabling socialization with family/friends	3.89 (2)	4.04 (1)	3.33 (3)
The main challenges are the lack of family interaction due to stay at home, social distancing, and older population families staying quarantined. Electronic communications work with some individuals; however, some do not seem to understand (USA) Issues relating to isolation from friends, family, and paid carers for people with ID (Australia) They were isolated from family... Sometimes we try to make phone or facetime arrangements, but it is harder for people with DD to see family they cannot hug or go visit (Canada) The main challenges were the social restrictions during lock down in NZ—not being able to see friends and family face to face, electronic platforms are a substitute but not the same (New Zealand) Using public health guidance, risk reduction strategies impact heavily on the social and activity opportunities for those with DD (Ireland)			
Ensuring adequate staffing of familiar support workers and caregivers	3.67 (3)	3.42 (3)	-
Challenges relate to availability of staff—particularly consistent staffing (Australia) Reduced staff due to inability of no cross over into another home (multiple group homes) . . . Can no longer have “relief list” (Canada) Staffing due to COVID guidelines (Ireland) Considerable need for additional staffing as everyone remained home for many months during the pandemic. Staffing levels so critically low that even meeting basic needs (showering, positioning, etc.) difficult to achieve some days (USA)			
Identifying/planning alternate entertainment activities (not including television)	3.52 (4)	3.38 (4)	-
The challenge is to try and make life nice for the service users in our care. We cannot go out on day trips or visit nice places and have dinner out. We try and come up with ideas for activities within the house due to level 5 restrictions. We can go out on the bus for a drive but cannot get off the bus. (Ireland) Individuals are not able to participate in community activities they enjoyed in the past and I think that a lot of facilities are struggling to keep individuals entertained and engaged while also quarantining (USA) Keeping people engaged in activities (New Zealand)			
Managing challenging behaviors	3.41 (5)	3.38 (4)	3.48 (2)
Struggling to meet the needs of those with behaviors of concern missing day services and their routine (Ireland) Challenging behaviors due to absence of regular programs/unable to facilitate regular outings (NZ) We have seen a great increase in the number of challenging behaviors, but I suspect that far more individuals are also struggling and not displaying challenging or dangerous behaviors. My concern is that folks are being traumatized by this, and we are not recognizing it (USA)			
Ensuring access to regular allied health specialists	-	-	3.33 (3)
The loss of face-to-face therapies and loss of stimulation and opportunities for sensory stimulation is unhealthy (USA) Appropriate and timely support from health and mental health professionals (New Zealand)			
Meeting mental health care needs and providing emotional support	-	-	3.33 (3)
It has been hard on people who like to hug/value personal touch and some of us decided that this was an acceptable risk under the circumstances given the risk minimization strategies we had in place (hand washing, etc) (New Zealand) Supports provided for recognizing mental health needs in ID population are limited (Australia)			

the simultaneous disruption of daily routines and activities, including work and day programming, was reported by many nurses ($n = 96$) as detrimental to the mental/behavioral health of people with IDD. Except for the United Kingdom, nurses in each country

identified how the long-term disruption in daily routines and absence of meaningful day-to-day activities contributed to rising rates of mental illness and challenging behaviors, in some cases requiring pharmacologic intervention.

TABLE 3 Level of organizational support for nurses per global region

Items	Mean score		
	USA/Canada (<i>n</i> = 260)	UK/Ireland (<i>n</i> = 25)	Australia/ New Zealand (<i>n</i> = 21)
Flexibility in scheduling related to childcare/ family obligations	3.17	3.27	3.24
Paid time off for COVID-related isolation and quarantine	3.04	3.24	3.35
Hazard pay for COVID-19 exposure	2.50	1.68	1.80
Emotional support	2.86	3.04	3.14
Resources for coping with grief and loss	2.65	2.81	2.67

Social distancing was reported as a challenge by nurses in every country surveyed. As one nurse from the United States stated “the absence of day program opportunities has proven quite challenging in managing person’s with IDD emotional health and well-being. Likewise, limitations of family/visitors has also made a difference in rising mental health needs.”

