






ORIGINAL ARTICLE

Key learnings from COVID-19 to sustain quality of life for families of individuals with IDD

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Abstract

COVID-19 has very publicly had profound impacts on the health system of every country in the world. Over 4.5 million people have lost their lives. School closures worldwide where up to 1.6 billion of the world's children have been out of school, are also prominent in world news. Behind these public impacts are the families. In this paper, we focus on the experiences of families with people with intellectual and developmental disabilities (IDD) through analysis of two data sets: the emerging research literature and contributions from our author team who have lived experience of intellectual and developmental disability in the context of COVID-19. From these two data sets, we discern five themes of the impact of the pandemic: on health, on education, on services and supports, on families and finally on relationships beyond the family. We conclude with lessons from those living with intellectual and developmental disabilities, the carers and the individuals themselves to draw implications for supporting families in the context of disability during future pandemics.

KEYWORDS

COVID-19, education, families, intellectual disability, quality of life

INTRODUCTION

In a short time, the COVID-19 pandemic has affected all groups in society and will continue to do so in the future. Frontline workers in healthcare have been a very visible group: another frontline group during the pandemic, with perhaps lesser visibility, are those family groups, including individuals with intellectual and developmental disabilities (IDD) in home settings. The experiences of these family groups as they negotiate sickness, death and lock-downs, educate children in home settings, deal with changes to employment and manage all aspects of family life can provide important lessons for future pandemics. Through personal accounts and findings from the

research literature, this paper will highlight the needs articulated by people with IDD, disability advocates, families, professionals and organizations to advise policymakers and other stakeholders. Perhaps this will allow some good to come of the extraordinary experiences of so many around the globe for future generations.

METHODOLOGY

In this paper, a qualitative research paradigm is adopted, acknowledging a situated or life-embedded truth (Braun & Clarke, 2022, p. 6). This stance is of particular importance to declare in a discussion of learning from the

global experience of families from COVID-19. A positivist paradigm is not helpful because an objective truth or experience does not exist. In this paper, we are not reporting the results of a research study; rather, we have discerned themes from research literature and the lived, situated experience provided by authors of sections of the paper. Our guiding research question is: “What can we learn from linking country experiences with emerging research literature to prepare for future pandemics?”

In our methodology, researcher subjectivity is regarded as a resource, and indeed essential for this type of research (Braun & Clarke, 2022, p. 8). The authors bring their lived experience to the data analysis. In this, our orientation to data is deductive, where themes are regarded as patterns in data that are actively produced “by the researcher through their systematic engagement with, and all they bring to, the dataset” (Braun & Clarke, 2022, p. 8). As authors, we are a collective of IDD researchers but also family members with lived experience of COVID-19. As a group, we have a range of international experiences. This is in no way intended to be representative—indeed, that would not be possible as even within a country each family will have different experiences and different responses, as well as their own unique family context. Therefore, our qualitative methodology (Kidder & Fine, 1987), is an appropriate, if not essential, choice. It does not presume objective truth to be uncovered, but truth that is situated and context dependent.

Data sets

In our research, there were two key data sets: the emerging research, policy and practice literature around the experiences of families, including people with IDD during COVID-19; and the authors’ narratives of their experiences in their countries.

To address the research question, the literature review (Grant & Booth, 2009) aimed to establish, firstly, what impact COVID-19 had on, and what challenges were faced by, families of children with IDD, and secondly, what support systems were available and what were the reported impact for families. Therefore, the PICo process (Munn et al., 2018) included the population (P) as families, carers, children with IDD, the interest (I) as the impact of the COVID-19 pandemic and the context (Co) as educational and home settings.

At the time the literature search commenced (April, 2021), there was emerging research focusing on the impact of COVID-19 on families of children with IDD. The steps for conducting a literature review outlined by Creswell (2014) were followed. Electronic databases were included in the search (e.g., ERIC, PubMed, EBSCOHost). We searched on the following terms: “intellectual disab*”, “family quality of life”,

“COVID*”, “education”, “learning” and then used reference lists and article keywords to further search for related, relevant research. We included peer-reviewed publications, grey literature, government reports, primary studies and narrative/qualitative studies. The aim was to identify relevant research that aligned with the research question. The titles and abstracts were screened to identify relevant research. At the full-text review, draft summaries of the articles were created to facilitate the identification of relevant themes.

In this paper, we present the findings of the literature review first. However, the data sets were obtained simultaneously. The first three authors undertook the literature review. The other authors prepared country perspectives separately, ensuring one data set did not influence the other. They were only combined at the data analysis phase.

Data analysis

We have undertaken reflexive thematic analysis where “Data analysis is conceptualised as an art not a science, creativity is central to the process, situated within a framework of rigour” (Braun & Clarke, 2022, p. 8).

