Article

Professional and Family Carers' Perspectives on the COVID-19 Pandemic and Its Impact on Supported Decision-Making with Adults with Intellectual Disabilities: A Qualitative Online Survey

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Abstract: *Background*: COVID-19 restrictions in Ireland varied in levels of severity throughout 2020 and 2021. The aim of the present study was to explore the experiences of professional and family carers in supporting people with intellectual disabilities to make their own decisions during these restrictions. *Methods*: Participants recruited between July and December 2021 via social media, disability services, and academic experts completed a qualitative online survey. Results were analysed using reflexive thematic analysis. *Results*: Data from 16 participants (eight professional carers, eight family carers) were included. Three main themes were identified: 1. centring the person, 2. adapting to COVID, and 3. restricted lives. Anxiety, confusion, and boredom among adults with intellectual disabilities during restrictions were reported by both professional and familial carers. Professional carers reported some positive outcomes, including greater chances for independence among service users and new activities becoming available via online resources. Family carers reported more negative outcomes, including isolation from disability services. *Conclusions*: People with intellectual disabilities had their choices markedly curtailed during the restrictions. Future studies should focus on improving the ability of services to reach users who may not have the ability to attend services in person.

Keywords: intellectual disability; supported decision-making; COVID-19; self-determination

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1. Introduction

Self-determination and independence are highly important in the lives of people with intellectual disabilities and are linked with a higher quality of life [1]. Supported decision-making (SDM), defined as a process which "allows individuals to make choices about their own lives with support from a team of people they choose" [2], is a key method of encouraging and promoting self-determination. SDM is gaining popularity across the world in both policy and practice [3,4]. In Ireland, a process is currently underway to enshrine the right of persons with disabilities to make their own decisions through the commencement of the Assisted Decision-Making (Capacity) Act [5]. This represents an important step forward in the country's adherence to the United Nations Convention on the Rights of Persons with Disabilities [6]. In this manner, the key components of SDM, namely, the right of the supported person to choose who supports them and to what extent, will be upheld in Irish statute, replacing previous legislation, which focused on paternalistic, best interests decision-making by guardians, rather than the will and preferences of the person themselves [7].

COVID-19 restrictions had a significant impact on the everyday lives of adults with intellectual disabilities over and above that of the general population. In Ireland, restrictions varied in levels of severity throughout 2020 and 2021, with the strictest of these requiring

people to remain within 5 km of their homes [8] and avoid meeting anyone socially indoors [9]. Adults with intellectual disabilities were considered a vulnerable population and were advised to self-isolate even earlier than the general population [10]. All recreational activities and in-person services stopped during this time, and those in residential homes were unable to see or visit family [11]. Restrictions, such as these, meant that people with intellectual disabilities were less able to make decisions about their everyday activities during the COVID-19 pandemic, leading to isolation, boredom, and anxiety [12]. Remote delivery of services appears to have been inconsistent. In a study conducted by Inclusion Ireland, where eleven people with intellectual disabilities were interviewed about their experiences with COVID-19, varied amounts of support from services were reported. Some received frequent phone calls from support workers while they were at home, while others said workers they would have known and spent time with were reassigned, leading to little contact with services [13]. A study in preparation by O'Donnell et al., where twelve people directly involved in the development and provision of online services for disability organisations were interviewed about the process, also found that factors, such as lack of technological infrastructure, understaffing, lack of funding, and concerns surrounding General Data Protection Regulation (GDPR), led to difficulties in establishing remote service provision [14].

In light of the pandemic and associated restrictions, we were interested in how the decisional freedoms of people with intellectual disabilities may have been affected. Therefore, we used a qualitative survey [15] to explore how these restrictions impacted professional and family carers' abilities to support people with intellectual disabilities to make their own decisions.

2. Materials and Methods

2.1. Target Demographic

The survey was intended for professional and family carers of persons ≥18 years with intellectual disabilities living in the Republic of Ireland.

2.2. Procedure

Ethical approval for this research was granted by Maynooth University Social Research Ethics Sub-Committee. The survey, which contained a series of open-ended questions regarding carers' experiences of supporting adults with intellectual disabilities to make decisions during the COVID-19 pandemic and associated restrictions (see Supplementary File S1), was hosted on Qualtrics [16]. A link to the survey was shared across social media platforms and was sent to disability services via email for dissemination to staff or colleagues. Relevant academic experts also disseminated the link to known contacts.Data collection took place between July and December 2021. The survey questions were devised by HC and DD based on review of the literature. They were formulated to reflect understanding of SDM as a method of support, as well as our understanding of the evolving impacts of pandemic related restrictions. Braun and Clarke's paper on using surveys as qualitative tools was formative in the construction of the questions [15]. The findings were reported in accordance with the Checklist for Reporting Results of Internet E-Surveys (CHERRIES) (See Supplementary Table S1) [17].