While the pivot to socialization via Facetime, Zoom, or telephone was widely used, nurses (*n* = 15) also described how this technology posed additional challenges for some people with IDD, including difficulties due to the person’s vision or hearing impairment, lack of technological equipment or skills, and limitations in the person’s ability to understand and meaningfully participate in virtual activities. Isolation and quarantine were aspects of social distancing that two nurses from the United States and Canada identified as concerning in terms of violating human rights. The loss of human touch due to social distancing was described as particularly difficult for people with IDD. One nurse from New Zealand described how she weighed the risks of spreading COVID-19 with the needs of those who value human touch, and decided, in some cases, that human touch was a greater need, especially considering other risk minimization strategies already in place.

Understanding and applying COVID-19 guidelines

Nurses described many challenges related to enacting COVID-19 public health guidelines. A lack of guidelines, conflicting guidelines, or clarity in the guidelines related to settings where people with IDD receive support was described by several nurses (*n* = 12), and resulted in nurses from the United States, Canada, and Ireland needing to develop guidelines or interpret existing guidelines for these settings, described as “daunting and a huge responsibility” (Ireland). The shortcomings of guidelines

that do not take into consideration the unique needs of people with IDD were articulated, including how having a designated COVID unit at a provider agency negatively affects healing and recovery by separating the person from their familiar support persons who best know their needs. Staying up to date with guidelines and adapting frequently changing guidelines was also identified (*n* = 13) as challenging. The abrupt guideline changes, and the resulting inability to prepare people with IDD for the changes to daily routine and activities, were problematic to those with IDD who thrive on order and routine.

Helping people with IDD, staff, and families to understand the need for COVID-19 guidelines, particularly the continued need for social distancing and masking, was reported by many (*n* = 33) of the nurses. The difficulty of people with IDD understanding COVID-19 guidelines was attributed in every case to the person’s level of ID, and a fine balance was described between explaining the necessary information while not frightening the person with IDD. Teaching staff all that they needed to know to keep people safe and ensuring they followed protocols was identified by many nurses (*n* = 27) as challenging, in particular, staff’s proper use of PPE and making sure that they did not come to work when ill or exposed to COVID-19. Pushback from families was a subject that several (*n* = 7) nurses identified as challenging, with some family members wanting the person with IDD to return to normal activities immediately despite the person not being vaccinated or able to tolerate wearing a mask, and other family members wanting to refrain from all outings until full vaccination.

Access, quality, and continuity of care and support

Across all countries surveyed, nurses described barriers to health care and disability support services during the COVID-19 pandemic.

TABLE 4 Ameliorative strategies identified by nurses for each qualitative category**Socialization, Meaningful Activity, and Mental/Behavioral Health***Socialization*

- Sending cards and care packages from people with IDD to friends and loved ones
- Telephone calls, virtual technology calls (Zoom, Facetime, and Google Duo) to maintain social connections visits through the window supplemented with telephone or virtual technology for sound
- Use of planned visits and emergency compassion visits
- Use of Internet for “visual awareness of what is happening outside of bubble”

Meaningful Activity

- Development of new person-centered goals, both COVID-19 and non-COVID-19 based
- Establishment and maintenance of daily home routine
- Going on community outings at nonpeak times of day
- Socially distanced outdoor activities and walks
- Virtual exercise classes
- Creation of in-home activity program: arts, crafts, exercises, movies, gardening, singing, dancing, fancy dress
- “Thinking outside the box”: Van rides to see new sights, outdoor holiday themed events, for example, Christmas lights or Halloween decorations, enlisting help from others to think of new activities
- Enlisting direct support professionals who know the person with IDD well to use their knowledge of the person to help encourage participation in activities
- Advocating with local leaders for decreased client to staff ratio at day program to allow return to program for those who need it
- Encouraging people with IDD to return to work and activities when safe and permitted to do so