In our data analysis, we moved back and forth through the data sets, drawing out common themes. Initially we had intended to use an existing framework, such as EQOL (Faragher & van Ommen) or FQOL (Zuna et al.). As our analysis proceeded, we did not find the existing frameworks to be useful in explaining the story from the data.

DATA SET 1—EXPLORATION OF RELEVANT RESEARCH LITERATURE

In the methodology section, the approach to exploring the emerging research literature is outlined. Within months of the pandemic’s outbreak, impacts on families, including individuals with IDD in terms of their quality of life, health and education, were starting to be discussed in the literature.

Italy was one of the first countries to experience the devastating impacts of the pandemic. In an early paper, Fontanesi et al. (2020, p. S80) reported severe impacts for parents.

We are currently studying the lock-down effects in a sample of 1126 Italian parents. Our preliminary data, collected 3 weeks ago, suggest that parents of children diagnosed with a mental or physical disease are experiencing higher levels of parental



burnout, than other parents are. Moreover, most of these parents are noting significant modifications in their children's behavior (pertaining to, e.g., their inability to concentrate, intolerance, and general discomfort), and have responded to these behavioral changes by shifting from authoritative to authoritarian parenting styles, increasing their verbal hostility, and decreasing their regulation reasoning.

Thus, the first signs of severe impacts for families emerged. Several studies have highlighted major concerns about how COVID-19 has had an impact on families caring for people with IDD in isolation (Chen et al., 2020; Dhiman et al., 2020; Farajzadeh et al., 2021). In the United Kingdom, parents reported feeling overwhelmed and struggling to meet all family members' needs (Asbury et al., 2020; Bailey et al., 2021; Greenway & Eaton-Thomas, 2020). These feelings were echoed by families in Italy (Fontanesi et al., 2020), India (Dhiman et al., 2020), Australia (Masi et al., 2021) and the United States (Mills et al., 2020).

From reading the extant literature, it is possible to discern five themes representing impacts on: health, education, services and supports, relationships within the family, and finally, relationships beyond the family. These are addressed in turn.

COVID affects the mental and physical health of all in the family

The isolation and effects of lock-downs on individuals with IDD increased healthcare needs and mental health concerns but not just for the individuals. The family unit experienced impacts that were complex in the interactions. This theme has three sub-themes: mental health of caregivers, effects of the lock-down and challenges resulting from inadequate access to COVID-19 information.

Effects of lock-down on health of people with IDD

It is expected that routines would change and adjust due to periods of lock-down and isolation; however, caregivers raised concerns about their child's physiological and psychological well-being. For example, in Australia, caregivers reported that the changes to their children's routine due to lock-down contributed to reduced sleep quality (43.6%), reductions in exercise (68%), dietary changes (32.4%) and increased time on social media and

engaging with digital media (81.6%) (Masi et al., 2021). Some studies indicated that disruption of daily routines for a prolonged period increased the incidences of challenging behaviour, especially when individuals had limited understanding of the need for sudden change (Narzisi, 2020; Willner et al., 2020; Zingale et al., 2020). In China, caregivers of children aged 6–15 years old with ADHD found their child's ADHD behaviours had worsened (Zhang et al., 2020). Increased prescription of psychotropic medication to manage challenging behaviours has also been reported (Courtenay, 2020).

Caregiver mental health

According to Willner et al. (2020), the mental health concerns (anxiety, depression, defeat/entrapment and wish fulfilment) of caregivers of children and adults with intellectual disability (ID) in the United Kingdom increased two to three times pre-pandemic levels and was higher in comparison to parents of children without ID. Caregivers had an increased challenge in managing their own mental health during the pandemic as well as having to navigate the mental health issues of their members with ID exacerbated by the pandemic (Pfefferbaum & North, 2020). Similarly, in Australia, caregivers reported their own pre-existing mental health conditions (42.4%) and physical health concerns (35.3%) had worsened (Zhang et al., 2020).

In the authors' data, the impact of the pandemic on mental health of caregivers is evident as well. This is indicated in the contributions from Kenya and India where abuse, excessive alcohol consumption and relationship breakdowns have been noted.

Access to COVID-19 information and telehealth

Caregivers felt disenfranchised for lack of information about COVID-19 for families with people with IDD (Paulauskaite et al., 2021). The fate of family members with IDD, should they contract COVID-19, was a constant worry for families in the United Kingdom (Embregts et al., 2021). Parents reported difficulties following government requirements for social distancing, self-isolation and/or shielding and implementing infection control measures at home (Willner et al., 2020). Additionally, most parents had difficulties motivating members with IDD to undertake telehealth (Willner et al., 2020). A study conducted in India showed an association between negative perception of tele-rehabilitation with poor mental health outcomes (Dhiman et al., 2020). In Australia, 69% of carers of children with IDD reported

they had engaged with telehealth services and only 30% felt the services were suitable or worked well for their child. Forty-one per cent reported that telehealth for therapy was not suitable for their child (Masi et al., 2021).

