



PERCEPTIONS OF THE IMPACT OF INITIAL COVID-19 LOCKDOWN RESTRICTIONS ON PEOPLE WITH INTELLECTUAL DISABILITY IN RESIDENTIAL CARE

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In March 2020 the World Health Organisation (WHO) declared the outbreak of the new coronavirus (COVID-19) as a global pandemic. The impact of pandemics on the behaviour and mental health of people with intellectual disabilities was hitherto unresearched due to the unprecedented nature of a pandemic in modern times. Long-term care residents, including those with intellectual disabilities, have been identified as being particularly vulnerable to COVID-19 (World Health Organization, 2020). People with an intellectual disability in residential homes are at a higher risk of contracting the COVID-19 because they are highly dependent on everyday physical assistance from relatives and practitioners, and because they invariably reside in group environments (Tummers et al., 2020). In 2020, the WHO and countries around the world took a variety of preventive steps to minimize the risk of infection, including advising people to stay at home and participate in social distancing in public spaces. In addition to these steps, many residential organisations for people with an intellectual disability implemented stringent guidelines for face-to-face communication with families, and many day-services for people with an intellectual disability closed (Embregts et al., 2021).

These restrictions have had a significant impact on the wellbeing of people with an intellectual disability (Courtenay, 2020). Previous research has shown that lack of productivity and other purposeful events in the lives of people with an intellectual disability, such as the loss of employment or daytime activity, can have had an especially severe impact on their wellbeing (Lysaght et al., 2009; Lysaght et al., 2017). It was also assumed that people with an intellectual disability would be subject to further distress, due to difficulties understanding the government guidelines and their purpose (Courtenay, 2020). While the steps put in place to minimise infection levels undoubtedly had a significant impact on the everyday lives of many people with an intellectual disability (e.g., increased anxiety, frustration, and loneliness; Courtenay, 2020), they also had a significant impact on direct support staff's work in this field (Embregts et al., 2021).

However, it has been suggested that this experience is not entirely negative (Hughes & Anderson, 2020), with some evidence that organisations have recorded a reduction in challenging behaviour (CB) among people with an intellectual disability, which they attribute to increased staff team stability (Embregts et al., 2022; Rose et al., 2022). Furthermore, some organizations have observed people with an intellectual disability to be more settled and relaxed than they were prior to the COVID-19 pandemic (Hughes & Anderson, 2020). As of yet, empirical research into the long-term impact of the COVID-19 pandemic is lacking, despite hypotheses and anecdotal observations

about the potential challenges and gains experienced by people with an intellectual disability. As a result, research into the possible challenges and benefits posed by the COVID-19 pandemic for both people with intellectual disabilities, and their direct care workers is critical.

Aims

The purpose of the naturalistic, exploratory study was to gain insights into work practices that supported residents in coping with the unprecedented COVID-19 restrictions. The period from 12 March - 18 May corresponded with the strictest period of COVID-19 public health restrictions in Ireland. Within this context, the study aimed primarily to answer the question:

1. What factors do front-line staff believe impacted positively or negatively on residents' behaviour during lockdown?

Methods

Design

The qualitative study comprised of survey responses by managerial staff working in the residential homes. Sample open-ended questions included: "Describe any impact (positive and/or negative) your Residents encountered during the COVID-19 restrictions" and "Describe staff experiences during the COVID-19 restrictions". Responses were analysed using the Braun and Clarke (2006) model of thematic analysis, using an inductive approach. Managerial staff responded in great detail, sharing their observations and insights in an often extended narrative. Data were coded and themes developed using NVIVO analysis software.

Participants

The participants were seven clinical nurse managers who worked as front-line staff managers across four residential sites for people with an intellectual disability. The inclusion criterion for residential sites in this project was sites primarily supporting individuals with behaviour management difficulties. All identifying information (both staff and residential site details) were removed before being shared with the researchers. A coded system for site identification was developed by the DSP (Sites A – D) to ensure the confidentiality of residential sites and managers. The project was approved by the Clinical Psychology Research Ethics Committee (CPREC) of UCC.

