

With the best intentions: Implications on self-determination during Covid-19 restrictions

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Abstract

Background: In times of crisis, the interests of the individual might be sacrificed for the health and safety of others. The aim of this study was to explore the situation under Covid-19 for persons with intellectual disabilities, focusing on implications on the right to self-determination within health protection.

Method: To understand how the relevant legal framework was governed by authorities and service providers during the Covid-19 pandemic, we have performed semi-structured interviews with 19 service providers in municipal home care services.

Results: Many residents were provided adequate and adapted information about Covid-19, but very few were involved in the introduction and implementation of infection control measures.

Conclusions: Our study has revealed how a crisis such as the pandemic not only puts the health of people with intellectual disabilities at risk, but also challenges their right to self-determination.

KEYWORDS

Covid-19, health protection, human rights, intellectual disabilities, pandemic, self-determination

1 | INTRODUCTION

1.1 | Background and research question

There is a growing literature discussing the effects of the Covid-19 pandemic on persons with intellectual disabilities, in terms of health (Gjærum et al., 2021; Henderson et al., 2022; Landes et al., 2020; Lunsky et al., 2022), access to health services (Jeste et al., 2020; Lake et al., 2021; Zaagsma et al., 2020), their social situation (Chadwick et al., 2022; Embregts et al., 2022; Friedman, 2021; McCausland et al., 2021), and so forth.

However, as underlined by Luckasson and Schalock (2020), while recent discussions have paid considerable attention to safeguarding the health of people with intellectual disabilities, there has been limited focus on the threats to the last decades' progress in securing their

rights and on the possible aftermath of the crisis. One exception is Panocchia (2021, p. 365), who stresses how individual rights such as self-determination can be challenged in times of crisis. Norway had more substantial protective measures than many other countries, yet the inhabitants showed high obedience (OECD, 2022; OECD/European Union, 2020). It is therefore interesting to investigate how such strong focus on restrictions can affect other rights. Our research question is therefore: *Persons with intellectual disabilities' situation under Covid-19: Implications on the right to self-determination within health protection.*

1.2 | Norwegian welfare services

Our context and data are Norwegian home-based services. Norway represents a welfare state, which can be defined as a "country with a

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comprehensive system of social welfare funded both by taxation and national insurance” (Oxford Reference, 2023a, 2023b). The securing of necessary welfare services is one of the characteristics of a welfare state, including universal public health- and care services, as well as securing income for its citizens (Graver, 2019, p. 62). Norway's municipalities are responsible for home-based services for persons with intellectual disabilities, such as personal and practical assistance (Health- and Care Services Act, 2011, sec. 3–2). All forms of service and assistance represent interventions in privacy and must mainly be based on an informed and voluntary consent from the service user ((-European Convention on Human Rights, 1950) (hereinafter: ECHR) art. 8); United Nations Convention on the Rights of Persons with Disabilities (2006) (hereinafter: CRPD) art. 22.

1.3 | Citizens' right to self-determination

Self-determination can be defined as “acting as the primary causal agent in one's life and making choices and decisions regarding one's quality of life free from undue external influence or interference” (Wehmeyer, 2001, p. 30). Thus, self-determination should be driven by one's own preferences and interests in making or causing things to happen in one's life, rather than someone or something else making one act in other ways (Wehmeyer & Shogren, 2017). Self-determination represents an inherent right for all human beings, irrespective of cognitive ability (Bigby et al., 2019, p. 396). Within the right to privacy, all citizens have the right to self-determination (ECHR art 10; CRPD art 3 & 12), and any limitation of this right must be authorised by national legislation (ECHR art. 8; CRPD art. 22). The rights of users of home-based health- and care services in Norway, including the rights to facilitated information and self-determination, are regulated within the Patient- and Users' Rights Act (1999) and the duties of service providers in the Health Personnel Act (1999).