In this theme of health impacts, implications are clearly beyond the impact on an individual. They are also more complex than considering the family as a unit. Individual impacts on each member interact to affect the family as a whole.

COVID impacts on education of learners with IDD affect all in the family

Inclusive education has been a focus of international efforts to improve education outcomes for learners with IDD (UN General Comment No. 4) and is explicitly addressed in the UNCRPD and the Sustainability Goals. The literature emerging around COVID-19 effects on education show disturbing impacts on the provision of inclusive education through access and provision of adjustments.

The onset of lock-down procedures resulted in school closures in late March 2020 and a rapid move to online and remote learning worldwide. In some countries, students remained in remote learning into 2021. In others, partial or rolling closures have occurred. Some countries (e.g., Australia and the United States) allowed “vulnerable” children, including those with IDD, to attend school during partial closures. School closures have brought a large disparity between students worldwide (Azevedo et al., 2020; UNESCO, 2021).

Remote learning exacerbating underlying inequity

Provision of education to the world’s children was inequitable before the COVID-19 pandemic and the situation has been exacerbated since (Page et al., 2021). In high-income countries where internet connectivity, technological platforms and software, and support staff are readily available, online learning has been possible. However, for many countries worldwide (and also for students from impoverished backgrounds in high-income countries), the ability to continue to learn when schools were closed has been dramatically compromised. The outcomes of remote learning are varied, and it is argued that digital technologies should supplement teaching, not replace it (Azevedo et al., 2020). Learning design, quality and teaching provision disparity (Middleton, 2020) have been identified as issues of concern in the provision of remote learning.

Some families gained insight about learning progress from the opportunity to work closely with their child. Sometimes this revealed that, with adequate support, students could accomplish more than schools had reported (Dickinson et al., 2020).

Provision of learning adjustments

Learners with IDD are entitled to education adjustments to support their learning. Parents reported that many assigned tasks were unsuitable and lacked adjustments or modifications for learners with IDD or were not provided at all (Dickinson et al., 2020; Greenway & Eaton-Thomas, 2020). Parents and carers were expected to shoulder the increased responsibility of educating their children on unknown content with little or no upskilling or training available (Asbury et al., 2020).

COVID-19 impact on services and supports affect families

Reduced family supports aggravated impacts of isolation and lock-down such as closure of community-based services and financial hardship (Aishworiya & Kang, 2020; Bailey et al., 2021). Due to the necessity of lock-downs, there was reduced availability of mental health services, social care, parent support, third sector services and community programs, educational and respite placements. The diversity of activities that could be performed at home reduced significantly (Wos et al., 2021). Under half of the caregivers in an Australian study (45.2%) were satisfied with the services and support they had received (Masi et al., 2021).

Effects on families of changes to services

Families that rely on care and support to enable daily activities (e.g., availability of someone to mind an individual with IDD while others leave the home) found service changes disruptive. Increased care responsibilities coupled with household tasks, some of which required parents to run errands outside the home, became a challenge when there would be no substitute support (Willner et al., 2020; Wos et al., 2021). Even if families wished to restrict access to others who might have the virus, complete isolation from the outside world was impossible. Families that required some form of respite from care/support responsibilities, despite the risks, found they needed to accept outside help to make their situation manageable (Embregts et al., 2021).

Impact of COVID-19 on social and economic progress previously gained by members with ID

Family members feared that the loss of other social contacts would negatively affect the social development of family members with ID (Wos et al., 2021). Prolonged lock-downs risked the regression of social skills achieved prior to the pandemic by people with IDD (Paulauskaite et al., 2021). Parents also raised concerns about the lack of employment for adults with ID following economy constrictions caused by the pandemic (Paulauskaite et al., 2021; Willner et al., 2020), exacerbating existing inequities.

Family choices on residential care during the pandemic

Some changes to supports and services were made by the choice of families. Out of concern for how members with ID would fare in residential settings due to past negative experiences and a lack of trust that the well-being of their family members with ID would be prioritized in residential settings, some families preferred to have their members with ID at home to provide their supports despite increasing family responsibilities (Vereijken et al., 2022).

Mixed effects on relationships within the family

Often services that provided support to people with IDD were shut down and during periods of lock-down, care and support responsibilities suddenly shifted to parents and family members who, in addition, had to juggle home-schooling requirements, working remotely (if they could) with reduced professional and in-home support (Chen et al., 2020). For other families, they faced losing work altogether with an impact on financial security. A majority of the remaining services shifted to being offered virtually. For families with lower socio-economic status, lack of internet connection and/or computer access translated to limited access to telehealth and virtual sessions for services they needed (Aishworiya & Kang, 2020).