Mental/Behavioral Health

- Providing emotional support and reassurance
- Use of trauma-informed approach for support of people with IDD during the pandemic
- Enlisting nursing students to “virtually” visit people with IDD to promote wellness, mental health, and reduce social isolation
- Use of stuffed animals, pillows, and weighted blankets to simulate human touch
- Weighing an individual's risk of COVID-19 with need for human touch
- Consulting with behavior specialists as needed related to change in routine and challenging behavior

Understanding and complying with COVID-19 guidelines*People with IDD*

- Educating people with IDD of protective measures taken to reduce risks of COVID-19
- Routine meetings with people with IDD to review guidelines and preteach before any/all outings
- Strong encouragement for people with IDD to receive vaccine and follow guidelines
- Accessible education materials for people with IDD (social stories, Easy Read, and video information)
- Regular opportunities for people to ask questions and express concerns
- Signs posted and stickers placed on the floor as visual reminders
- Frequent direction and redirection, verbal prompting for hand washing and social distancing
- Step-by-step programs to help support people with IDD to use PPE
- Use of social scripting emphasizing that “we are all in this together” and “we are all in the same boat”
- Staff role modeling of adhering to guidelines
- Enlisting family and team members to help people with IDD understand need for guidelines
- Gradual desensitization and different choices (e.g., face shields) for adherence to masking mandates
- 1:1 staffing for isolation, with a staff experienced with IDD

Staff and Families

- Daily emails to update/remind staff of COVID-19 guidelines
- Virtual meetings with staff (Zoom, Facetime) for staff education about guidelines
- Reviewing guidelines, in clear and concise writing, with families and staff to promote understanding

(Continues)



TABLE 4 (Continued)

Understanding and complying with COVID-19 guidelines

- Enlisting support of agency physicians and nurse practitioners to re-inforce COVID-19 guidelines with families and staff
- 24/7 COVID-19 hotline for staff calls related to COVID-19 questions/reporting of cases
- Designated COVID Compliance person at facility/residence to remind staff to adhere to guidelines
- Daily monitoring of staff signs and symptoms of COVID-19 with referral to testing as needed
- Reviewing guidelines, in writing, with families and staff to promote understanding
- Use of risk tools with communication of results to staff/families
- Encouraging people to keep person with IDD home from programs if guidelines are not being followed
- Requiring negative COVID-19 test for participants to return to residence from families who do not comply with guidelines
- State/regional nurse telephone call to every agency reporting a case of COVID-19 with follow-up email of listing of state and private resources and Powerpoint presentation on COVID-19 and infection control for education of people with IDD and staff

Modifying the Environment

- Implementing regular intervals for hand washing and sanitation
- Repurposing different areas of buildings to use to enhance social distancing
- Use of new homes as surge homes to keep people who have been recently discharged or had diagnostic procedures separate from medically frail people
- Rotating free time out of room for each person with IDD in the residence
- Staggered mealtimes to promote social distancing

Access, quality, and continuity of care and support

Access to and quality of health care

- Advocating for same level of care as person without IDD in mainstream care settings by discussing duty to care with health care providers
- Training staff to advocate for people with IDD in health care settings
- Educating local health care facilities on how to care for and support people with IDD
- Educating local public health department about pandemic-related needs of people with IDD
- Changing health care providers to those willing to provide care
- Requesting first or last appointment of the day for people with IDD unable to wear masks/socially distance
- Evaluate importance and appropriateness of face-to-face appointments on ongoing basis
- Use of telehealth for primary care appointments, as appropriate based on person's needs and risks
- Use of urgent care when health care provider refuses needed face to face visit
- Defer to primary care provider/general practitioner for specialist care, like eye exams, in the case of care refusal by specialist
- Working with national groups to elevate people with IDD in prioritization for care

Access to vaccination

- Liaising with individual's general providers to obtain vaccine
- Use of drive-up vaccination clinics
- Collaboration with local and state health departments to form a vaccine team to vaccinate people with IDD in group homes and residential settings