The individual right to self-determined consent to welfare services and -measures can be facilitated through supported decision making, referred to as a “process whereby a person with a disability is enabled to make and communicate decisions with respect to personal or legal matters” (United Nations Office of the High Commissioner on Human Rights, 2009) (OHCHR). Such support can include, for example, information individually adapted to the person's needs and abilities, in order that the individual understands the scope of the consent he/she is giving and understands the services or measures he/she is entitled to. As stressed by Davidson et al. (2015: 61), both law, policy and practice have tended to focus on decision making as if people are either globally capable or incapable of this. This is despite the fact that most people require some level of support with decision making, drawing on their social as well as their cognitive resources. Hence, CRPD art. 12 has been interpreted “breaking the nexus between mental and legal capacity, by asserting that everyone has the right to make decisions about their own life, irrespective of cognitive ability, and to have the necessary support to do so” (Bigby et al., 2019: 396).

Whilst formal decision support is regulated by law, informal decision support, in practice, is integrated in the everyday support

provided by family, friends, and service providers. This latter is not mainly inspired by law, but rather by professional codes of ethics or practice frameworks (Bigby & Frawley, 2010). Though self-determination is a right on equal basis of all citizens, people with intellectual disabilities have historically been majorly excluded from this right in Norway. Promoting this right and counteracting existing paternalism were aims of the reform of health protection for persons with intellectual disabilities; the so called HVPU-reform from 1991 to 1995 (Sandvin & Anvik, 2020; Tøssebro, 2019). The institutional care before the reform, limiting freedom regarding participation in society and everyday decisions, was seen as incompatible with the idea of citizenship. Following the HVPU-reform, institutions were closed, and the responsibility for persons with intellectual disabilities transferred from the state to the municipality where they should live as independently as possible and be integrated into their local communities (Barne- og familiedepartementet, 2013). (Meld. (2012–20)). The reform can therefore be described as a turn towards active citizenship (Johansson & Hvinden, 2007). Being an active citizen includes, according to Halvorsen et al. (2018), exercising social rights and duties, enjoying choice and autonomy, and participation in political decision-making processes which are important in one's life.

1.4 | Citizens' right to health protection

During the Covid-19 pandemic, different countries implemented various infection control measures, with different degrees of restrictions for citizens, interfering in their privacy and self-determination. Such restrictions were aimed at securing citizens' human right to health protection in general. Authorities must prevent, treat, and control epidemic and endemic diseases (ECHR, art. 12) for all citizens, whilst CRPD art. 11 states that authorities must take “all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk.” Still, the individual's right to protection from unlawful interference must be respected, “regardless of place of residence or living arrangements,” as stated in both ECHR art. 8, the United Nations International Covenant on Civil and Political Rights (1966) and in CRPD art. 22.

People with intellectual disabilities have higher risk of complications due to their higher prevalence of comorbidities connected with more severe Covid-19 outcomes, and a higher fatality rate (Turk et al., 2020). They also seem to have a higher risk of getting infected with Covid-19 than others, due to physical health problems, social circumstances (such as relying on support from other people and services, living close to others in residential settings) (Tummers et al., 2020), and challenges in understanding or adhering to public health guidelines to protect themselves from the Coronavirus (Courtenay & Perera, 2020). Failing to comply with infection control measures, puts not only their own health at risk, but also the health of co-residents, family and friends.

The right to participate and decide in the implementation of health and care services, and to receive the necessary information enabling such choices thus represented an important aspect of self-

determination during the pandemic. Information and freedom to choose is particularly relevant when there is a large power imbalance between service providers and residents with intellectual disabilities, illustrating the importance of adapted and facilitated information and participation for the individual prior to making one's decisions. As pointed out by Bigby (2020), people with intellectual disabilities very much rely on others to uphold their rights, which makes them vulnerable during crises, as it is easy for service providers to slip back into paternalism.

1.5 | Human rights under cross-pressures

When authorities effectuated infection control measures for the protection of citizens in general, and citizens with higher risk of complications in particular, human rights were put under cross-pressures. Whilst protecting citizens from infection and serious health complications, authorities were also obliged to secure each citizen his/her individual rights to privacy and self-determination. However, with a public health crisis such as the pandemic, the community's health takes precedence over the individual's health, meaning that the interests of the individual are sacrificed for the safety and health of the community (Panocchia et al., 2021). Regarding values, the focus in the provision of welfare services changes from having a focus on autonomy over to solidarity. Panocchia et al. (2021) warns how this shift challenges the existing paradigm for service provision with person-centred services and decision support for people with disabilities, and under disguise of public health concerns causes a return to paternalism.