Perhaps surprisingly, not all effects on relationships were negative, with some families reporting positive changes.

Financial impacts of COVID-19 on families exacerbated in the context of disability

Aside from pandemic impacts on employment that affected families with and without members with IDD, additional

financial impacts were experienced in the context of disability. Parents and carers reported an increase in financial pressure due to additional required resources (e.g., art therapy) and difficulties accessing financial assistance available through individual funding schemes, such as Australia's National Disability Insurance Scheme. In places where government financial assistance packages were provided (e.g., Australia, the Philippines and the United Kingdom) the financial impact of COVID-19 may have been delayed, although the long-term financial impact remains unknown (Bailey et al., 2021).

Households of people with challenging behaviour and families with lower income in the United Kingdom received less social support (Willner et al., 2020). This finding was corroborated in Iran where the lower the income, the higher the incidences of anxiety (Farajzadeh et al., 2021).

Poverty also has an impact on access to education and inequities have been exacerbated by COVID-19. Lower SES families expressed concerns surrounding internet access and required technology (e.g., computer or iPad). For remote learning to be successful, multiple delivery strategies are required and lack of availability disproportionately affects poor communities and low socio-economic families (Azevedo et al., 2020; Page et al., 2021).

Increased emotional load carried by caregivers

The increased emotional load for parents and carers included fears of adverse effects on their child's development and academic work, in addition to fears and anxiety about their physical well-being and confinement at home. This increased emotional load emphasized the need for self-care of caregivers in having moments where they are free from support responsibilities to manage physical, emotional well-being (Aishworiya & Kang, 2020).

Siblings

Siblings have articulated the need for self-care which often becomes neglected when there are competing demands for their time in their own personal lives as well as having to mind the welfare of parents and siblings with IDD (Redquest et al., 2021).

In situations where individuals with IDD were not living with siblings, COVID-19 restrictions led to further challenges. Social restrictions where siblings of individuals with IDD could not visit each other led to a negative impact on their mental health. The need to have virtual connection possibilities has been emphasized (Redquest et al., 2021).

Positive outcomes for families

Not all impacts on relationships in families were negative. One study in Spain indicated that family cohesion increased due to increased interaction of individuals with autism with family members, programming family activities during the pandemic, and increased virtual interaction with relatives (Mumbardó-Adam et al., 2021). This was also corroborated by studies from Italy and the United Kingdom, where some families reported the ability to spend more quality time with their children (Bailey et al., 2021; Fontanesi et al., 2020; Greenway & Eaton-Thomas, 2020). For parents and individuals with ID and Autism, who found the school environment challenging, being at home increased their sense of safety (Asbury et al., 2020).

COVID-19 impacts on relationships beyond the family

The research literature reviewed revealed impacts as families interacted with others. Families interact with the broader community and these relationships were affected by COVID-19. Prior to the availability of vaccination, the only defence against the virus was to avoid contact with infected individuals. Even with the roll out of vaccinations around the world, minimizing contact with others remains a key strategy for preventing transmission of the virus. For individuals with IDD, this has led to significant impacts on relationships beyond the family in three key areas: detrimental changes to daily activities; increasing discrimination; and increased poverty.

Avoiding the virus reduces community engagement

Engagement with the community increases the risk of contracting the highly contagious COVID-19. Fear of contracting COVID-19 made basic activities, such as going shopping challenging to do (Embregts et al., 2021).

Residential settings in many countries attempted to reduce the risk of the virus entering their premises by “locking down” with residents prevented from leaving and only workers allowed to enter. This had immediate impacts on residents’ quality of life and their families. There are further impacts feared by families. Parents feared that keeping their members with IDD locked in residential settings to protect them from the pandemic may lead to individuals being unable to resume their social life post-pandemic (Vereijken et al., 2022).

Discrimination in the provision of services

Loss of services have raised concerns over the discrimination of people with IDD. In the United States, caregivers have expressed worry about the loss of ID services during and possibly post-pandemic where issues of people with ID have been given the least priority (Neece et al., 2020). When social restrictions were eased for the general public in Israel, the same did not apply to individuals with IDD in supported accommodation settings (Araten-Bergman & Shpigelman, 2021).

In the United Kingdom, a reduction of services was permitted if an individual became critically ill with COVID-19 (Frankova, 2020). Media coverage has also had discriminatory undertones conveying that people with ID might not have been considered for palliative care during the pandemic (Paulauskaite et al., 2021; Taggart et al., 2022).

Discriminatory policies and practices have been reported. Embregts et al. (2021) found that negative perceptions and misinformation led to medical doctors placing less value on people with IDD which had implications for prioritizing emergency treatment if required. This concern was reiterated in a Dutch study where families were not informed about how ethical decisions would be made about how their members with ID would be treated should they contract COVID-19 and require intensive care (Vereijken et al., 2022).