Access to and quality of disability direct support

- Hiring more staff and shifting day staff into residences while day programs closed to meet increased staffing needs due to more people remaining home
- Virtual job fairs and referral bonuses
- Incentive pay to retain existing direct support staff
- Emotional support of existing staff using frequent phone calls to the sites, asking how the staff is in addition to the people they are supporting, listening to them, answering questions and encouraging they reach out when needed, acknowledging that this is a difficult time, providing EAP [employee assistance program] phone number.
- Improved shift to shift communication so no shift is left feeling unsupported
- Holding staff accountable for coming into work when knowingly symptomatic or exposed to COVID-19

TABLE 4 (Continued)

Access, quality, and continuity of care and support

Supporting families to seek disability support from family/friends in the absence of formal supports

Identifying staff who had COVID or were COVID positive and reaching out to them to assist homes that were experiencing a COVID crisis. If staff are willing, they help at homes that have COVID.

Use of volunteers to prep meals and drop them off at homes to make meal times easier and bring needed supplies to homes to decrease the burden on staff in homes

Access to and quality of disability nursing support

Hiring nurses new to IDD but with considerable nursing experience

Frequent communication and collaboration with DSPs [disability support persons] to be “nurse’s eyes and ears”

Emotional support for the DSP

Meeting people outside for nurse visits to meet regulations for nursing supervision

Development of pandemic plans early in pandemic for future surges

Liaising with state/regional IDD nurse for support

Seeking out community of practice of other IDD nurses for support

Encouraging people to stay home from programs if guidelines are not being followed

Use of dynamic risk tools to prioritize work

Staying up to date on guidelines by checking CDC website daily

Participating in online COVID-19 education webinars for nurses

Access to PPE

Change PPE suppliers who will provide consistent supply without raising price

Use of reusable gloves for cleaning tasks rather than disposable gloves

Applying for grants, emergency funding assistance and community donations to purchase PPE

Continuity of Care

Use of patient portal information and multiple calls/messages for updates on hospitalized person’s condition

Using virtual technology to check in on people with IDD when nurse is prevented from visiting face-to-face, including when person is in acute or subacute care

Use of ICN to assist with coordination of medical and vaccination visits

Linking person to available service providers in the area

Support families to go outside of formal care network for assistance

Supporting families to seek disability support from family/friends in the absence of formal supports

Identifying staff who had COVID or were COVID positive and reaching out to them to assist homes that were experiencing a COVID crisis. If staff are willing, they help at homes that have COVID.

Volunteers that were not allowed into homes would prep meals and drop them off at homes to make meal times easier. Would also get supplies when homes were low if requested to decrease burden on staff in homes.

COVID-19 fatigue and the influence of time

Ongoing re-education and retraining

Ongoing nurse role modeling and demonstration of adhering to COVID-19 guidelines

Employee surveillance

Providing various types of mask to minimize masking fatigue

Encouragement: “We are almost through this”

Reminding people in a friendly manner of COVID safe practices

Presenting factual information in a variety of ways from factual sources

Posters and reminders about guidelines on display

Use of checklists

Regular discussion about COVID safe practices at staff meetings



Health care

Limited access to primary, specialist, mental health, and dental care was described by many ($n = 34$) of the nurses, in the form of closed offices during periods of shut down, or long wait times for needed appointments. In addition, there were numerous ($n = 12$) reports of practitioners, facilities, and transportation companies who refused to provide services to people with IDD who were not able to wear a mask. As stated by one nurse “We have some clients that simply will not wear a mask and therefore the physician refuses to see them” (USA). Care refusals due to mask intolerance also extended to vaccination appointments. Other challenges to vaccination included a slow rollout to people with IDD who did not reside in congregate care settings, and the inappropriateness of some vaccination sites for people with IDD who are medically frail, for example, in the case of long lines outside and cold weather.