Results

The qualitative responses provided by the managers from the various residential sites were broken into four primary themes (See Table 1).

Table 1: Themes, subthemes and descriptions that emerged from the qualitative dataset

Theme	Description	Subthemes
Above and beyond the call of duty	Observations of staff experiences throughout the lockdown period, adapting to new work regimes in a time of uncertainty	<i>We had to think and think fast</i> <i>Thinking outside the box</i> <i>Helping residents adapt</i> <i>Stress and sacrifice</i> <i>Togetherness brings strength</i>
Slowing things down	Observations of residents' experiences throughout the lockdown, adapting to uncertainty and new routine	<i>Fun, joy & lots of laughter</i> <i>The relaxed approach</i> <i>Negative impacts of lockdown</i>
Managers' reflections	Looking back at the lockdown and how it felt on a personal and professional level	<i>Additional pressure</i> <i>Pride in staff</i>
Where do we go from here?	Consolidated learning points from the experience of a lockdown, and future directions on an organisational level	<i>Back to basics</i>

Theme 1: Above and Beyond the Call of Duty

Managers across all sites highlighted the impact of the hard work of their staff, who were doing more than what was expected of them, at a challenging time, despite risk to themselves. Managers noted that staff were cooperative and willing to take on additional tasks that were asked of them. They also noted staff taking additional precautions outside of work, to ensure they could protect their vulnerable residents.

"Staff have in my opinion worked above and beyond their call of duty to make this difficult time bearable for the residents and for themselves... The staff were fully supportive of any measures that were put in place e.g., cleaning regimes. Infection control to a point of OCD. As a result, the precautions worked, and we remained COVID free." Site D1 Manager

With the subtheme, **We Had to Think and Think Fast**, it was evident that in lieu of official protocols (which managers noted were often slow to be disseminated), staff drew on their own natural instincts to care for the residents. Staff were forced to think on their feet to ensure the safety of the people they care for.

"Drawing on our instinct to care, support, protect and prevail, with having this anticipatory anxiety with a sense of fear of the unknown brought out an inner fight in myself and the team - to do our best against the virus. Keep those we support safe and well, virus free." Site B Manager

It emerged that this quick thinking was not just required of staff to keep residents safe, but also to keep them entertained, and staff had to be creative when access to the outside world was restricted, informing the subtheme of **Thinking Outside the Box**.

"Thinking outside of the box by staff to alleviate feelings of confinement and restrictions associated with loss of routine became a new experience for many. This was very well received and very much continues to be the cornerstone of meeting the needs of those we support daily." Site B Manager

All seven managers that took part in the survey made note that staff made efforts to increase telecommunications to support communication with families. Staff helped residents understand the pandemic, while simultaneously making efforts to make life feel as normal as possible. This was reflecting in the subtheme, **Helping Residents Adapt**.

"Resident's understanding of COVID-19 was for many difficult to accept... however timely group meetings within small groups in their homes proved to be beneficial, and easy read formats and information was delivered by all staff and management to all residents to a level of their understanding." Site B Manager

Managers reflected on how hard staff members worked to do their best for the residents, all while facing additional personal challenges in a time of global uncertainty, captured as **Stress & Sacrifice**.

"Staff generally felt afraid and concerned for their own safety and the safety of their families. They were stressed for the safety of the residents as well." Site D2 Manager

With the subtheme, **Togetherness Brings Strength**, it was noted that, despite the additional stress in both their personal and professional lives, the managers observed their teams coming together, united in their goals. Many managers observed a boost in morale across staff members.

"Togetherness brings strength... One day at a time, in a moment when needs are great, we came together to protect - Life!" Site B Manager

Theme 2: Slowing Things Down

In discussion of managers' observations of the residents' experience throughout the lockdown period, the majority emphasised seeing a benefit from a change of pace. Managers noticed that having fewer activities during the day and spending more time in the facility together had many positive impacts.