Nankervis and Chan (2021) raise human rights concerns about the care of individuals with IDD who may exhibit behaviours of concern exacerbated by COVID-19 restrictions and other impacts. There is high risk for violations of the United Nations Convention on the Rights of Peoples with Disabilities without protective measures such as targeted behaviour support processes.

The double standards applied on residential regulations (where support workers would go in and out while parents were not allowed to visit their loved ones) were concerning with respect to how the parenting role often gets disregarded in institutional settings and in society at large (Vereijken et al., 2022).

DATA SET 2—AUTHORS’ EXPERIENCES OF THE IMPACT OF COVID-19 ON FAMILIES INCLUDING PEOPLE WITH IDD

COVID-19 has had very public, profound impacts on the health system of every country in the world. Similarly, school closures worldwide, where up to 1.6 billion of the world’s children have been out of school (UNESCO, 2020), are also prominent in world news. Much has already been written about COVID-19 impacts, although the voices of families including people with IDD are not common, and



even less available from those living in low- or middle-income countries. Here we provide contributions from co-authors living around the globe. These are not representative of global experience and instead are intended to provide lived experience that will contextualize our review of the literature.

From Kenya

Author 6, Margaret, is a parent of a child with Autism from Kenya. Her experience reflects the concerns and experiences of families in the literature. Up to August 2021, the total duration of school closures in Kenya was 37 weeks (UNESCO, 2021).

Stigma around disability in Kenya has often led to families of individuals with ID and Autism being ridiculed and spreading notions in society that these individuals are cursed. Families of such individuals do not receive supports and are left to their own designs to make meaning of circumstances. Some have resorted to alcohol as a coping mechanism. Often this compounds the difficulties the family is going through leading to family break ups. The need for proper information about disability cannot be emphasized enough. The few Community Based Programmes that provide disability services in some communities reduced or closed down during the COVID-19 pandemic. Mothers of individuals with ID and Autism were particularly negatively impacted since they are the majority primary caregivers in Kenya.

Information regarding the pandemic was exclusively being received from the President on national television. Families without television sets had no way of accessing this information. There was no attention being given to specific, vulnerable populations or high-risk individuals. Schools were shut down and where families relied on relief time afforded by their members being at school, they had to suddenly juggle through care and support, work and family. This imposed a lot of strain on parents and coupled with being left to their own designs to manage through the pandemic, increased ill mental health on families. There were negative impacts from the pandemic for many families. Life was interrupted significantly with loss of jobs that were the main source of family sustenance.

As many jobs were in urban areas, this led to massive immigration back to rural areas, with a majority of people experiencing the impact of COVID-19 on employment. There are lessons to be learnt about pandemic effects on employment. The massive immigration disadvantaged people with ID and Autism who could no longer live close to places where they received services. Expensive health care services given to individuals with ID and Autism were not waived despite the difficult economic hardships families experienced. The rural immigration led people to invest heavily on buying land in rural areas for farming or self-employment. With a lack of regulation, land prices sky-rocketed, creating a negative impact on people who could not afford it.

Accommodations that in the past have been afforded to caregivers who are supporting individuals with ID or Autism (such as express counters for public services) were closed with an uncertainty of when they would return. The effect on caregivers was either to forego receiving services that they required or have moments where they have to leave their member without the support they need.

Official communication regarding vaccination for COVID-19 in Kenya prioritized civil servants and the aged. Other high-risk groups were not considered including individuals with ID or their families.

There were positive impacts reported in Kenya. For instance, technology was embraced very well since parents and caregivers relied on mobile phones for meetings, payments, and bank transactions and employees could work from home. The necessity to improve hand hygiene imposed by the pandemic saw innovations of hand washing equipment installed everywhere in public and private entities, rural and urban settings. Families were able to save more money due to reduced travel and community gatherings. Family time also increased due to curfews that required everyone to be home early.

The points raised in this experience relate to the provision of healthcare information in relevant formats, inequities that are exacerbated in a pandemic, issues of access to schooling and services and supports. It is important to acknowledge the positive experiences as well. A point not commonly raised is the impact of migration on families

with members with IDD. We return to these in the discussion.

From Canada

Strict policies to mitigate the spread of COVID-19 have caused inadvertent consequences with people with IDD kept away from their families and close friends. Author 9, Devis, a support worker from Canada, shares his experience:

I personally found it challenging to try and find ways to maintain the quality of life for people with ID in my care while trying to navigate my own self care needs and to stay afloat and get through these difficult times.

There was also limited access to different programmes and activities that people with IDD take part in and enjoy, which in turn put stress on caregivers. Devis explains how access to essential disability services became impossible because of COVID-19 and the lock-down.