One nurse described how “Supports provided for recognising mental health needs in ID population are limited” (Australia), with several ($n = 5$) nurses expressing concern over the poor availability of mental health care for people with IDD during the pandemic, especially given the increases in anxiety, depression, and challenging behaviors because of social isolation and disruption to routines.

Access to care changed over the course of the pandemic and was described as inconsistent across providers, as described:

I work as the nurse in a day program. The residences/families are responsible for MD [medical doctor] appointments. In the beginning of covid the residences report[ed] not being able to see the MD at all. Then it was via telehealth appointments. Some clients can see their PCP [primary care provider] while others are only allowed by telehealth appointments. (USA).

Telehealth was identified as a welcome alternative to long wait times for appointments, but as previously described, virtual technology posed challenges for some people with IDD. In addition to technology-related barriers, limitations in the usefulness of telehealth were identified for people with IDD with complex health conditions for whom face-to-face care is necessary. As stated by one nurse “Most of our clients/students need to be auscultated and have various tubes assessed and/or changed out. These things need to be done in person so telehealth is not an option” (USA).

The quality of face-to-face health care was also reported as challenging by some nurses ($n = 7$), related

to acute, primary, and mental health care services. As one nurse stated: “GP [primary] care is still questionable—limited understanding of disability and the implications of COVID on this group, and their supports, [for] mental health and well-being” (New Zealand).

With acute care, nurses described the challenge of acquiring needed reasonable accommodations or adjustments to care, related to moving around the organization, use of masks, and having a support person present in the hospital setting, to assist with communication and medical history. Problems with continuity of care were identified by three of the nurses: “Frequently these residents will come back from the ED [emergency department] without any medical information/ treatment records/ meds administered . . . because they cannot advocate for themselves” (USA); “Where the hospitals have been overwhelmed, we are finding that poor discharges are being made resulting in a decline in health or frequent readmission” (UK).

Disability support services

A dire shortage of staff, both nursing and direct support professionals (DSPs), was a challenge described by nurses in the United States, Canada, Australia, and Ireland ($n = 36$). In some cases, the staffing shortage related to COVID-19 guidelines. For example, in Canada nurses described how staff were not permitted to work in multiple group homes due to concerns of spreading COVID-19, which limited availability of staff, as well as tight restrictions on respite care and emergency beds. In the United States, with COVID-19-related limits on gathering size, day programs and work sites were forced to close. This increased demand for in-home staff support, with negative outcomes in the absence of available staff. One nurse reported that staffing levels were “so critically low that even meeting basic needs (showering, positioning etc.) [were] difficult to achieve some days” (USA). Barriers to the recruitment and retainment of qualified staff related to the poor compensation and difficult working conditions for DSPs. In addition to poor working conditions with long hours of overtime, nurses from the United States described how short staffing resulted from the fact that workers were able to make more on unemployment than coming to work. The quality of staff recruited and retained during the pandemic was also identified as a concern, as the staffing crisis necessitated that unqualified and unmotivated staff were hired to “be a body” (USA). At the same time, nurses also described the increased reliance on DSPs for health-related concerns including reporting signs and symptoms, taking daily vitals, and reporting changes in condition, as some nurses were separated from providing face-to-face care during the pandemic. This was concerning for nurses who recognized the limited training of

direct support staff to meet health-related needs. As stated: “The biggest challenge, from my point of view, is that many folks with IDD are living in group homes, cared for by DSPs with minimal education, being led by managers who themselves have limited education” (USA).

COVID fatigue and the influence of time

COVID-19 fatigue and time-related barriers to care were major challenges identified by nurses ($n = 20$) in the United States, New Zealand, and Australia. Nurses described: “both staff and clients are becoming fatigued with these issues” of social distancing and masking (Australia), “COVID exhaustion from the clinical team” (New Zealand), and:

COVID fatigue; individuals’ patience running out for loss of day programs, limit to day activities and the necessity of wearing masks; baseline support staff seems to be the same and getting sloppy at own adherence to protocols let alone reinforcing it for the individuals (USA).

