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COVID-19: Evolving challenges and opportunities for residential and vocational intellectual disability service providers

Henrietta Trip[1] | Ruth Northway[2] | Elizabeth Perkins[3] |
Brigit Mirfin-Veitch[1,4] | Reece Adams[5]

[1]Centre for Postgraduate Nursing Studies, University of Otago, Christchurch, New Zealand

[2]Faculty of Life Sciences and Education, University of South Wales, Pontypridd, UK

[3]Department of Child and Family Studies, University of South Florida, Tampa, Florida, USA

[4]Donald Beasley Institute, Dunedin, New Zealand

[5]Centre for Developmental Disability Health, Monash Health, Melbourne, Victoria, Australia

Correspondence
Henrietta Trip, Centre for Postgraduate Nursing Studies, University of Otago, Level 3, 72 Oxford Tce, P O Box 4345, Christchurch 8140, New Zealand.
Email: henrietta.trip@otago.ac.nz

Abstract

The sustainability of service provision continues to be a challenge in the field of intellectual disability due to changes in delivery as part of intermittent or ongoing lockdown requirements during the COVID-19 global pandemic. There are many facets to this that may have temporary or permanent impacts not only on the sector, but ultimately for service access and outcomes for people with intellectual disability themselves. This narrative literature review identifies both opportunities for, and impacts on, service providers across jurisdictions. These are explored in terms of the effects that suspension, adaptation, continuity or the cessation of service delivery have had, and those that are projected. Such impacts include, but are not limited to, changes in service access and delivery, employment roles and responsibilities, financial sustainability and the need to diversify the services and supports provided and how they are delivered. The relevance of these impacts for family carers and people with intellectual disability is also discussed. Nonetheless, there have also been opportunities which inform the shape of service delivery and pandemic planning into the future.

KEYWORDS
COVID, impacts, intellectual disability, practice, service provision

INTRODUCTION

Service provision is a multifaceted concept. It maps the identified unique needs of a person against the possible responses that could be provided either by volunteers, individuals or services that are formally recognised as having the skills, resources and/or funding to reduce the impact of unmet immediate or long-term support needs. Since the closure of long-stay settings in many countries, service provision for people with intellectual disability can be delivered in a variety of ways: in a person's own home in which they may live independently, with family or flatmates, in a supported living or residential context (Bigby & Ozanne, 2001), or in-patient settings (Perera & Courtenay, 2018). Individuals may also attend school (either mainstream or population specific), vocational settings which

were, historically, called sheltered workshops (Visier, 1998), or be supported to attend and achieve ongoing education and employment opportunities.

Changing models of service delivery denote evolving philosophies of care regarding disabilities; from segregation and containment to a community-based, lifespan approach that seeks to support an individual to learn, develop and optimise their skills and abilities so as to live a life that has meaning to them. These include but are not limited to (i) Normalisation (Wolfensberger, 1972) and Social Role Valorisation (Wolfensberger, 1983), (ii) Social Model of Disability (Shakespeare, 2006) and (iii) O'Brien and Lyle's Principles for Community Living of respect, choice, community presence, participation and skill acquisition (O'Brien & Lyle, 1986). The Articles contained in the United Nations General Assembly (2007) *Convention on the Rights of Persons with Disabilities* encapsulate these and provide both a contemporary and international mandate for signatory countries. These aforementioned approaches are operationalised in New Zealand through the principles of: self-determination; beginning early; person-Centred; ordinary life outcomes; mainstream first; Mana enhancing (honour or respect); easy to use and relationship building (Enabling Good Lives, 2021). The fundamental tenets of each of the philosophical models intersect and continue to inform service development and delivery through contemporary approaches to service delivery and, while they may be reflected in other jurisdictions, implementation may be variable. There are both clear similarities and key differences in residential and vocational service provision across jurisdictions and these are typically informed by each model's individual perspective, value and the societal positioning they each place on people with disabilities (Kishore, 2017).

The global presence of COVID-19 since early 2020 has required both intermittent and long-standing changes to individualised and population-based service delivery per se. This is no different for the wider disability sector, which includes the provision of services and support for people with intellectual disability. The need to adapt, suspend or cease operational service delivery has been (Bignal & Gouvier-Seghrouchni, 2020), and is, a continued threat. These impacts may result in a loss of revenue and financial sustainability, the employment and retention of suitably trained staff, changes being made in service accessibility, and the need for flexibility to diversity (Andrews et al., 2021; Hewitt et al., 2021).

Underpinning any decision for continued service delivery within the COVID-19 climate is the need for consideration of both service delivery approaches and the workforce itself—each of which is informed by the respective jurisdiction in response to the presence of the virus. In Australia, Kavanagh, Dimov, et al. (2020) for example, captured the impacts for disability support professionals (DSPs) and identified that work place settings, similar to group homes, were not conducive to social distancing. However, the nature of support needs and health literacy of the people being supported, coupled with DSP knowledge about COVID-19, infection control measures and varying levels of confidence with the use of PPE (personal protective equipment) still enabled them to engage in the required practice. There were other impacts, however, that were not able to be alleviated, including DSPs experiencing burnout and greater financial hardship over extended periods of time. In jurisdictions with higher rates of COVID-19, workplace settings for people with intellectual disability, including day programmes, vocational and recreational services were closed for longer than in Australia and New Zealand for example, and staff from those settings were redeployed.

The biological and psychological impact of COVID-19 on the well-being of people with intellectual disability themselves are reported elsewhere, as are the educational experiences and responsiveness as they pertain to service delivery. The aim of this review therefore was to identify the opportunities and impacts on service providers for people with intellectual disability during the COVID-19 pandemic: This is explored with a specific focus on the experienced or projected impact of suspension, adaptation and continuity of service delivery.

METHOD

Due to the breadth of the subject, a narrative approach was undertaken for this literature review. A key strength of a narrative review is the opportunity to "provide interpretation and critique" about a topic or issue (Greenhalgh et al., 2018, p. 3), while still enabling the appropriate depth of critical thinking, analysis and application.

SEARCH STRATEGY

An initial search of online review registers (Joanna Briggs Institute; Cochrane; Figshare) was undertaken to identify whether any previous reviews had been published on this topic. The current narrative review involved searching a number of key databases (Google Scholar, CINAHL, Embase, PsychInfo) and grey literature using the search terms: learning disability, intellectual disability, developmental disability, COVID-19, service provider, service delivery, residential, community, vocational and impact.

The first, second and third authors independently screened all available abstracts and titles of the articles identified that had relevance to the inclusion and exclusion

criteria. This included reviewing literature retrieved from a search undertaken by a member of the wider JPPIDD Special Edition Team, to ascertain relevance to this article.