2.3. Data Analysis

Responses were transferred to Microsoft Excel and analysed using reflexive thematic analysis [18]. Reflexive thematic analysis is distinct from thematic analysis in its centring of the knowledge of the researcher at the heart of the analysis. It encourages the researcher to revisit, review, and reflect upon their own understanding of the data throughout the analysis [19]. This reflexive method was practiced throughout the analysis to ensure trustworthiness. The first author (HC) was motivated to carry out this research due to her own family situation. She has a family member with an intellectual disability who currently lives in a residential setting. She experienced difficulties staying in contact with

this person during the COVID-19 pandemic. In this manner, the author acknowledged her own biases in relation to the topic at hand. However, this was mitigated by working alongside her co-authors to ensure an open, unbiased analysis of the data (see the section on Author Contributions for further details). [15]

Responses were read and re-read for familiarisation with the data. Free coding was completed using colour coding and the comment feature in Excel. Codes were refined into more concise thematic categories, which were reviewed and streamlined into the final themes. We also consulted Braun and Clarke's survey paper to refine our approach to analysis [15]. All investigators reviewed and discussed the themes before they were finalised to ensure the trustworthiness of the findings.

3. Results

Sixteen responses were analysed. Eight participants were professional carers, and eight were family carers. For family carers, four were male, and four were female, with ages ranging from 48 to 70 years. Two were employed full-time in addition to care duties, two were not currently employed, and the remaining four were retired. One family carer reported being the sibling of a person who lived in a residential setting, while all other family carers reported being a parent cohabiting at home with the person with intellectual disabilities. For professional carers, six were female, and two were male, with an age range of 36 to 63 years. Five were employed in the public sector, two were employed in semi-state companies, and one was employed in a private company as an employee. All worked full-time, and the number of clients cared for ranged from 5 to 43 (see Table 1).

Table 1. Participant Demographic Information.

Family Carers					
ID	Age	Gender	Employment Status in Addition to Care Duties	Relationship to Person with Intellectual Disabilities	Living Arrangement of Person with Intellectual Disabilities
F1	53	Female	Employed full-time	Sibling	Residential home
F2	58	Female	Not currently employed	Parent	Cohabiting with family
F3	62	Female	Retired	Parent	Cohabiting with family
F4	63	Male	Retired	Parent	Cohabiting with family
F5	60	Male	Retired	Parent	Cohabiting with family
F6	56	Female	Not currently employed	Parent	Cohabiting with family
F7	70	Male	Retired	Parent	Cohabiting with family
F8	48	Male	Employed full-time	Parent	Cohabiting with family
Professional Carers					
ID	Age	Gender	Sector	Full or Part-Time	Number of Clients Cared for
P1	56	Female	Employee, private sector	Full-time	6
P2	36	Male	Public sector	Full-time	13
P3	63	Female	Semi-state company	Full-time	8
P4	30	Female	Public sector	Full-time	9
P5	46	Female	Public sector	Full-time	3
P6	34	Male	Public sector	Full-time	4
P7	63	Female	Public sector	Full-time	43
P8	40	Female	Semi-state company	Full-time	5

Three main themes were identified in the analysis: 1. centring the person, 2. adapting to COVID, and 3. restricted lives.

3.1. Centring the Person

This theme describes how professional (*n* = 8) and family carer respondents (*n* = 8) spoke of their efforts to support people with intellectual disabilities by ensuring they listened to and assisted them in any way they needed before and throughout the pandemic. The emphasis was very much on the individuals with intellectual disabilities themselves, as well as what they required to fulfil their goals and wishes.

Professional carers described how their organisations had formal approaches to support decision-making by their clients. Person Centred Plans (PCPs), Personal Development Plans (PDPs), and Personal Outcome Measures (POMs) were mentioned as tools used to record and develop the plans and wishes of clients.

> *"We have PDPs, personal development plans for each individual, and the individual with her key workers and support of multi-disciplinary team where needed, work together to aim to achieve the ladies wishes, dreams and aims."* [P1]

Some professional carers reported receiving training to ensure the centring of their clients through adoption of their preferred communication methods, as well as of their organisation's ethos of respect.