Masking was a key element contributing to COVID-19 fatigue. Nurses reported the difficulty with wearing masks for those with sensory issues or behavioral challenges, and how “staff wearing face masks has had residents on edge as they cannot see facial expression and at times are unable to hear staff clearly” (Australia).

Nurses also described other challenges related to time. Nurses reported that obtaining PPE and supplies were issues earlier in the pandemic and had resolved as community transmission decreased. As previously described, COVID-19 guidelines were rapidly changed without time for advance planning and preparation for people with IDD and staff. Nurses had concerns about the amount of time people with IDD spent waiting for routine and urgent health care needs. Nurses’ time spent on COVID-19 impacted them personally and professionally. As one nurse stated: “The long hours and lack of leave may have long term impact on staff and recuperation” (Ireland).

DISCUSSION

This study highlighted, that for people with IDD, who are most likely to be in receipt of nursing care and support for often multiple and complex health problems, their existing entrenched and multiple disadvantages were exacerbated by the COVID-19 pandemic. IDD nurses were then left to work within an already stretched system

to continue to provide best practice but were hampered to achieve this due to the range of challenges identified. Nonetheless, with creative and “outside of the box” thinking, IDD nurses pivoted to innovative strategies to meet these challenges during this unprecedented global public health crisis. In the spirit of learning from this unprecedented crisis, we identify implications for future health care practice, policy, and research.

Implications for health care practice

Person-centered care for mental well-being

Despite differing government and health systems within the respective countries represented in our survey, the impact of COVID-19 manifests similar challenges. Our results support the need for greater understanding and promotion of person-centered approaches to care with intentional attention to supporting individuals with IDD, to the extent they are able, to discover and enjoy meaningful activities for their own well-being and mental health. This is especially important given that daily activities have been found to promote resilience during difficult times in people with IDD (Scheffers et al., 2020), by providing daily structure and a sense of predictability (Taggart et al., 2009). Recently updated IDD nursing standards and models all promote person-centered approaches to nursing care American Nurses Association (ANA) Ethics Advisory Board, 2020; Developmental Disabilities Nurses Association (DDNA), 2020; McCarron et al., 2018; Professional Association of Nurses in Developmental Disability Australia Inc. (PANDDA), 2021; Queen’s Nursing Institute & Queen’s Nursing Institute Scotland (QNI/QNIS), 2021, which are founded in the principles of respect for autonomy and self-determination, the driving purpose of the UN Convention for the Rights of Persons with Disabilities Optional Protocol (United Nations, 2006). Assisting people with IDD to construct and make choices that fit their skills and capacities in their daily lives is important to foster a “sense of control,” an important contributor to resilience during challenging times for people with IDD (Scheffers et al., 2020). None of the promising practices identified in the UN’s guidance for COVID-19 and the human rights of people with disabilities (2020) include enhanced supports for mental and social well-being, even though people with disabilities experienced greater social isolation and lower mental well-being than people without disabilities prior to the pandemic (Emerson et al., 2021).

In the United States, the National Center on Advancing Person-Centered Practices and Systems studied the experiences of people with disabilities during the COVID-19 pandemic and identified trauma as a single overarching theme



(Bailey et al., 2021). People with disabilities recommended person-centered strategies like those recommended by nurses in this study to help get through the trauma of the pandemic, including re-establishing routines and consistency, advanced planning, and promoting self-determination by honoring dignity of risk and informed choice (Bailey et al., 2021). Self-determination for people with IDD, however, is limited by the bias of health care professionals who largely operate from the medical model of disability, which identifies health care professionals as most capable to make decisions regarding people with IDD (Smeltzer, 2021). The COVID-19 pandemic presents the vital opportunity for IDD nurses to demonstrate their commitment to person-centered care, by championing informed choice for people with IDD and their network of supporters for decision-making. IDD nurses can be central to developing person-centered routines and procedures that allow a middle way between total isolation and full participation, as opposed to paternalistically promoting unquestioned adherence to all public health recommendations. The use of dynamic risk tools to appraise an individual's risks and facilitate conversations about care, as reported by one nurse in our study, is a strategy worth further investigation to move toward person-centered care during pandemics and public health crises.