- *Population of interest*: Residential, vocational and other service providers for people with intellectual disability.
- *Phenomena of interest*: Planning and decision-making undertaken pertaining to changes in service provision, supports and the corresponding outcomes, which may have included but were not be limited to reduced access and decreased contact delivery, closure and/or re-opening.
- *Context*: The COVID-19 pandemic. Peer-reviewed articles, published reports, reputable expert opinion.
- *Search parameters*: Full-text, English-language only, January 2020–June 2021.

Terminology—Service delivery settings

Across the jurisdictions of the authors, service delivery for people with intellectual disability includes a range of residential living options and vocational services and support. In the UK (United Kingdom), the USA (United States of America) and Australasia (includes New Zealand, Australia and respective islands and territories), group homes range from full time care with awake staff through to supported living where individuals are tenants in their homes with paid carers coming in to provide a range of assistance depending on a person's needs. For people with complex needs, care homes providing higher levels of assistance, and facilities that have registered nurses more readily available, can be part of the formal support service landscape. While the size of the organisation may vary, this may not capture individuals who reside in larger, long-stay congregate or institutional settings. Notwithstanding, this review may still have relevance for these settings. Each country also has a unique range of respite care options.

Vocational services and support have evolved from historical notions of sheltered workshops and now usually provide a range of activities which may include: individualised programmes of support, educational opportunities, volunteer work and/or employment. One or more of these settings may include programmes to enable individuals to learn functional skills for daily living, socialisation and recreation, literacy, work preparation or access to college or tertiary education. In New Zealand, the Enabling Good Lives (EGL) Principles include *Mainstream First* (2021) which is in keeping with approaches in Australia, the United Kingdom, the United States of America, Canada and many other jurisdictions, to seek integrated access, engagement and/or a form of employment based on community citizenship.

Data analysis

A synthesis of the included studies was undertaken through a process of deductive thematic analysis (Nowell et al., 2017) using a reflexive process: the latter refers to the perception and interpretation of meaning within data (Byrne, 2021). In reviewing the quality of source and relevance of articles selected for this review, all authors took responsibility for identifying key findings from a subset of articles that had relevance to the aim of this review. These findings were entered on a spreadsheet, then subsequently analysed and synthesised into themes (Braun et al., 2016; Table 1).

FINDINGS

Some of the impacts of COVID-19 for individuals with intellectual disability are reflected in the experiences of the persons and organisations entrusted with ensuring continued service provision. A range of restrictions across jurisdictions demanded significant adaptations and accommodations to service provision, often in a short space of time. The identified themes of: *Service access, delivery and diversification; employment—changes and impacts; and expectations and outcomes for staff and Financial sustainability*, were each found to reflect the measures and subsequent impacts for service providers both in the short term and into the future.

Service access, delivery and diversification

The provision of vocational services and supports as well as other community based structured daytime activities, quickly reduced as lockdowns were introduced, and while many individuals remained within supported accommodation, some also returned to stay with family members for unspecified periods of time (Bradley, 2020). Despite 22% of DSPs not having received any training to be equipped for such an outbreak (Kavanagh, Dickinson, et al., 2021), changes required accommodation and vocational staff to predict and respond to the impacts of sudden pandemic restrictions and implement the identified need for increased public health habits in order to maintain the health and wellness of all (Bobbette et al., 2020; Courtenay & Perera, 2020). Landes et al. (2021) identified differing COVID-19 outcomes for people with IDD based on the setting and level of nursing care as those who were in larger congregate settings were at greater risk of mortality. While some settings had a greater number of registered nurses, clarification is needed as to the pre-existing underlying co-morbidities and associated factors for these

TABLE 1   Included studies

Citation	Country	Population and context	Design	Focus	Findings relevant to aim of review
Alexander et al. (2020)	UK	People with ID inpatient MH	Guidelines	Guidelines for the care and treatment of people with ID during the COVID-19 pandemic for both community teams providing care to people with IDs and inpatient psychiatric settings	Vulnerability and restrictions due to co-morbidities increases the risk for people with ID of other impacts. Maintaining connections, health surveillance vital and workforce requires education on infection prevention and management
ANCOR USA	USA	People with DD and disability supports	Report	Establish a blueprint for a transformed system of community-based disability supports	Quality, sustainability and individualised choice for people accessing and receiving inclusive disability services and supports requires flexible funding mechanisms
Araten-Bergman and Shpigelman (2021)	Israel and Australia	Family carers and Supported accommodation	Survey research	Family caregivers' interactions and support of their relatives with DD residing in supported accommodation during the pandemic	Maintaining connections is important and role of staff to enable is pivotal. Need to assess suitable IT access for individuals.
Bignal and Cassani (2020)	European Union	Disability services in Europe	Report	Overview of the impact of COVID-19 on service delivery	Pre-COVID issues compounded such as staff illness and shortages, competition across sectors, funding limitations yet increased costs for service delivery
Bobbette et al. (2020)	Canada	DSPs working with people with DD	Survey research report	Evaluate the mental health of a DSP workforce to identify interventions for essential staff	DSPs in accommodation and vocational settings predict, adapt and implements public health measures. A workforce that requires ongoing education on infection prevention and management
Bradley (2020)	USA	People with DD vocational services and support	Discussion paper	Learning the strengths and weaknesses of the service system for people with disabilities to provide a roadmap for building a more robust and agile system going forward	Pandemic highlighted service gaps. Impact on family carers as individuals moved from supported accommodation to stay for unspecific periods of time. Change in funding models, relationships between family and service staff evolve

(Continues)

TABLE 1 (Continued)

Citation	Country	Population and context	Design	Focus	Findings relevant to aim of review
Courtenay and Perera (2020)	UK	People with ID	Discussion paper	Impacts of the pandemic for people with ID and their vulnerability due to changing community support and access. Learnings for future outbreaks	Risk of harm and infection, access to information, impact on others, mental health and& ID, supporting those infected with COVID-19, advance care planning and considerations for future pandemics
Datlen and Pandolfi (2020)	UK	People with LD	Evaluation research	The development of online art therapy during the COVID-19 pandemic	Therapeutic activities are possible and have a role when delivered by distance. Maintaining connections
Embregts et al. (2021)	Netherlands	Direct support professionals (DSPs) residential care or supported living	Qualitative research	Exploring the experiences and needs of direct support staff during the initial stage of the COVID-19 lockdown in the Netherlands	Hours of work, access to PPE, stigma and discrimination. Increased responsibilities regarding infection prevention and control, health monitoring
Ervin (2021)	USA	DSPs	Report	Exploration of whether enough was done to prepare, manage and respond during the pandemic	Impact on well-being of staff with change in routines, strengthen relationships and collaborations, financial implications for the organisation
Ervin and Hobson-Garcia, 2020)	USA	Organisations for people with IDD	Discussion Paper	Support people with IDD to make informed, self-determined choices during the pandemic.	Protection and risk management versus the promotion of self-determination. Balance rights of individual, wishes of family and collective well-being. Call for representation of people with ID and representatives in public health policy
Guidry-Grimes et al., 2020)	USA	People with ID vocational services and support	Discussion paper	COVID-19 highlights systemic disadvantages that people with disabilities face in the healthcare system. Inclusion of disability rights in disaster planning	DSPs are essential care workers and need health and safety recognition. Increased responsibility for infection prevention and control, health monitoring. Inclusion in health planning needed
Health Services Executive and New	Ireland	Day services for adults with disabilities	Guidelines per region	Identifies guidance for assessment, training and service delivery	As stated with the aim of ensuring inclusion and citizenship amidst the