There weren't enough simplified tools and other resources to educate people with ID about COVID-19. I found it difficult and was challenged when explaining to some of the individuals with ID why it is important to keep their distance from others or to not go out during the lock-down to their daily programs or to do fun activities they used to do. To make it even harder, the lack of clear timelines of how long programs would remain closed made it more stressful to answer the question, "When can I go back to day program/outings?"

Government support systems did not evolve fast enough to support caregivers. There was a large shortage of personal protective equipment (PPE) and other supplies to protect caregivers and the people with ID. Caregivers at times put themselves at risk when providing care to individuals with ID that were showing symptoms of COVID-19. Devis explains how this impacted on his role.

We have the emergency response plans in place for outbreaks and other emergencies, but these plans were not sufficient for this kind of outbreak and it took a while for us to get the support we need. In my organization we had to ask volunteers to sew masks and

gowns because they were short in supply. There was increased solidarity with the community where neighbours and friends made and provided PPE and helped with shopping for groceries and supplies.

Devis shares how the use of technology presented a safe option during periods of lock-down.

Technology has been useful in keeping some services going virtually and keeping everyone safe. It enabled different activities such as ordering food and medical supplies, monitoring health especially checking for COVID-19 symptoms, telehealth care and other social well-being tasks like check-ins with family and friends.

Finally, the impact on caregivers was clear.

For the right reasons, there was a lot of emphasis on educating caregivers about COVID-19 to stop its transmission but there was not enough emphasis on how to mitigate ill mental health on caregivers as a result of the pandemic. The pandemic put more strain and stress on caregivers which could have been reduced by extra personnel support so that the caregivers had a little more time for self-care. Without sufficient government funding, this was not possible.

From Tanzania

The experience of author 7, Cecylia, and her colleague, Miriam from Tanzania highlighted the situation faced by caregivers and parents of children with IDD. As of August 2021, the total duration for school closures had been 15 weeks (UNESCO, 2021).

During the COVID-19 lock-down, schools and other therapy services shut down. Children were not allowed to go playing outside in their neighbourhoods. Parents found it challenging to work from home full-time while at the same time taking care of children.

The sudden shift of education from schools to homes along with general social life was challenging for parents. It was especially a tough transition for children with intellectual disability for whom it was difficult to understand the reason for the transition.

In Tanzania, there weren't COVID-19 interventions focused on people with intellectual disabilities and their families. Paid professional caregivers were not able to meet the children with intellectual disability in their homes. Families of people with intellectual disabilities felt there was need for COVID-19 focused support services from whom families can access information.

The pandemic caused mass job losses, and there was a need to support families with basic needs such as food and find ways to make necessary healthcare provisions continuous and accessible. Cecylia explains her experience surrounding the use of technology for supporting learning. It is important to note the positive benefit afforded by technology.

For us we had to adapt the use of technology tools. It had worked wonders for our son's development especially in recognition of numbers and general knowledge. It was only possible and that easy because we had been using the method since 2016 when we learnt that our son is autistic and had access to the online applications which could be useful on digital devices.

The experience shared by Cecylia and Miriam is echoed by the research surrounding the impact of COVID-19 on people with ID and their families and we return to these in the discussion.

From India

The profound impact of COVID-19 on Indian society has been widely documented in news reports around the world. Indian schools have been closed for 69 weeks (UNESCO, 2021). Here, authors 4 and 5, two doctors with extensive experience of IDD, give an account of what they have seen.

COVID-19 has devastated many families and they are experiencing an ongoing, pervasive sense of loss: loss of social networks, jobs, financial security and loss of near and dear ones. Children have been affected the most, particularly those with disabilities. Closure of schools, lack of extracurricular and outdoor activities, altered eating and sleeping habits, lack of peer time have fostered monotony, anguish, irritation and diverse neuropsychiatric symptoms. Anxiety and adjustment issues top the list of psychological problems. In a developing country like

India, children from the lower socio-economic strata are the most affected. Children who were getting free mid-day meals from the school have lost that privilege. Classes have become online and interaction between teachers and children are not satisfactory; children have started to hate the process of learning. Children with disabilities need various ongoing therapies, which are available online now but not so effective. These too are available only to the privileged with at least a smartphone; but connectivity is again a problem in many places.

Regular immunization is being missed/delayed. Online medical consultation is available but has many restrictions; and has also adversely affected people with disabilities. People are mostly indoors, resulting in restricted physical activity, leading to sedentary life-style, weight gain and obesity as against under-nutrition. Although home is considered the safest place for a child, sexual and physical abuse have shown a significant rise, to add on to other domestic violences.

The impact of grief is noted in this Indian contribution. Grief is often subsumed within mental health issues, and lost in discussion of other points. More research addressing the ongoing impact of grief on individuals with IDD and their families is needed.