Human rights and advocacy

The fact that socialization, meaningful activity, and mental/behavioral health were the greatest challenges identified in both the quantitative and qualitative data analyses raises a critical debate about the fact that while most members of the public were still able to see and spend time with family and friends, this was eliminated overnight for most people with IDD living in residential care, with often negative outcomes on health and well-being. If we were able to ask someone with IDD what they wanted and what risks they were prepared to take, would they opt for long periods of their life without contact, often centered on loving and touch-based interactions, from their family and loved ones? That is, much of the provision of care and support for people with IDD is about balancing duty of care versus dignity of risk, where we should always promote self-determination. Yet, with COVID that was upended for people with IDD without discussion and without finding out what they might have wanted. Person-centered approaches became much harder to maintain, if not impossible.

These findings are consistent with the perspectives of people with IDD themselves, who reported that the interruption of social relationships with family and friends was the greatest consequence of lockdown, followed by missed recreational and leisure activities (Navas

et al., 2021). Significant differences in self-reported quality-of-life outcomes of people with IDD in pre-pandemic 2019 and 2020 have been reported, with people with IDD being less likely to interact and participate in the community, have intimate relationships, and experience continuity and security (Friedman, 2021), all of which stand in violation of the UN's Convention on the Rights of Persons with Disabilities Optional Protocol (United Nations, 2006). IDD nurses and health professionals must act on their duty to safeguard the human rights of people with IDD and to support people with IDD to engage in self-advocacy efforts, particularly during public health crises where human rights of people with disability are more highly threatened.

Implications for policy

Public health preparedness

Our findings support the need to strengthen connections between public health and people with IDD and their support persons, with respect to preparedness and education about the needs of people with IDD. IDD nurses, with professional knowledge related to both infection control and the health needs of people with IDD, are important players to forge connections between the disparate public health, health care, and disability support systems. Ensuring that guidelines are accessible, understandable, responsive to the unique needs of people with IDD, relevant to settings where people with IDD live, work, and spend their time, and are released with time for advance planning, are important contributions that IDD nurses can make to public health planning and response. We recommend, as an important first step, the inclusion of IDD nurses on all public health task forces.

Nursing and direct support professional education

Access to equitable care for people with IDD is a longstanding problem, exacerbated by the COVID-19 pandemic, as our findings reveal, and additional consideration should be given to an expansion of the IDD nursing role to fill this health care gap. A few such models currently exist. In the United Kingdom and Ireland, IDD nursing education includes preregistration and postgraduate nursing specialty programs, with nurses being the only health profession specifically educated in IDD (Bur et al., 2020). The learning disability liaison role in the United Kingdom provides IDD nursing specialist support to people with IDD, their supporters, and health care

professionals in the general hospital setting (Brown et al., 2012). In Ireland, IDD clinical nurse specialists and nurse practitioners provide specialist health care to people with IDD (McCarron et al., 2018). In Australia, the preregistration IDD nursing specialty was discontinued in 1999 in favor of general nursing education. In 2015, in Queensland, Australia, the disability nurse navigator role was rolled out to assist people with complex health needs and disability to move efficiently and effectively through acute, sub-acute, and community care (Brunelli et al., 2021). In the United States, general nursing education has been the long-standing paradigm, with little to no disability content in undergraduate or graduate nursing curricula (Auberry, 2018). The opportunity exists for global collaboration to develop innovative nursing roles and best practices to address the mental and physical health care needs of people with IDD throughout the lifespan.