TABLE 1 (Continued)

Citation	Country	Population and context	Design	Focus	Findings relevant to aim of review
Directions Subgroup (2020)				approaches to manage and monitor the recommencement of day services in line with public health measures	required adaptations in approach
Hughes and Anderson (2020)	UK	Disability health professionals r/t community living & vocational services	Report	An account of the COVID-19 pandemic as experienced by clinicians in LD/IDD service—considering not only the consequences of the virus itself, but also the impact of the disruption to all services and day to day life	Information regarding changes in practice for health staff working in an inpatient unit. Use of PPE, visiting, streamlining care
Kavanagh, Dimov, et al. (2020)	Australia	DSPs—Vocational services/supports	Survey research	Disability support workers are the forgotten workforce. This collates data from a second survey from staff who have worked during the pandemic	As with residential, vocational settings are not conducive to social distancing. A need to rely on knowledge of DSPs about measures and PPE use during COVID
Kavanagh, Dickinson, et al. (2021)	England & Australia	People with a disability in congregate	Discussion paper	Healthcare responses of England and Australia with recommendations for rapidly improving the healthcare for people with disability in the pandemic and beyond	Need for the inclusion of disability service settings in pandemic planning as was delayed with limited to no consultation nor strategy. Includes social supports not just health. Lack of preparedness for DSPs and change in service delivery roles and engagement with individuals and their families
Landes et al. (2021)	USA	People with IDD in residential homes and nurses	Research data audit	Determining 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	People in congregate settings had an increased risk of mortality, were likely to have greater morbidity, and the role of nurses may reflect attendant needs
Lunsky et al. (2020)	Canada	DSPs working with people with IDD in residential and/or supported living	Survey research	To describe DSPs' experiences assisting adults with IDD in accessing virtual and in-person healthcare during COVID-19	Aside from technology access, ensuring adherence to protocols such as mask wearing, impact of not "being seen" of not seeing the health professional. A

TABLE 1 (Continued)

Citation	Country	Population and context	Design	Focus	Findings relevant to aim of review
					number of recommendations to adjust and accommodate
McConkey (2020)	Northern Ireland	Learning disability health and social non-statutory services and supports	Mixed methods review	To identify what did or did not work for the community or voluntary sector in responding to the pandemic and the opportunities for building capacity	As day services closed, residential to provide increased engagement. PPE costs increased financial constraints. Risk of re-institutionalisation and need for inclusion in strategic health and social planning
McKenzie et al. (2021)	UK	Health professionals	Research qualitative	Experiences of social care staff regarding the provision of PBS to people with ID at the height of the COVID-19 restrictions	Maintain routines when applying and adapting PBS. Need to education to enable interaction with services
Murray et al. (2021)	UK	Health professionals	Survey research	Rate the impact of COVID-19 on factors related to positive behavioural support to people with an intellectual disability	Activities negatively impacted but DSPs were more creative. Amount of time and engagement with staff was positive & promoted choice, skill development and active support
Power et al. (2021)	UK	Health professionals and residential or community support services	Research analysis of records	Capture experiences of art therapists working with people with LD during the pandemic to describe the barriers and facilitators for online art therapy	Attendance lower as dependent on engagement with or facilitation of DSPs
Thompson and Nygren (2020)	USA	DSPs in vocational services or support roles	Discussion paper	Recommendations to; support people with IDD and the sector during the pandemic, and place the IDD community in a strong position to engage in post-pandemic policy planning	The well-being of people with IDD were prioritised and there is an identified need for the provision of appropriate education pathways and financial recognition of the DSP workforce to maintain viability

individuals and corresponding attendant needs. In instances where there was limited clarity as to what was needed for DSPs, the lack of confidence and ability to provide informed direction impacted upon staff morale (Hughes & Anderson, 2020) and it emerged that inconsistent initial public health responses resulted in many services making their own decisions (Kavanagh, Dickinson, et al., 2021).

Furthermore, some of the models used involved limiting the rotation and casualisation of shift workers (Dean, 2020), increased rostered hours for staff (Embregts et al., 2021; Hewitt et al., 2021), staff living in for extended

periods of time and staff from vocational settings moved into accommodation supports and services. For some, these measures also had a compounding effect on DSPs' continued sense of well-being (Ervin, 2021). For those in residential care, additional planning was required to provide meaningful engagement 24 h per day, 7 days per week by staff who were also managing their own personal health and circumstances (Bradley, 2020; McConkey, 2020). Many of these DSPs placed their own well-being second to their commitment to ensuring people with intellectual disability were safe and well (Thompson & Nygren, 2020). In regard to the latter, Embregts et al.'s (2021) study noted several impacts upon DSPs that were linked to an absence of sufficient PPE, and that included a fear of infection and delay in ascertaining if they had tested positive. This was coupled with a heightened sense of responsibility to the people they support and invoked an emotional impact in that they had to fill the gap of family, and console when loved ones died.

As people with intellectual disability are at a higher risk of infection due to underlying pathology or co-morbidities, the need to reduce direct contact with community intellectual disability teams or specialist mental health services across primary and secondary care, potentially places people at additional risk for anxiety, distress, isolation and health impact when such usual contacts are disrupted or removed (Alexander et al., 2020). This had an impact for disability service providers: while the introduction of telehealth services saw many consultations occurring online (Bradley, 2020) and offered a means by which clinical services streamlined care for individuals supported in the disability sector, a potential risk was identified regarding the ability to maintain confidentiality under such conditions (Courtenay & Perera, 2020; Hughes & Anderson, 2020)—a responsibility that fell to DSPs within accommodation contexts. Additionally, the ability to provide in-person access to ongoing or newly established behavioural and psychological input was also significantly limited (Courtenay & Perera, 2020; Hughes & Anderson, 2020). Similarly, it is recognised that the direct in-person engagement of art therapy is key when it occurs alongside others and promotes the secondary benefit of socialisation. However, in regard to the latter example, Power et al. (2021) noted that despite the proven benefits, engagement with people with intellectual disability in art therapy was lower due to its dependence on DSPs, the organisation with which they were employed, and the shared awareness of all parties involved of the alteration in roles in terms of professional identify. There are few publications as to how targeted therapies were provided so Power's study highlights the reliance on DSPs and the therapeutic value of in-person engagement. Notwithstanding, online platforms still offered some opportunity to engage and be included during

COVID-19 restrictions although the limitations on the quality of reciprocal engagement are duly noted (Datlen & Pandolfi, 2020).