> *"Rights based approach; core learning modules in induction and updates—UNCRPD and Assisted Decision-Making; staff learning includes communication, sign-language. Service values and culture focus is relationship and support frameworks (e.g., Supported Self-Directed Living) not rules & regulations (though we have them)."* [P7]

> *"To the best of our ability, we attempt to have a person-centred approach. The ethos of the organisation is 'Love and respect in every action'."* [P6]

A number of the professional carers who took part reported adopting a variety of techniques in order to facilitate the choices of their clients. Techniques to establish preferences included taking note of interest expressed in certain activities, introducing options, and facilitating communication.

> *" . . . by sampling a variety of activities, recording interest levels and participation levels, using picture boards, communicating through Lámh [Irish keyword signing method] and giving the person options they may like as we get to know them."* [P2]

All professional carer respondents reported how they adopted techniques and strategies to suit the needs of their clients wherever possible. For example:

> *"Assume capacity to make choices; each person supported by an Individualised Planning Coordinator, Key Worker, Circle of Support; each person encouraged to engage with independent advocate for their independence."* [P7]

> *"Our organisation uses a system where people supported are represented by their peers in the interview process."* [P8]

Family respondents reported centring their loved one in decision-making through conversation and communication. They discussed potential decisions with them and ensured they were given clear choices using simple language.

> *"Giving her choices."* [F2]

> *"He is always asked his views on trips, feeling comfortable in certain situations."* [F3]

One family carer respondent spoke about how the COVID-19 restrictions had affected their usual methods of support. The suspension of in-person visits with loved ones in residential care meant they were less involved in their day-to-day decisions.

> *"Pre covid she would come stay with us, we called to see her regularly and we knew all the staff in her house. We were involved in her future plans and would advocate for her whenever there was a problem. We still do as much of this as we can but it definitely became more difficult during lockdown."* [F1]

Family members detailed the types of decisions they helped their loved one to make. All spoke of everyday decisions, such as clothing and outings; only one family member indicated that they helped with bigger decisions such as those related to health or interpersonal relationships.

> *"It can be something as simple as to what kind of food/clothes she wants to buy/eat to more complicated issues of helping her negotiate relationships or health decisions."* [F1]

> *"Clothing, personal hygiene, eating, recreational activities."* [F7]

> *"Plenty of warning of trips and Outings with large crowds. Offering opportunity not to participate with no feelings of disappointment."* [F2]

3.2. Adapting to COVID

This theme discusses how professional and family carers described their attempts to support decision-making during the COVID-19 pandemic and subsequent restrictions. Professional carers reported making use of online resources to facilitate activities, but they also reported how the world of their clients became rather limited due to governmental restriction of movement and group activities being disbanded. Family carers, on the other hand, reported that their loved ones received little in the way of communication or remote support from services, which led to feelings of increased isolation and removed much of their loved ones' social activities outside of the family home.

The internet was reported as a vital resource by professional carers. In-person activities were suspended and, as such, this was the most effective way for clients to continue to enjoy recreational activities of their choice, with varying degrees of success. Some respondents faced difficulties, such as poor internet connection or a remaining sense of isolation. However, others described the pleasure and usefulness of online classes as a source of entertainment.

> *"A lot of online activity occurred which was great e.g., zoom activities, exercise classes, music sessions, family video contact etc. however our Internet service was poor and although we have tvs etc., many times we had difficulties. Shopping for groceries, clothes etc., was very difficult for the ladies to choose online products. It was a lot of remote clinics for services and the ladies found communicating in this way difficult."* [P1]

> *"Some of the people supported activity sampled Boxercise online and absolutely loved it."* [P8]

The internet also proved effective for keeping in touch with family members. The clients availed of video chat services regularly, as the restrictions also prevented travel and family visits. The initial set-up of technology to facilitate contact took some time, and staff members reported that clients were confused and upset by not being able to see their families in person.

> *"It took a number of months to get technology up to speed for everyone to keep in touch ie equipment like tablets etc. so that our people supported could use TEAMS."* [P8]

> *"Shopping, the ladies had limited choice as they were more dependent on staff to use technology."* [P1]

> *"Technology (video calls, tablets with apps etc.) needed a lot of work to get off the ground initially but very useful."* [P2]

> *"Family and friends contact to each individual is so important to feel loved and cared for and included, without this, without being able to go home was tough and heart breaking for many of our ladies."* [P1]

Despite the limitations described above, some professional carer respondents reported an increase in opportunity for their residents, both in activity choices and independence.

Many spoke of the new hobbies and activities clients engaged in over the pandemic. One discussed how the calmer schedule meant each person was more able to do the

things they wanted to do, which led to a decrease in distress. They were also given more opportunities to try new activities that they might otherwise never have attempted.