Furthermore, our study results highlight the important role of the DSP in meeting physical, mental, and social health needs of people with IDD during the pandemic. An extreme staffing shortage of DSPs prior to the pandemic (Baines et al., 2019; President's Committee for People with Intellectual Disabilities, 2017; Wolfert & Dijkema, 2020) has now exceeded crisis levels with negative physical and mental health outcomes for people with IDD. Our results reveal that during the pandemic, many nurses relied on DSPs to be their "eyes and ears" while nurses were prevented from seeing people with IDD face-to-face. This is consistent with research on the experiences of DSPs, who have identified less frequent contact with other professionals during the pandemic, and variable effectiveness of digital communication (Embregts et al., 2020). Several nurses in this study expressed concern over the lack of education and training of DSPs and the negative effects on people with IDD. DSPs are, in fact, part of the healthcare workforce, but receive little training in basic issues of supporting health and being part of a coordinated team to manage health (Baines et al., 2019; President's Committee for People with Intellectual Disabilities, 2017). High turnover rates due to lack of recognition and low wages contribute to the challenge of recruiting, retaining, and training a qualified DSP workforce (Baines et al., 2019; President's Committee for People with Intellectual Disabilities, 2017). We strongly advocate for enhanced education, increased compensation, and access to career pathways to support recruitment and retention of DSPs. Clear policy related to delegation of nursing care to DSPs is also needed, as in many settings, the IDD nurse does not have legal supervisory authority of DSPs who provide most of the hands-on care to people with IDD (Auberry, 2018). A clear

delegation policy would legally protect IDD nurses and DSPs as they collaborate to ensure the health and safety of people with IDD during the pandemic and beyond.

Strengths and limitations

While ours is the only line of research that we are aware of which explores the experiences of the IDD nurse during the COVID-19 pandemic, this study has several limitations. To minimize participant burden, we did not collect detailed demographic information from nurses, including gender or racial information. Despite our best efforts at sampling, our sample size from countries outside of the United States was small, limiting our ability to conduct statistical cross-country comparisons. Finally, the cross-sectional nature of our study captured each nurse's responses at a single point in time; had we collected longitudinal data, nurses' responses may have varied based on differences in COVID-19 severity and public health response during the 3 months of data collection.

Implications for future research

More research on nursing challenges and ameliorative strategies to caring for people with IDD during public health crises from an international perspective is needed, with a larger international sample size and inclusion of other countries where the IDD nursing specialty exists. Research is needed that compares COVID-19 policy responses and outcomes for people with IDD across countries and settings. In addition, future research should explore how IDD nurses and DSPs can employ person-centered strategies to reduce the trauma of public health crises for people with IDD and to clarify for whom and in what situations telehealth can be used safely and effectively for people with IDD. Intervention development is needed to support people with IDD to cope with pandemic-related changes and promote mental health and well-being, and to bridge the health care access gap with innovative IDD nursing care delivery models.

CONCLUSION

The COVID-19 pandemic exposed existing but unrecognized inequities for people with IDD. This is especially tragic in a group already experiencing inequitable distribution of healthcare, compounding existing disadvantages across a multitude of life domains. These problems are accentuated by the stigma associated with disability, ableism, and a lack



of understanding of the healthcare needs of this population. Nurses as health care providers and advocates for self-determination, social justice and equitable care for persons with IDD, are central to the solutions to these problems and need to be included in healthcare and policy decision-making.

CONFLICT OF INTEREST

The authors have no conflict of interest to declare.

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ENDNOTE

¹ Due to the international perspectives shared in this manuscript, varied acronyms are used to reference the conditions of intellectual and developmental disability. Intellectual disability (ID) is a cognitive disability with limitations in intellectual functioning and adaptive behavior, including conceptual, practical, and social skills (AAIDD, 2021). This is referred to as learning disability (LD) in the United Kingdom. Developmental disability (DD) represents a broader group of conditions involving physical, cognitive (including intellectual), language and/or behavioral impairments that arise before adulthood, and which impact day-to-day functional activities and endure throughout a person's lifetime. DD conditions include but are not limited to ID, autism, cerebral palsy, attention deficit disorder, and congenital blindness or hearing loss. Because ID and DD commonly overlap, we will use the acronym IDD in this article to refer to this population. We will not change the original acronyms used by study participants when presenting direct quotes.

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