Planning and protocols for re-opening services have equally required just as much precision and consideration. The Health Service Executive and New Directions Ireland (2020) published a guideline to inform the resumption of adult day disability services. It centred on personal plans and community citizenship to promote inclusion while safeguarding and recommending the following: stakeholder communication, staff training and support, location and transport readiness, adaptive service delivery and considerations for transitions. As providers may be concerned about staging a phased return, the decisions also need to be informed by the people themselves while simultaneously safeguarding public health and the expressed wishes of family (Ervin & Hobson-Garcia, 2020). Such considerations were identified by Inclusion Ireland - National Association for People with Intellectual Disability (2020), who interviewed people with an intellectual disability about the impact of closure on them, and used that knowledge to inform planning for resuming access to day services. Of note, across jurisdictions, such considerations need to occur more than once as restrictions eased and then intensified as the pandemic unfolded.

Employment—Changes and impacts

Prior to the pandemic, staff shortages (particularly in relation to appropriately qualified staff) were common among social care provision for people with intellectual disabilities. It is clear that COVID-19 has compounded these issues through staff sickness, absenteeism and staff departures (Bignal & Cassani, 2020; Hewitt et al., 2021; Lunsky, Bobbette, et al., 2021). The additional demands on health services also led to enhanced pay and working conditions in other areas such as aged care, and this has had the unintended consequence of attracting staff away from social care settings (Bignal & Cassani, 2020) although 30 % of DSPs in a nationwide survey in the United States of America reported having received some salary augmentation (Hewitt et al., 2021).

Staff working in social care settings have faced additional challenges during the pandemic. For example, a qualitative study by Embregts et al. (2021) in the Netherlands identified that during the initial period of lock-down direct care staff experienced emotional, cognitive, practical and professional impacts. Many staff and their families experienced stigma and discrimination for working with this vulnerable population, although it was found to be mitigated by engaging in hobbies or in seeking mental health support as needed (Lunsky, Bobbette,

et al., 2021). Of grave concern during the pandemic were the competing lockdown parameters, and the impact of these on DSPs' ongoing connectivity with their own family. As little is known, attention to the stewardship of DSPs would support recruitment and retention in the sector thereby ensuring a sustainable workforce. Therefore, longitudinal research is needed to identify the long-term impacts of the pandemic. Furthermore, overt recognition of DSPs' work status as being essential would demand greater attention and commitment to health and safety protections in the disability service workplaces (Guidry-Grimes et al., 2020; Hewitt et al., 2021).

Expectations and outcomes for staff

Supporting and maintaining contact between significant others through the use of videoconferencing played a key role for carers, individuals and their families (Alexander et al., 2020; Araten-Bergman & Shpigelman, 2021). While not a replacement for social connectedness, videoconferencing went some way towards ensuring that the informal and formal relationships between all parties involved in supported accommodation, residential and vocational services and support were sustained (Araten-Bergman & Shpigelman, 2021). Of note, the expectations by family of frontline staff were heightened insofar as being proactive in this role to initiate and facilitate the communication between families and their member supported within service (Araten-Bergman & Shpigelman, 2021). This was despite just over 70% of families never having used technology to keep in touch with relatives prior to lockdown.

Learning about managing precautions to reduce the transmissibility of COVID-19 for people with intellectual disability was a new key role and responsibility for staff across service settings. This included, but was not limited to, screening for the susceptibility of COVID-19 contraction and the development of care plans that included inflexion prevention and control by means of social distancing and hand hygiene (Alexander et al., 2020; Bobbette et al., 2020; Bradley, 2020; Dean, 2020; Embregts et al., 2021; Guidry-Grimes et al., 2020). Undertaking the monitoring of care such as temperature and other symptoms (Embregts et al., 2021; Guidry-Grimes et al., 2020), implementing isolation precautions in the event that a person contracted COVID-19, and initiating and promoting access to clinical care created additional responsibility for DSPs. This included being party to conversations and plans about levels of care, ACPs (Advance Care Plans) and positive behaviour support plans to inform a response to the potential for emotional distress in individuals with an intellectual disability during the pandemic (Bradley, 2020).

The impact and potential for distress of DSPs cannot be underestimated: within these adjusted roles, however, there were also positive impacts; increased time spent by staff with the people themselves provided improved, longitudinal opportunities to learn more about them. McKenzie et al.'s (2021) study focused on adaptation in the implementation of positive behaviour support (PBS) during lockdown restrictions. Staff learned about the PBS principles and how to apply them within the changing context, while simultaneously seeking to maintain routine and sameness thereby reducing distress for all concerned (McKenzie et al., 2021; Murray et al., 2021). Anecdotally, changing routines and rhythms have been reported as possibly reducing incidences of behaviours that challenge in some cases. It is postulated that the latter may have been due to some of the pre-pandemic routines inducing hurry and resultant anxiety in getting people with intellectual disability to attend their day placements. The increased and unhurried time spent with DSPs because of lockdowns may have improved the stability and sense of mutual relationship for some individuals (Bradley, 2020). However, for others, this was not the case (Hewitt et al., 2021).

Financial sustainability

Bignal and Cassani (2020) highlight that, in Europe, many disability services had been operating in "survival mode" prior to the pandemic due to years of underfunding in the context of an extended period of austerity. They note that funding should not only be about maintaining services but that it should also be sufficient to improve such services. However, the pandemic increased costs for providers of social care due to the need to provide personal protective equipment for staff and to adapt their methods of service delivery for example (Bignal & Cassani, 2020; McConkey, 2020). Across Europe and Australasia there is a range of different experiences in terms of who covered these additional costs. This is due to pandemic costs not being included in prior contractual arrangements, with some authorities agreeing to meet these costs while others did not acknowledge their existence (Bignal & Cassani, 2020; Kavanagh, Dickinson, et al., 2021).