"Play was more meaningful, engagement with each other a plenty, talking, listening, actively happy, and more appreciative of one another. I feel this is sometimes lost, in this crazy world... Slowing things down and acknowledging quality instead of quantity in terms of activity, more butterfly moments." Site B Manager

As part of the subtheme, **Fun, Joy and a Lot of Laughter**, managers noted an increase in residents' engagement with one another, and with staff, and highlighted that the quality of interactions improved when external pressure to stick with rigid schedules was removed.

"Staff enjoyed having more time with some residents who may have previously attended day service." Site C1 Manager

"Creativity, together with staff, residents had fun, joy and a lot of laughter." Site B Manager

Residents appeared to enjoy this more **Relaxed Approach** and managers observed them to be calmer, and to have fewer instances of CB.

"Residents spent a lot more time outside and not restricted to day centres. Residents were not rushed and there appeared to be a much more easy approach to the day as residents were not under pressure to reach timelines." Site D1 Manager

However, despite having a calmer atmosphere, some managers reflected that the pandemic also had **Negative Impacts for Certain Residents**. Many noted an atmosphere of uncertainty, as well as some residents' feeling isolated from loved ones. One manager noted an increase in CBs in their resident.

"Resident's understanding of COVID-19 was for many difficult to accept, and the uncertainty was felt" Site B Manager

"Increased levels of mental health indicators such as withdrawal to bedroom, talking to self." Site C2 Manager

Theme 3: Managers' Reflections

Managers across the sites felt **Additional Pressure** due to the uncertainty of the situation both on a national and local scale. Many felt that this pressure was bolstered by additional duties, keeping up to date with documentation for the DSP itself.

"Difficult and confusing to keep up to date with ever changing guidelines and procedures as well as never ending risk-assessments and plans." Site C1 Manager

It was evident from the transcripts that the managers felt **Proud of the Teams** they managed, emphasising how they came together as a team to combat uncertainty and do whatever they could. Managers reflected on the hard work of their staff, highlighting their combined achievements, such as the low COVID numbers within the residential sites.

“Statistically based on our numbers of residents and staff around the organisation our COVID numbers should have been higher, and this is testament to hard work of frontline staff.” Site D1 Manager

Theme 4: Where do we go from here?

As part of the subtheme, **Back to Basics**, managers gave recommendations for the future of the facilities, consolidating the learning they had taken from the experience of the pandemic. The majority of managers observed positive results from having fewer demands on residents and felt that this learning should be taken forward.

“Really look at what residents want to do in their lives. Explore possible new experiences with them. More person-centred goals... Find the right balance between regulation standards and quality of life.” Site B Manager

Discussion

The findings of the present study highlight some of the factors that supported people with intellectual disabilities in residential homes during the initial lockdown, which may have contributed to positive experiences including reduced stress and demands. For example, anecdotal reports of reduced stress in residents with intellectual disabilities during lockdown may be accounted for by increased consistency in staff teams. According to Larson et al. (2011), people with intellectual disabilities can present with significant attachment difficulties. Mullen (2018) claimed that people with intellectual disabilities in residential care are predisposed to attachment behaviour towards their support staff and can feel emotionally insecure when this input is inconsistent, or when they have to compete with others for limited carer attention. In group-care settings, formal carers such as support staff are often the primary caregivers of individuals with intellectual disabilities, and therefore having consistent staff members present can allow reduce attachment-related stress and increase feelings of security and safety (Schuengel et al., 2010). In the present study, managers reported an increase in staff levels during the period of restrictions, as well as more consistency within the teams. This predictability in staff members, and the resulting increase in individual attention, may therefore have contributed to reduced stress in the residents.