"Lots of incidents of challenging behaviour were lowered, more person focused and less rushing around trying to fulfil activity plans/sporting groups/group events." [P2]

"The menu of activities which we offer to our residents has become varied in ways which were previously unforeseen. It has forced us to adapt on extremely short notice, and many of our residents have thrived in this process." [P6]

"However, some enjoyed having regular team with little rotation and learned to dine, garden, share music, do classes on-line (fitness, yoga, cooking, art, singing.......so much to do)." [P7]

Although separation from family proved difficult for clients, professional carers reported that it also gave them an opportunity to make more decisions independently.

"Not much impact, some positive effects also noted due to not having to fulfil families' requests to see them, meetings with families were dictated by the people we support not the families." [P2]

"Have been able to make more decisions themselves." [P5]

One respondent spoke of seeing new resilience in their clients, who adapted well to the changes.

"For the residents which I care for, it has led to a change in their daily lives, where many have learned to become more resilient. Many have adapted to change well, utilising technology to connect with their families and friends, as opposed to in-person visits." [P6]

When asked how COVID-19 had led to changes in their loved ones' lives, family carers primarily discussed how the closure of services affected their ability to offer choice and activities at home. The absence of their disability services' day service and community activities were most commonly mentioned.

"Severely restricted because his day services closed for the first 21 weeks on the pandemic and only operated on a 2-day and 3-day basis for the months following. No social outlet." [F7]

"Huge, our son's life was his social life and day services." [F6]

For one respondent, their inability to visit their family member meant they were unable to help her in the usual way, which they found difficult.

"As we were unable to meet in person due to the restrictions, we were not involved with her the way we normally would. During times when she was upset or worried, we were dealing with her over the phone." [F1]

Very little service support was reported by any of the family carer respondents, with only three of the eight who participated giving examples of contact with services.

"[Service] encourage independence but at home I find that hard to transfer. She will do it for everyone else but not her mother!" [F2]

"[Name] services. Support with keyworker, social worker and psychiatrist." [F3]

"Setting goals etc. [website of service given]." [F4]

Of the remaining five respondents, one expressed frustration with the lack of contact from disability services. They had previously asked for more support, but they had not received it.

"Minimal support, we are constantly looking for more support, due to have a meeting with day services next week when I will bring it up again." [F6]

3.3. Restricted Lives

COVID restrictions had a confining effect on the activities and choices of people with intellectual disabilities, according to respondents. Restriction of choice occurred as a result of group activities being cancelled and day services being shut down. Respondents also discussed the isolation and confusion experienced by the people with intellectual disabilities they supported because of social distancing and restrictions on movement.

Professional carers reported that the people they supported were bored, confused, and upset by not being able to attend activities outside of their homes:

"The ladies love interacting in the community, and this was stopped for long period. The ladies were bored with the limited amount of activities and movement they were used to having pre covid." [P1]

"Covid has restricted people with ID from simple stuff like going out for a coffee. Eating out. Attending a gym, going Bowling." [P3]

An effect of greater dependency on staff was reported. Residents could not go out in the community or perform their usual tasks, such as shopping or picking up medication by themselves, and they became more reliant on staff to complete these tasks for them. The added complication of having to conduct all banking and shopping online meant that previously enjoyable and manageable tasks became inaccessible in some cases. This dependence was described by one respondent as being like a return to institutional practices:

"Lots of other scenarios occurred and the ladies eventually accepted these, but I feel they did not really understand why so many changes, it was like removing a lot of development and positive moves in our residence and we were going back to institutionalisation." [P1]

"Shrinking opportunities had the effect of greater dependency—going to the shop/pharmacy for them instead of with them; the outdoor life was extremely limited." [P7]

Two respondents also reported an increase in fear and anxiety among their clients, especially when in public due to worry about contracting COVID-19.

"In some cases been afraid to attend their Day Services." [P3]

"When we got to go out, fear and anxiety was increased." [P7]

Family carers discussed how the restrictions meant their loved one was unable to make their usual variety of choices, leading to feelings of distress and confusion.

"We used to plan activities ahead with calendar, had to put it away, this was very difficult and depressing, day services were very slow to open, only going back to 5 days next week." [F6]

"Had very few choices left once covid hit." [F2]

Some respondents said the lack of routine due to the closure of day services and government restrictions on meeting others meant their loved ones' general distress and anxiety was increased, as well as confusion over why they could not attend their usual activities.