In the context of the pandemic, the financial viability and sustainability of existing disability services into the future have been questioned in some quarters, and this line of questioning has inevitably also served to reduce the potential for any improvements to be forthcoming at this time (Bignal & Cassani, 2020; Kavanagh et al., 2020). While flexibility in funding mechanisms is needed (ANCOR Foundation and United Cerebral Palsy, 2021), vocational services largely bore the financial brunt of altered viability during lockdowns. Many services adapted and provided

resources to supported accommodation settings to make online programming available. This along with multiple staged re-openings also heralded a declining enthusiasm for the people with IDD themselves to return to pre-pandemic attendance and engagement: such options are not sustainable in the absence of ongoing funding (Bradley, 2020). A further financial impact for service delivery was related to undertaking increased infection prevention management measures in terms of in-house linen supplies, laundering thereof, and ensuring the grocery and medication deliveries for example (Ervin, 2021). Generally speaking, the congregate environments, across jurisdictions in the pre-pandemic context may not have the agency, resources or facilities needed to reduce transmission in future events (Guidry-Grimes et al., 2020), therefore the approaches established during the pandemic need to be implemented in the longer term.

DISCUSSION

There is a need to address ongoing uncertainties, anxieties and disparities during and post-pandemic for people with intellectual disability, staff and family carers alike. While the focus of this article was to identify the opportunities and impacts for service providers on the suspension, adaptation and continuity of service delivery to people with intellectual disability during the COVID-19 pandemic, acknowledgement of individuals and family carers needs to be made. For many, the changes in residential, respite care access, vocational and service supports also had a significant impact when individuals returned to live with family carers for indeterminate periods of time (Bradley, 2020)—including on carers' mental health and well-being (Willner & Kroese, 2021). Resuming 24-hour care provision is a significant ask for many family carers, many of whom may have experienced and confronted complex challenges in making decisions about out of home accommodation options for their child or sibling with intellectual disability and who may themselves be older and/or in poor health (Trip et al., 2019). Negative impacts have also been identified for people with intellectual disabilities as they were unable to attend their usual activities due to changes in day service provision required by health authorities (Albuquerque, 2021). Concern has been identified as to the reliance on formal disability services and family carers: while reduced access to the latter was identified by some individuals, the pandemic has illustrated a need to develop greater natural supports for people with intellectual and developmental disabilities who may also have been the ones providing support to others (Navas et al., 2021).

Individuals and families may have missed out on mutual celebrations due to the increased need to use digital technologies to connect with each other (Onwumere et al., 2021). For those who remain in residential or supported accommodation, it is recognised that the shift in communication between service providers, individuals and their families has also been a key focus throughout the pandemic. In the future, there may be an expectation by families that this increased mode and access to communication with their family member continues beyond the pandemic and becomes an established aspect of ongoing service delivery in the future (Ervin & Hobson-Garcia, 2020; Kavanagh, Dickinson, et al., 2021).

The expectations, evolving and developing scope of practice roles for DSPs within residential and vocational settings was also seen to gain momentum during the pandemic (Bobbette et al., 2020; Hewitt et al., 2021). Planning to ensure initial and consistent access to PPE as well as ongoing education, for example about infection prevention and control, should be implemented by disability service providers and must include co-designed approaches (Bobbette et al., 2020; Courtenay & Perera, 2020). It would be important this approach to education and its implementation is also applied to the need for ongoing testing as a prevention strategy, and vaccination procedures for individuals with ID and staff alike.

There is thus an opportunity to recognise the workforce skills that have been acquired and those still needed and this must be commensurate with support and resources for DSPs in regard to their own mental health and well-being (Bobbette et al., 2020; McMahon et al., 2020), and the provision of appropriate education pathways and financial recognition going forward (Bobbette et al., 2020; Hewitt et al., 2021; Thompson & Nygren, 2020). Recruitment incentives alongside formalised acknowledgement of the significant contribution made by staff across the intellectual disability service sector are also due (Hewitt et al., 2021). A key outcome of their commitment has been the strengthening of relationships both internally and externally, including collaboration between registered and unregistered professionals alike (Embregts et al., 2021; Ervin, 2021). For some people with intellectual disability, the use of telehealth may be preferred over time (Hughes & Anderson, 2020; Kavanagh et al., 2020). However, despite the possible convenience and reduced travel demands for DSPs under pandemic restrictions, it remains critical to identify and collaborate with the individual as to the best approach for them. The relationship itself may be a pivotal core component of the in-person setting, may facilitate more effective communication, and better enable the development of meaningful patient–practitioner relationships (Lunsky et al., 2020).

In addition to the diversification of communication needed to maintain connectedness, staff were also required to assess each persons' unique needs and abilities to use a

range of IT platforms (Araten-Bergman & Shpigelman, 2021). Despite the proven benefits, the issue of digital exclusion requires attention (Chadwick et al., 2022). Future-proofing sustainable programmes across disability service contexts must include the development of infrastructure within disability services that includes availability of reliable broadband for accessible technologies. This would require and enable an emphasis on increasing IT literacy for both staff and individuals with intellectual disabilities (Bradley, 2020; Courtenay & Perera, 2020). This need extends to family and significant others by ensuring that such access is commensurate with the skills, knowledge and resource to enable ongoing connections that provide meaning to all parties (Onwumere et al., 2021).

Re-conceptualising service configuration per se is seen to be a natural outcome of the pandemic. It has been recommended that an increase in opportunities for individualised self-management of funding is a natural progression (Bradley, 2020) including how such funding could be used. The viability and value of returning to pre-pandemic vocational or day service programme structures is yet to be seen as it is clear that, without continued additional government assistance, many have been (or may yet be) forced to further reduce their service or close (Thompson & Nygren, 2020). This in turn, could lead to a decrease in the availability of appropriate service options for both people who are funded through population-based existing mechanisms, and those who are self-funding meaningful community access. There is a risk of institutionalised approaches re-emerging in some form that is contrary to the philosophical tenets of citizenship in community (McConkey, 2020).

The need for intersectorial collaboration, equitable healthcare preparation and access continues to be identified as a core focus. The co-production of Easy-Read information about the rights of people with intellectual disability to access healthcare during and post the pandemic, integrating this into care planning, along with advice about resuming supports and flexibility in the context of continued health risks—have been all been identified as requiring ongoing attention (The Scottish Commission for People with Learning Disabilities, 2020). Further-more, the inclusion of people with intellectual disabilities and their representatives within statutory systems that determine public health policy and strategy is also warranted—not only in the current pandemic, but also in strategic health planning (Ervin & Hobson-Garcia, 2020; Kavanagh et al., 2020; Majnemer et al., 2021; McConkey, 2020) as with the wider disability community (Guidry-Grimes et al., 2020). Moreover, tracking case data (Strydom et al., 2021), the implementation of annual health checks, health passports and advance care planning are also both recognised and recommended as being pivotal to inform national health datasets and the education of registered health professionals and DSPs alike (Alexander et al., 2020; Kavanagh, Dickinson, et al., 2021; McKenzie et al., 2017) for ongoing healthcare and in preparation for future pandemics.