Prior literature focusing on how the Covid-19 pandemic influenced people with intellectual disabilities' autonomy and self-determination is still limited. Ervin and Hobson-Garcia (2020) highlight practical issues which service providers must consider in the challenging balance between providing services to protect the health and safety of people with intellectual disabilities, whilst safeguarding their right to self-determination. Melbøe et al. (2021) and Kane and Melbøe (2022) discuss how the individual's right to infection control measures can represent unreasonable limitations considering the right to an independent, active and meaningful life, and may imply new forms of "institutionalisation." Desroches et al. (2022) stress how the right to self-determination regarding socialisation was restricted to a much greater extent for people with intellectual disabilities than for others. According to Liddell et al. (2021, p. 14), a "blanket policy" on isolation rather than individually adapted restrictions "is likely to be unlawful," and the authors highlight the importance of exhausting "soft" protection strategies before imposing "hard" ones. This is in line with the "non-intervention principle" in EHCR art. 8.

In summary, several human rights were put under pressure during the Covid-19 pandemic, for persons with intellectual disabilities. On this basis, we have raised the importance of investigating these pressures also from a Norwegian perspective. This article represents the fourth research theme in our project regarding independent living and infection control during Covid-19 (Gjærum et al. 2021; Kane & Melbøe, 2022; Melbøe et al. 2021).

2 | METHODS

To examine the implications on the right to self-determination for persons with intellectual disabilities within health protection under the Covid-19 pandemic, we performed qualitative interviews with 19 qualified service providers in municipal home care services in rural and urban areas in Norway, during first lockdown commencing 12th March 2020. Interviewing the residents themselves was not an option at this time, as no "outsiders" were allowed access to the residential settings due to infection control measures. Moreover, we did not find it ethical or methodological justifiable to interview the residents digitally. Ethical, as pandemic experiences were a sensitive topic, and we would not be able to accommodate possible reactions. Methodological, as meeting the recommendations for how conducting interviews with people with intellectual disabilities (Hollomotz, 2017) digitally would be difficult.

Participants were recruited through purposeful sampling, characterised by Creswell and Plano Clark (2011) as identifying and selecting individuals with special knowledge and experience within a phenomenon of interest. Most participants (17) were recruited digitally through professional networks such as health- and social services, competence centres, and so forth, and two through advertising the study on social media.

In total 19 service providers consented to participating in the study, 13 women and six men aged 21–67, employed in different residential settings providing services to approximately 160 persons with intellectual disabilities aged between 20 and 90. There were significant differences in infection rates between the municipalities represented, and two of the residential settings had experienced Covid-19 infection outbreaks at the time of the interviews. Our semi-structured interview guide addressed five main topics: infection control measures, work/daytime activities, leisure, social participation, and digitalization. Due to infection control measures, most of the interviews were conducted digitally, whilst some were conducted in person. The interviews, with duration 30–60 min, were performed in June 2020. With the participants' informed consent, we audiotaped the interviews and transcribed these verbatim. The interviews were conducted by three researchers at UiT The Arctic University of Norway, not including the second author of this article. Still, both authors have participated in the preparations, designing of interview guides, analysis of interview material and in the production of this article. Our study has been carried out in accordance with the National Ethical Committee for the Social Sciences and was approved by the Norwegian Centre for Research Data (NCRD) (no. 702777). Oral consent was obtained at the start of the interviews, and all data have been treated anonymously in accordance with the approval from NCRD.

Our data analysis was guided by Braun and Clarke (2012) techniques for thematic analysis; to systematically identify, organise and get insight into the patterns across our data set. After reading the transcripts in detail, we generated codes to identify data relevant for our research question. Potential themes were identified and actively discussed between the two authors, before we organised our findings in accordance with the following two overarching themes:

(1) Provision of information, and (2) Implementation of infection control measures. Examples and citations presented are chosen as they illuminate the cross pressure experienced by the service providers (being responsible of safeguarding both the residents' health and right to self-determination), at the same time as they represent the breadth of our material. In the result section citations are provided with the number of the interview. Hereinafter we refer to service providers as "carers" and the service users as "residents."