Another issue raised with likely ongoing detrimental effects is that of reduction in provision of regular healthcare and preventative medicine.

From the Philippines

The Philippines has faced educational challenges before COVID-19 (as discussed in Faragher et al., 2021). As at August 2021, schools were closed for 52 weeks due to COVID-19, exacerbating already difficult family circumstances. Author 8, an education officer, conveys some of the challenges.

Containment measures that resulted in school closures and isolation from social networks brought serious impacts on people with disabilities. Considering as an emergency response in the Philippines, people with disabilities have been categorized under vulnerable groups which qualified them to receive cash subsidies (Velasco et al., 2021) regardless of their disabilities. Health and other support services for children with disabilities were

classified as “non-essential” (UNICEF East Asia and Pacific, 2020b) and lack of transportation made access to support more difficult. There was also a significant decline in mental health and increase in domestic violence (Council for the Welfare of Children, 2020) which can be attributed to loss of income and other stressors linked to the pandemic.

Although governments enacted laws and deployed different forms of intervention to address the needs of people with disabilities, much is needed to see the implementation (Toquero & Talidong, 2021). These include strengthening the provision of mental health services using applicable online modalities such as tele-counselling (UNICEF East Asia and Pacific, 2020b) and unifying systems to register people with disabilities (Toquero, 2020). Information must be accessible in various formats so they can seek help and explore employment opportunities (Ambiong, 2020). The carers of individuals with disabilities such as their parents, the teachers, specialists and other frontline workers also need support to continue fulfilling their roles. Teachers and other staff need more training to provide quality education to children with disabilities while preventing transmission when schools reopen (UNICEF East Asia and Pacific, 2020a). Finally, even if face to face classes resume, there should be options for distance learning ensuring that platforms to be used are accessible and safe for children with disabilities and their families.

Again, the experience from the Philippines echoes that of other countries. The need for information in an accessible format and available to all, regardless of socio-economic status, is essential. So is support for those assisting people with IDD in all areas of society as well as within the family.

It is clear from the lived experience contributions from various countries that the impact on families in terms of health, education, support and engagement within families and others is widespread with common themes. So, too, the research literature that is emerging indicates similar findings. We turn now to explore these themes that we discern from the two data sets.

DISCUSSION

In the consideration of the two data sets—the emerging research literature and the experiences of authors living

in five different countries—thematic analysis is used to discern five themes. These themes are a way of “telling the story” (Braun & Clarke, 2022) of the research literature and in the lived experiences, the same themes are evident.

Health impacts on families are clear and not surprising. An issue that is starting to emerge is the potential impact of missing routine health checks on individuals and families through being unable to access medical services, or avoiding contact to reduce the risk of exposure to COVID-19. This is a known issue in the general community (see e.g., Czeisler et al., 2021) but the impacts on the IDD community as reported here in the experience of our authors in India appear not to be available in the research literature at this time.

Within families, the challenges to relationships reported in our literature review have also been discussed in the country experiences, although two areas added to what was found in the literature. Impacts of substance abuse (including increased alcohol consumption) and domestic and family abuse in the context of IDD need investigation. Changes to patterns of child and elder abuse during the COVID-19 pandemic have been reported in the general literature (see, e.g., Han & Mosqueda, 2020; Harris et al., 2021), although studies relating to the population of those with IDD appear not to exist at this stage. Our review identified papers that anticipate risk by extrapolating from pre-COVID-19 findings (see e.g., Buonaguro & Bertelli, 2021; Nankervis & Chan, 2021), although we could not find studies investigating incidences of abuse in the context of IDD and COVID-19.

Both research literature and our country experiences indicate the need for accessible information. There is a difference between resources that are not provided in accessible formats and where no resources exist at all. In Kenya, for example, information was not available to anyone without access to television, exacerbating poverty inequity. Information and resources were available in other countries but not provided in suitable formats.

Migration patterns and their impacts on families with people with IDD appear not to be studied in the extant research literature. A study by Safta-Zecheria (2020) raised the concern of large numbers moving from areas of high COVID infection to rural areas increasing risks of infection to people with disabilities. The issues raised by our Kenyan contributor regarding the social impacts of moving away from established networks of friends, supports and services appear not to have been researched and deserve study to understand impacts and ways to mitigate negative outcomes in future pandemics.

Emerging in the country experiences was themes of positive benefits to families of people with IDD arising

from improvements introduced as a response to COVID-19. Where access was available, technology features have become mainstream with benefits to individuals with IDD. Telehealth services—enabling access to medical and therapy care without having to attend a facility—have been appreciated by families for the convenience. Like education, there is no suggestion that accessing services on line will always be the preferred option; however, when necessary, this use of technology has been seen in a positive light. Another positive aspect was the improvement to family quality of life arising from reduced calls on time and finances by staying at home.