Strengths and Limitations

A key strength of this review is the range of literature available since the onset of the COVID-19 pandemic in early 2020. There are, however, some limitations which include the potential bias given the number of reports based on either clinical opinion or existing data for example. Notwithstanding, there were still a number of qualitative, quantitative and mixed methods research articles, the findings of which correspond to the wider literature available at this time. The diversity of service provision represented for people with intellectual disability included residential, vocational, employment settings and access to health and specialist services may be seen as a limitation. Conversely, it provides a unique cross-section of disability service delivery that captures unique and intersecting experiences and challenges across the COVID-19 pandemic to date that the opportunities identified for reimaging the future. There is, however, a need for more longitudinal research to fully inform the experience and changing service provision alongside people with intellectual, and developmental disability and family carers as the COVID-19 pandemic continues.

CONCLUSION

While the experience, presence and response to the pandemic have played out differently across jurisdictions, a number of key similarities are evident. More investment is needed, and increasing health literacy through accessibility to technology can be seen as a positive outcome for both staff working in disability service contexts, and for the people with intellectual disabilities whom they support (Bradley, 2020) and family carers. Reflection, creativity and perseverance were key factors amidst a period of decreased contact of DSPs with colleagues: Not only were they reliant on technology to connect with others but there was an ongoing requirement to ensure the people with whom they worked were equally able to maintain their own personal, social and vocational connections and had opportunity to occupy themselves in a meaningful way during pandemic restrictions.

The conceptualised person-centric, accessible and flexible service delivery options which have been recommended, reflect pre-pandemic evidence. There is a need for greater educational and financial investment,

across jurisdictions, to recognise and develop the role of DSPs across residential, vocational and service supports to be more responsive to this population. Similarly, there is an identified responsibility to equip not only service providers, but also family carers and individuals alike to be reflexive in adapting to changing circumstance. Ultimately, inclusion in health and social statutory and strategic planning will, ultimately, inform the quality and meaningful life outcomes for people with intellectual disability.

Yet to be examined is the impact and uptake of vaccination programmes amidst ongoing outbreaks of new COVID-19 variants. It has been identified, for example, that staff vaccination rates may yet pose a further risk to people receiving support from intellectual disability services (Gimenez et al., 2010). A Canadian survey, identified that younger DSPs tended to have greater non-intent to be vaccinated than their peers. This has the potential to reduce the uptake of vaccination rates for the people with whom they work who may look to them for support in this regard (Lunsky, Kithulegoda, et al., 2021). However, it is acknowledged that increasing mandates, by some governments, about the requirement for vaccination will further impact the challenges and opportunities noted in this review which would benefit from longitudinal monitoring and research. Given the learnings from the current pandemic, there is now both the task and responsibility to use these to both plan for, and reduce, the potential impact of future events (Taggart et al., 2022).

CONFLICT OF INTEREST

The authors declare no conflict of interest.

AUTHOR CONTRIBUTIONS

Contribution – Principal investigator, literature searching, article appraisal, analysis and synthesis, manuscript drafts and final edits: Henrietta Trip. *Contribution – Conceptual development, literature searching, article selection and appraisal, analysis, manuscript reviewer*: Ruth Northway. *Contribution – Conceptual development, literature searching, article selection and appraisal, analysis*: Elizabeth Perkins. *Contribution – Literature searching, article appraisal, analysis, manuscript reviewer*: Brigit Mirfin-Veitch. *Contribution – Conceptual development, literature searching, article appraisal*: Reece Adams.

ETHICAL APPROVAL

This review has been undertaken with ethical care and conduct to check and uphold the integrity of the information sourced and the utility thereof.

ORCID

Henrietta Trip https://orcid.org/0000-0001-5844-3400

REFERENCES

Albuquerque, C. P. (2021). COVID-19 and Portuguese adults with intellectual disabilities. *Journal of Intellectual Disability – Diagnosis and Treatment*, *9*(5), 565–570. https://doi.org/10.6000/2292-2598.2021.09.05.15

Alexander, R., Ravi, A., Barclay, H., Sawhney, I., Chester, V., Malcolm, V., Brolly, K., Mukherji, K., Zia, A., Tharian, R., Howell, H., Lane, T., Cooper, V., & Langdon, P. E. (2020). Guidance for the treatment and management of COVID-19 among people with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, *17*(3), 256–269 https://onlinelibrary.wiley.com/doi/pdf/10.1111/jppi.12352

ANCOR Foundation and United Cerebral Palsy. (2021). *A special report on the sustainability of community disability services in America*. United Cerebral Palsy & ANCOR Foundation. https://caseforinclusion.org/resources/key-findings

Andrews, E. E., Ayers, K. B., Brown, K. S., Dunn, D. S., & Pilarski, C. R. (2021). Nobody is expendable: Medical rationing and disability justice during the COVID-19 pandemic. *American Psychologist*, *76*(3), 451–461 https://doi.apa.org/fulltext/2020-54103-001.html

Araten-Bergman, T., & Shpigelman, C.-N. (2021). Staying connected during COVID-19: Family engagement adults with developmental disabilities in supported accommodation. *Research in Developmental Disabilities*, *108*, 103812. https://doi.org/10.1016/j.ridd.2020.103812

Bigby, C., & Ozanne, E. (2001). Shifts in the model of service delivery in intellectual disability in Victoria. *Journal of Intellectual & Developmental Disability*, *26*(2), 177–190. https://doi.org/10.1080/13668250020054495

Bignal, T., & Cassani, I. (2020). *The impact of COVID 19 on disability services in Europe*. The Second EASPD Snapshot Report https://www.easpd.eu/fileadmin/user_upload/Publications/second_report_impact_of_covid-19_on_disability_services_in_europe.pdf

Bignal, T., & Gouvier-Seghrouchni, R. (2020). *The impact of COVID 19 on disability services in Europe*. A report by the European Association of Service Providers for Persons with Disabilities (EASPD) https://www.tcd.ie/tcaid/assets/pdf/ImpactCOVID19DisabilityServices.pdf

Bobbette, N., Hamdani, Y., Thomson, K., Abou-Chacra, M., Volpe, T., & Lunsky, Y. (2020). *Recognizing the mental health needs of an essential workforce: Being a direct support professional in the time of COVID-19*. CAMH.