3 | RESULTS

3.1 | Provision of information

While many carers, from the outbreak of the pandemic, continuously tried to keep the residents informed, others provided them with no or restricted information. The extent to which residents were informed or not, was mainly justified by the residents' cognitive abilities to understand information, but also a wish to protect residents against anxiety.

Many carers did try to provide the residents with accessible information, given both in groups and individually, orally and in writing, and facilitated in different ways. While one residential setting invited the habilitation services to offer the residents a course about Covid-19 (14), some used an animation video for children provided by a national tv channel (17), and others created their own information-material. For example, one of the carers (14) described how they made an easily accessible information folder, with pictures, and so forth, used in individual conversations with the residents. Some service providers (9, 14 & 19) depicted how they had also given practical information, such as showing the residents various infection protective equipment. This aimed to familiarise residents with such equipment, so they would not become anxious if this equipment became necessary. Some informants stressed how residents did not necessarily perceive the intended meaning of the information provided. Moreover, several informants described it as difficult, often even impossible, to inform residents with severe and profound intellectual disability about Covid-19 (4, 6, 8, 12, 13, 14, 18 & 19).

According to several informants, many residents followed general news on radio and television regarding the pandemic (1, 2, 4, 5, 9, 10 & 11), but with great variation regarding how much of this they understood. For some residents their challenges with understanding caused anxiety. For example, one informant (11) described how one resident, after hearing about the virus being airborne, asked her "to close the window so that the corona would not get in!"

Some informants described how they tried to give as little information as possible, justified by the intention of protecting the residents. As one stated, they "tried to shield the residents from this Covid fear" (5). In this case it also meant withholding information about matters connected with the residents' everyday life, such as Covid-19 disease among their carers. However, some carers also deliberately partly misinformed the residents. For example, one informant (13), when residents wanted to go shopping, told them shops were closed rather than explaining infection control measures.

The concern for creating Covid-19 fear was in some cases justified. One informant (9) described how a resident, after watching TV-news regarding how many people had died of Covid-19 in his hometown, became anxious and needed extra care. However, another informant (6) described how lack of information about the virus caused anxiety as the resident understood that "something" was going on, but not what. In hindsight, this informant stated: "I should have argued even more to get permission from management to inform this resident /.../ Because I saw how much better she felt (after being informed)."

3.2 | Implementation of infection control measures

The first lockdown in Norway resulted in the closure of almost all work- and leisure activities for people with intellectual disabilities, as well as limited access to various health- and social services. Thus, most residents suddenly spent all day at home. Residents also had restrictions imposed outside their homes, for example, a ban on public transport and going shopping or to the cinema, and so forth, (3, 4, 5, 7, 8, 9, 10, 12, 13, 14, 15, 17, 18, 19). Several measures were also implemented in their own homes, strictly restricting their everyday life, for example, regarding visitors, where many were denied visitors at all, including close family (e.g., parents), their partner or closest friends. Several were also denied socialising with co-residents. For example, service-providers at one residential setting drew a line on the floor (using tape), denying the residents to cross this line, to prevent such contact (2, 3). Residents were also denied access to common rooms where they lived.

In some residential settings, the municipal doctor redefined the residences' status from *homes* to *institutions*, resulting in carers thereafter referring to the residents as 'patients' (2). Moreover, in several residential homes, carers started wearing uniforms, scrub tops, gloves, and so forth, traditionally associated with institutions rather than private homes (2, 4, 5, 6, 10, 11, 13, 15, 18).

A recurring finding was how the residents' influence in the implementation of infection control measures was minimal. The informants generally described how infection control measures were mostly based on decisions made higher up in the system, such as health authorities on the national or municipal level. As one informant (8) pointed out: "We just followed what came from the top ... We're not supposed to think for ourselves, we just do what we're told." Whilst their own role in the implementation of measures was perceived as minor, the involvement of residents was described by many as next to nothing. As one informant (14) put it: "The residents have only had to adapt to what has been decided /.../ they have had no say in this."