IMPLICATIONS AND RECOMMENDATIONS

The documented lived experiences align with the emerging literature to indicate the lessons that must be learnt from COVID-19 to improve outcomes for people with IDD and their families in similar events in the future. Eight clear implications have emerged.

Health

Access to healthcare and treatments on the same basis as any other individual in the community must be provided. Adjustments to protocols to support the specific requirements of individuals with IDD need to be provided, in consultation with families, and provided in formats that are accessible.

Public policy

It is essential that policymakers consider IDD populations when making public health directives. Lock-downs, particularly those that prevent families visiting members with IDD, can have serious acute and chronic implications for individuals, as noted in the themes from both data sets. Similarly, school closures or learning at home, can have disproportionately serious implications for the progress of learners with IDD.

Information on the pandemic

Having the correct information regarding a pandemic in an accessible format is essential. Public announcements must simultaneously be available in Easy Read and other accessible formats and channels. Additional information, such as advice about health directives and the use of personal

protective equipment, should be provided to families and support workers in accessible formats. This could mean that they are in a format such as Easy Read that would enable or assist a support worker or family member to understand and then explain the information to the individual.

Use of technology

In a pandemic, priority access to required technology needs to be provided for families with individuals with IDD, along with support for their use. However, technology is not a panacea and options for health (e.g., telehealth) and education (e.g., online learning) should not be presumed to be optimal.

Returning to school

Any interruption to schooling can lead to a loss of learning, losses of lifetime educational attainment, and increased dropout rates. Concerns are already being expressed that children may not return to school once they have been away for many months. Planning for seeking out children who have not re-enrolled is urgently needed. Plans are also required for recovering learning once learners with IDD are back in the classroom. This planning should be at three levels: individual, school and system. Methods such as adjustments to year-level curriculum should be made to allow students to continue making progress.

Supports and services

The sudden closure or reduction of supports and services caused a considerable detrimental impact on families. The role that caregivers played when IDD supports and services shutdown went unnoticed by many policymakers in COVID-19. In preparation for future pandemics, supports and services for people with IDD need to be regarded as essential services that cannot be abandoned. Protocols are needed for maintaining services in a safe way (for staff and clients), and plans made for ensuring the rapid training of staff as required to cover those unwell or in lock-down. Families need timely, professional assistance to support their family member to understand required changes to routines.

Provision of alternative virtual social programmes for people with IDD can help continuation of daily routines, reduce the occurrence of challenging behaviour, provide family supports and prevent regression of already acquired social skills.

Supports for families

Care-giving takes time and this is increased during pandemics. Parents of individuals with IDD need to have time for caregiving responsibilities considered and allocated by their employers without punitive outcomes (such as reduced pay, job loss or job discrimination). Planning psychological support for parents and caregivers is also required. There is high demand for provision of psychological services in pandemics and priority needs to be given to families of individuals with IDD. Caregivers also need information on where and how they can receive social and psychological support.

School closures also affected support for families. School attendance of children with IDD allows other family members to have respite from caring responsibilities. With children at school, adults can work in paid positions, can rest, and attend to other family responsibilities. In closing schools, policymakers need to factor in the need for respite services for families.

The finding of improvements in family quality of life due to reduced daily demands during the pandemic needs careful consideration post-pandemic to find ways to reduce the strain different service demands place on families of people with IDD.

Safeguarding

Historical abuse scandals on people with IDD have necessitated increased vigilance on the treatment and care people with IDD receive or get denied. In the absence of pandemics, some contexts have systems of safeguarding and monitoring in place. During COVID-19, there was an increase in domestic violence (WHO, 2020) but little was known about the impact on individuals with IDD. Since systems of safeguarding may be incapacitated by a pandemic, there is a need to reimagine the systems to work despite the pandemic.

CONCLUSION

This paper is aimed at learning from this pandemic so families of individuals with IDD may fair better in future pandemics. Families need to be of central concern. Policymakers can reduce the strain on families by planning mitigation measures with families of people with IDD in mind. There is still work to be done to bring about human rights for people with IDD due to the discriminatory tendencies that surface during difficult times such as a pandemic.

In this paper, we have folded in accounts of lived experiences, including some from low- and middle-income

countries. These voices have not been prominent in the research literature to this point. Combining these accounts with the extant research literature, the themes distilled give a flavour of issues emerging, leading to the recommendations we have drawn.

There are limitations to work such as this. The lived experience accounts are not representative, nor can they be. They are intended to record personal experiences in this most extraordinary time. Even so, many of the issues raised in these accounts were also noted in the research literature. Some new points suggest areas where research is needed.

The disruption to families including a person with IDD across the world continues after two years. The cliché “build back better” will be hollow words unless serious attention is given to learning from the experiences of families in terms of health, education and general quality of life.

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