Bradley, V. J. (2020). How COVID-19 may change the world of services to people with, how COVID-19 may change the world of services to people with intellectual and developmental disabilities intellectual and developmental disabilities. *Intellectual and Developmental Disabilities*, *58*(5), 355–360. https://doi.org/10.1352/1934-9556-58.5.355

Braun, V., Clarke, V., & Weate, P. (2016). Using thematic analysis in sport and exercise research. In B. Smith & A. C. Sparkes (Eds.), *Routledge handbook of qualitative research in sport and exercise* (pp. 191–205). Routledge.

Byrne, D. (2021). A worked example of Braun and Clarke's approach to reflexive thematic analysis. *Quality & Quantity*. https://doi.org/10.1007/s11135-021-01182-y

Chadwick, D., Alfredsson Ågren, K., Caton, S., Chiner, E., Danker, J., Gómez-Ouerta, M., Heitplatz, V., Johansson, S.,

Normand, C., Murphy, E., Plichta, P., Strnadová, I., & Flygare Wallén, E. (2022). Digital inclusion and participation of people with intellectual disabilities during COVID-19. A rapid review and international bricolage. *Journal of Policy and Practice in Intellectual Disabilities*, 1-15. https://doi.org/10.1111/jppi.12410

Courtenay, K., & Perera, B. (2020). COVID-19 and people with intellectual disability: Impacts of a pandemic. *Irish Journal of Psychological Medicine*, 37(3), 231–236. https://doi.org/10.1017/ipm.2020.45

Datlen, G. W., & Pandolfi, C. (2020). Developing an online art therapy group for learning disabled young adults using WhatsApp. *International Journal of Art Therapy*, 25(4), 192–201 https://www.tandfonline.com/doi/full/10.1080/17454832.2020.1845758

Dean, E. (2020). COVID-19 pandemic presents new challenges for learning disability nurses. *Learning Disability Practice*, 23(3), 8–9.

Embregts, P. J. C. N., Tournier, T., & Frielink, N. (2021). Experiences and needs of direct support staff working with people with intellectual disabilities during the Covid 19 pandemic: A thematic analysis. *Journal of Applied Research in Intellectual Disabilities*, 34, 480–490.

Enabling Good Lives. (2021). *Principles*. Wellington, New Zealand: Office for Disability Issues, Ministry of Social Development. https://www.enablinggoodlives.co.nz/about-egl/egl-approach/principles/

Ervin, D. A. (2021, February). *Did we do enough?* EP Magazine.com.

Ervin, D. A., & Hobson-Garcia, D. (2020). Community supports and COVID-19: Self-determination in a pandemic. *Intellectual and Developmental Disabilities*, 58(6), 453–457. https://doi.org/10.1352/1934-9556.58.6.453

Gimenez, J. D., Galmes, A. T., Nicolau, A. R., Reina, J. P., Gallegoes, C. A. M., Pareja, A. B., & Vanrell, J. B. (2010). Outbreak of pandemic virus (H1N1) 2009 in a residence for mentally disabled persons in Balearic Island, Spain. *Revista Espanola de Salud Publica*, 84, 665–670.

Greenhalgh, T., Thorne, S., & Malterud, K. (2018). Time to challenge the spurious hierarchy of systematic over narrative reviews? *European Journal of Clinical Investigation*, 48, e12931. https://doi.org/10.1111/ecu.12931

Guidry-Grimes, L., Savin, K., Stramondo, J. A., Reynolds, J. M., Tsaplina, M., Blankmeyer Burke, T., Ballantyne, A., Feder Kittay, E., Stahl, D., Leach Scully, J., Garland-Thomson, R., Tarzian, A., Dorfman, D., & Fins, J. J. (2020). Disability rights as a necessary framework for crisis standards of care and the future of health care. *Hastings Center Report*, 50(3), 28–32. https://doi.org/10.1002/hast.1128

Health Services Executive and New Directions Subgroup. (2020). *Framework for the resumption of adult disability day services. Supporting people with disabilities in the context of COVID-19: The next year*. Ireland: Health Services Executive. https://www.hse.ie/eng/services/list/4/disability/newdirections/

Hewitt, A., Pettingell, S., Karamme, J., Smith, J., Dean, K., Kleist, B., Sanders, M., & Bershadsky, J. (2021). *Direct support workforce and COVID-19 National Report: Six-month follow-up*. Institute on Community Integration, University of Minnesota.

Hughes, N., & Anderson, G. (2020). The experience of the COVID-19 pandemic in a UK learning disability service: Lost in a sea of ever-changing variables – A perspective. *International Journal of Developmental Disabilities*, 1–4. https://doi.org/10.1080/20473869.2020.1773711

Inclusion Ireland – National Association for People with Intellectual Disability. (2020). *COVID-19 and the impact of the closure of day services on people with intellectual disabilities*. Inclusion Ireland. https://inclusionireland.ie/wp-content/uploads/2020/08/day-services-final.pdf

Kavanagh, A., Dickinson, H., Varey, G., Llewellyn, G., Emerson, E., Disney, G., & Hatton, C. (2021). Improving health care for disabled people in COVID-19 and beyond: Lessons from Australia and England. *Disability and Health Journal*, 14, 101050. https://doi.org/10.1016/j.dhjo.2020.101050

Kavanagh, A., Dimov, S., Shields, M., McAllister, A., Dickinson, H., & Kavanagh, M. (2020). *Disability support workers: Follow up findings from the forgotten workforce in COVID-19* (Research Report. The University of Melbourne. https://doi.org/10.26188/14331344.v3

Kishore, M. T. (2017). Service delivery models for people with intellectual disabilities in low and middle income countries: Strategies and solutions can emerge from within. *Journal of Intellectual Disabilities*, 21(3), 201–202. https://doi.org/10.1177/1744629517721344

Landes, S., Turk, M. A., Ashlyn, W. W. A., & Wong, B. A. (2021). COVID-19 outcomes among people with intellectual and developmental disability in California: The importance of type of residence and skilled nursing care needs. *Disability and Health Journal*, 14(2), 101051. https://doi.org/10.1016/j.dhjo.2020.101051

Lunsky, Y., Bobbette, N., Abou Chacra, M., Wang, W., Zhao, H., Thomson, K., & Hamdani, Y. (2021). Predictors of worker mental health in intellectual disability services during COVID-19. *Journal of Applied Research in Intellectual Disabilities*, 34(6), 1655–1660. https://doi.org/10.1111/jar.12892

Lunsky, Y., Bobbette, N., Selick, A., & Jiwa, M. I. (2020). "The doctor will see you now": Direct support professionals' perspectives on supporting adults with intellectual and developmental disabilities accessing health care during COVID-19. *Disability and Health Journal*, 14(3), 101066. https://doi.org/10.1016/j.dhjo.2021.101066