Many of the managers in the present study observed residents becoming calmer during the lockdown period, which some attributed to a reduction in stimulation and activity scheduling. Janssen et al. (2002) note that stress in people with intellectual disabilities is seen as a function of the gap between perceived societal demands and perceived competence to handle them, highlighting the need for a predictable and consistent environment. Bigby and Beadle-Brown (2018) posit that over-scheduling can lead to over-stimulation in people with intellectual disabilities and can lead to feeling stressed and unfulfilled. Furthermore, the study highlights that people with intellectual disabilities report improved quality of life when engaging in fewer, but more meaningful activities in a consistent environment. This is in line with the staff observations in the present study, where residents appeared happier with fewer demands placed on them and were seen to have more meaningful engagements with one another and with staff. Staff helping residents engage in meaningful play and

creative activities within their homes, with fewer time-bound pressures, may have contributed to a reduction in CB and/or their severity.

The staff managers in present study also reported an increase in job satisfaction and staff-wellbeing in the workplace (despite external pandemic-related stressors), which likely impacted resident wellbeing. While this finding is in line with the similar finding that residents became calmer and happier when staff were happier (i.e., the cyclical nature of happier staff, breeding happier residents and vice versa; Schuengel et al., 2010), this experience of increased job satisfaction was not mirrored by support staff elsewhere. Increased anxiety and frustration among people with intellectual disabilities as a result of the pandemic restrictions, posed additional difficulties for support staff, particularly when service-users were unable to comprehend the reasoning behind and importance of the restrictions (Embregts et al., 2021). Under regular circumstances, support staff in residential units for people with intellectual disabilities face a variety of psychological difficulties on a personal level (e.g., heightened risk of work-related stress and anxiety, burnout, frustration, and emotional exhaustion), particularly when engaging with service-users who show persistent CB (Edwards & Burnard, 2003; Embregts et al., 2021). This stress can be exacerbated when also dealing with organisational concerns (i.e., with management and/or the wider organisation) (Mutkins et al., 2011).

Although staff may have been experiencing an increase in anxiety in their personal lives due to the pandemic, studies have noted that shared adverse experiences can facilitate team bonding and increased the sense of community in the workplace (Anmar et al., 2020; Bastian et al., 2018; Cohn et al., 2004; Seitz, 2016). Anmar et al. (2020) also notes that staff believing their work was meaningful and was positively impacting their community in a time of crisis, may also have served to strengthen bonds between teams, and increase provision of individual attention for their clients. This is consistent with the findings of the present study, where despite an increase in personal stress and anxiety outside work, staff reported feeling more bonded as a team and more fulfilled in work. Generating novel ideas to enhance the wellness in others can lead to an increased sense of fulfilment in the carer, and this visible effort can be perceived by those being cared for, making them feel valued and supported (Haslam et al., 2018).

Due to its small-scale, this study may be viewed as a preliminary scope into staff perceptions of initial COVID-19 restrictions, with need for further investigation. One of the strengths of the present study was the use of a qualitative approach, with open-ended questions allowing managers to express opinions and share insight from their experiences throughout the lockdown. The present study also had several limitations, most notably the small sample size for both managers surveyed (n=7) and residential settings represented (n=5). This has implications for our ability to extrapolate to other settings and indeed other staff within these settings. Future research should seek to gather the lessons learned during the period of COVID-19 restrictions through more in-depth retrospective interviews with staff. In addition, there is scope to examine trends in CB on a greater scale, perhaps using routine organisational data during subsequent lockdowns to draw more substantive conclusions as any objective changes in behaviour during these periods. Future studies should also seek to include the voices of the people with an intellectual disability who live in residential settings, to better understand their own views.

Findings from this exploratory study highlight the potential benefits from service providers reflecting on their staffing quotas post-pandemic, with managers highlighting that greater staffing numbers was associated with reduced stress in both staff and residents. Providers could consider fostering more consistent teams with less lateral movement for staff across different sites and homes and reconsider the timetables of their residents and level of daily activities, perhaps allowing for more in-house activities and fewer scheduling demands. While the COVID-19 pandemic raised unprecedented challenges for the disability sector, there is clear scope to learn from these experiences.

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