"Little issues were magnified, her routine was completely changed and she had very little to occupy her." [F1]

"The whole experience was very confusing." [F8]

"My son suffered during the lockdown as everything he loved was curtailed. No sport and only telephonic support from his keyworker." [F3]

4. Discussion

The findings of this study indicate that the pandemic and resulting restrictions had a significant impact on the choices and freedom of people with intellectual disabilities in Ireland. Both professional and family carers noted little in-person contact with friends or family, and there were limited activities during this period, leading to confusion, anxiety,

and distress. Family carers reported sporadic and infrequent communication or support from disability services during this time. Other research highlights similar feelings of restriction, boredom, and isolation among people with intellectual disabilities during this time [10,20–22]. Other vulnerable communities, such as people with chronic health conditions and older people, were similarly affected [23–25]. This suggests that vulnerable groups were disproportionally affected by the restrictions.

The buffering impact of online communication was a key finding in the present study. It enabled persons with intellectual disabilities to speak to loved ones, despite not being able to visit, and it afforded opportunities to try new activities that may not have otherwise been available to them. Previous researchers have found that using online resources, particularly communication apps, allowed people who were vulnerable or self-isolating to keep in contact with their families and friends, which helped to decrease feelings of loneliness and isolation [26–28]. The literature also echoes this study's findings on the limitations and challenges of online activities among adults with intellectual disabilities. Communicating with friends and family online was not the same as seeing them in person, and difficulties were experienced in using online shopping or learning how to use the computer itself [20,21,29,30]. Future research should explore how the accessibility of online resources could be increased to allow for greater ease of use among people with intellectual disabilities.

The finding that the pandemic often afforded greater, rather than lesser, choice to people with intellectual disabilities living in residential care settings is notable. Although previous research found evidence of great adaptability and resilience among people with intellectual disabilities and other vulnerable populations during this period, there was no evidence in the literature pertaining directly to an increase in decisional independence or support in decision-making due to the pandemic [27,31–33]. Luckasson and colleagues wrote a theoretical paper in 2020 discussing methods of maintaining independence and decisional support, which echoes elements discussed here. Their paper included suggestions that professional services should take a flexible, holistic approach to support during the pandemic, should not allow safety concerns to eclipse this, and should use multifaceted techniques, including online resources, to maximise independence [34]. It appeared in the present study that family carers had a particularly difficult time implementing such measures, and a lack of resources or service support was frequently commented on. Themes of restriction of choice and isolation featured more prominently in their responses than those of professional carers. McCausland and colleagues, similarly, reported that people with intellectual disabilities living in residential settings had greater access to, and use of, technology during the first wave of the pandemic [11].

This highlights a potential gap in service provision for people with intellectual disabilities who attend day services or avail of outreach services. Further investigation into how day and outreach services might be better equipped to support and communicate with families remotely should be conducted to ensure all people with intellectual disabilities can be afforded the same opportunities for this holistic, inclusive support.

Strengths and Limitations

This survey was limited by its small sample size. However, those who did respond provided detailed replies on this under-researched topic. This survey was designed to capture the experiences and perceptions of the included groups; while statistical generalisability was not the aim, we acknowledge potential limitations in theoretical generalisability. Data pertaining to levels of disability or co-occurring conditions were not collected; these may be important considerations in future studies. People with intellectual disabilities themselves were not included as participants in this survey, which is a limitation. The voices of people with intellectual disabilities should be taken into account, and future research on this topic should include them as central participants.

5. Conclusions

Although people with intellectual disabilities were limited in their everyday choices by the pandemic restrictions, professional carers reported increased opportunities to try new activities, leading to gains in independence and decision-making. This was not achieved without difficulty, as many stated that the necessary infrastructure for online and remote support was not present before the pandemic began, and it took some time before they were up and running. Furthermore, the internet proved inaccessible to the service users at times, which led to a greater dependence on professional carers to carry out previously independent tasks. Online inaccessibility has long been discussed by people with disabilities and their supporters [35,36], and, in this modern age of technology, it should be more keenly addressed to facilitate independence among people with intellectual disabilities. Family carers reported more restriction and isolation for their loved ones who lived with them in their homes. This has highlighted a gap in service provision and suggests that a focus on how to assist and support people who may not have the means to travel to an in-person service every day should be implemented. Future studies should further explore how the pandemic has afforded opportunities for remote service provision for residential settings and investigate how to extend the reach of these innovative practices to include day and outreach services. This would ensure that people with intellectual disabilities in all settings and support networks have access to resources to facilitate independence.

Supplementary Materials: The following supporting information can be downloaded at: https://www.mdpi.com/article/10.3390/disabilities3020014/s1, File S1: questionnaire; Table S1: CHERRIES checklist for survey trustworthiness.

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