Lunsky, Y., Kithulegoda, N., Thai, K., Benham, J. L., Lang, R., Desveaux, L., & Ivers, N. M. (2021). Beliefs regarding COVID-19 vaccines among Canadian workers in the intellectual disability sector prior to vaccine implementation. *Journal of Intellectual Disability Research*, 65(7), 617–625. https://doi.org/10.1111/jir.12838

Majnemer, A., McGrath, P. J., Baumbusch, J., Camden, C., Fallon, B., Lunsky, Y., Miller, S. P., Sansone, G., Stainton, T., Sumarah, J., Thomson, D., & Zwicker, J. (2021). Time to be counted: COVID-19 and intellectual and developmental disabilities – An RSC policy briefing. *Facets*, 6, 1337–1389. https://doi.org/10.1139/facets-2021-0038

McConkey, R. (2020). *A review of the impact of COVID-19 on learning disability services provided mainly by the voluntary sector in Northern Ireland*. Northern Ireland: ARC - Association for Real Change & Department of Health. https://arcuk.org.uk/northernireland/files/2021/02/Final-report-ARC-Review-17th-November-2020.pdf

McKenzie, K., Murray, G. C., & Martin, R. (2021). "It's been adapted rather than impacted": A qualitative evaluation of the impact of COVID-19 restrictions on the positive behavioural support of people with an intellectual disability and/or autism.

Journal of Applied Research in Intellectual Disabilities, *34*(4), 1089–1097 10.1111.jar.12859.

McKenzie, N., Mirfin-Veitch, B., Conder, J., & Brandford, S. (2017). "I'm still here": Exploring what matters to people with intellectual disability during advance care planning. *Journal of Applied Research in Intellectual Disabilities*, *30*(6), 1089–1098. https://doi.org/10.1111/jar.12355

McMahon, M., Hatton, C., Stansfield, J., & Cockayne, G. (2020). An audit of the wellbeing of staff working in intellectual disability settings in Ireland during the COVID-19 pandemic. *Tizard Learning Disability Review*, *25*(4), 237–246.

Murray, G. C., McKenzie, K., & Martin, R. (2021). The impact of COVID-19 restrictions in the United Kingdom on the positive behavioural support of people with an intellectual disability. *British Journal of Learning Disabilities*, *49*(2), 138–144. https://doi.org/10.1111/bld.12379

Navas, P., Amor, A. M., Crespo, N., Wolowiec, Z., & Verdugo, M. Á. (2021). Supports for people with intellectual and developmental disabilities during the COVID-19 pandemic from their own perspective. *Research in Developmental Disabilities*, *108*, 103813. https://doi.org/10.1016/j.ridd.2020.103813

Nowell, L. S., Norris, J. M., White, D. E., & Moules, N. J. (2017). Thematic analysis: Striving to meet the trustworthiness criteria. *International Journal of Qualitative Methods*, *16*, 1–13. https://doi.org/10.1177/1609406917733847

O'Brien, J., & Lyle, C. (1986). *Framework for accomplishments*. Responsive Systems Associates.

Onwumere, J., Creswell, C., Livingston, G., Shiers, D., Tchanturia, K., Charman, T., Russell, A., Treasure, J., Di Forti, M., Wildman, E., Minnis, H., Young, A., Davis, A., & Kuipers, E. (2021). COVID-19 and UK family carers: Policy implications. *The Lancet Psychiatry*, *8*(10), 929–936 https://www.thelancet.com/psychiatry

Perera, B., & Courtenay, K. (2018). Mental health services for people with intellectual disability in the United Kingdom. *Advances in Mental Health and Intellectual Disabilities*, *12*, 91–98. https://doi.org/10.1017/ipm.2020.45

Power, N., Dolby, R., & Thorne, D. (2021). Reflecting or frozen? The impact of COVID-19 on art therapists working with people with a learning disability. *International Journal of Art Therapy*, *26*(3), 84–95 https://www.tandfonline.com/doi/full/10.1080/17454832.2020.1871388

Shakespeare, T. (2006). *Disability rights and wrongs*. Routledge. https://doi.org/10.4324/9780203640098

Strydom, A., Corcoran, E., & Rebillat, A.-S. (2021). The COVID-19 pandemic should be last orders for poor care of people with neurodevelopmental disorders. *The British Journal of Psychiatry*, *218*, 302–304. https://doi.org/10.1192/bjp.2021.22

The Scottish Commission for People with Learning Disabilities. (2020). *The impact of coronavirus on people with learning disabilities and their parents, carers and supporters: Survey findings*. Retrieved from The Scottish Commission for People with Learning Disabilities. https://www.scld.org.uk/wp-content/uploads/2020/06/SCLD-Coronavirus-Report-Easy-read-Designed-FINAL.pdf

Thompson, J. R., & Nygren, M. A. (2020). COVID-19 and the field of intellectual and developmental disabilities. Where have we been? Where are we? Where do we go? *Intellectual and Developmental Disabilities*, *58*(4), 257–261. https://doi.org/10.1352/1934-9556-58.4.257

Trip, H., Whitehead, L., Crowe, M., Mirfin-Veitch, B., & Daffue, C. (2019). Aging with intellectual disabilities in families: Navigating ever-changing seas – A theoretical model. *Qualitative Health Research*, *29*(11), 1595–1610. https://doi.org/10.1080/10376178.2018.1503549

Taggart, L., Mulhall, P., Kelly, R., Trip, H., Sullivan, B., & Wallén, E. F. (2022). Preventing, mitigating, and managing future pandemics for people with an intellectual and developmental disability - Learnings from COVID-19: A scoping review. *Journal of Policy and Practice in Intellectual Disabilities*, *19*(1), 4–34. https://doi.org/jppi.12408

United Nations General Assembly. (2007). *Convention on the rights of persons with disabilities: Resolution/adopted by the General Assembly*. UN General Assembly. https://www.refworld.org/docid/45f973632.html

Visier, L. (1998). Sheltered employment for persons with disabilities. *International Labour Review*, *137*(3), 347–365 https://www.ilo.org/public/english/revue/download/pdf/visier.pdf

Willner, P., & Kroese, B. S. (2021). Effects of the pandemic on the mental health of carers of people with intellectual disabilities: Quantitative and qualitative research findings. *Journal of Intellectual Disability Research*, *65*(8), 691–759. https://doi.org/10.1111/jir.12869

Wolfensberger, W. (1972). *The principle of normalization in human services*. National Institute on Mental Retardation.

Wolfensberger, W. (1983). Social role valorization: A proposed new term for the principle of normalization. *Mental Retardation*, *21*(6), 234–239.