Some informants described the implementations as rather unproblematic, as they found that the residents accepted the measures without any protests due to their anxiousness of becoming ill (1 & 5). One informant (7) described how residents found the Covid-19 outbreak hard to accept, arguing that they "did not like Covid" and that they wanted the virus just to "go away."

Several informants reflected on how the strict implementation of measures had challenged the residents' right to self-determination. As one informant (9) put it: "As it (complying with measures) requires quite some persuasion, it has definitely limited their self-determination." Both this and other informants justified this limitation by their responsibility for securing the health of other residents with considerable increased risk from Covid-19: "A bit of heart problems, asthma, and so forth. We must be careful. There are 10 residents living here, and we must protect them all /.../ Even if it is strict, it would be worse if they became ill" (9).

Looking back, however, some informants were critical of their own practice, thinking they had been too harsh in restricting the residents from making their own decisions. One informant (12) emphasised how they, at the first outbreak, due to lacking knowledge about the virus, were very worried, and thus had insisted on more and stricter measures than they later would have done. Few informants problematized the legal aspect of the strict implementation of measures, though some did. One (11) emphasised: "We don't have the right to .../ because they have the right to self-determination according to the law. If it's in their own home, we cannot restrict them!" Another (14) stressed how the residents' right to self-determination also included the right to make less wise decisions: "They are not always careful even if they claim to be, and we cannot stop them. They are living their own lives, and we cannot deny them without using coercion." Moreover, a few informants stressed that most national guidelines were only advisory, and thus gave some leeway for involving the residents in the implementation of infection control measures. Thus, they pointed at the importance of not making collective decisions regarding whether the residents could go shopping, use public transport, visit family, and so forth. As one informant (7) emphasised: We must assess each resident, concerning the person's understanding of the situation and ability to comply with the infection control rules /.../ some can go to the shops, others cannot. However, while limitations in the residents' understanding of Covid and infection control measures by most carers were explained by their cognitive abilities, one informant (4) stressed how lack of necessary information decreased the residents' possibilities for gaining insight, and thus also their chances of making their own decisions.

Some informants raised concerns about the consequences of the residents' limited involvement in the introduction and implementation of infection control measures. One (4) pointed at that a possible ripple effect of this practice, was residents changing their mindset to thinking that they always had to do as they were told by the carers. The informant raised questions regarding how the residents, after a lengthy period with infection control measures beyond their control, could be able to distinguish between situations where they did have the right to decide for themselves and situations where they did not. As one of the other service providers (2) stated: "They have so much trust in us, and in what we say and decide." Another informant (14) stressed, in hindsight, how implementation routines should have been more discussed among the staff, but such deliberations were hindered because of all meeting points being banned.

4 | DISCUSSION

4.1 | Adequate and adapted information: A prerequisite for self-determination

Regarding **provision of information**, our informants have described how they have made individual assessments of whether to inform residents or not, whether and to what extent individual residents were able to make use of the information, and of how to facilitate information according to each resident's ability to make use of the information. Thus, many were provided facilitated information, while many others were not, and one informant (4) even highlighted information as a prerequisite for insight – which again represent a prerequisite for self-determination. Adequate information as a necessary basis for allowing the decision maker "to reach his or her own conclusions" is emphasised by Hogarth and Soyer (2015, p. 227).

Even when done with the best intentions, our data shows examples of how withholding information about the pandemic can have negative consequences, for example, causing anxiety, as one understands that "something" is going on, but not what. Withholding necessary information to persons with intellectual disabilities, can cause different negative consequences. Tuffrey-Wijne et al. (2009) find that although carers' intention is to protect, a lack of information concerning health-issues can cause considerable anxiety and also deprive the possibility of being provided emotional support. According to Bakken (2020) the perception that limiting information is the best for persons with intellectual disabilities now is seen as unfounded, old-fashioned and paternalistic, and that the most appropriate approach, both medically and ethically, is to have open conversations about health issues. In addition, since a main criterion for a consent' validity is that it is informed (Patient- and User Rights Act, 1999, § 4–1), withholding information will also impact on the right to self-determination.

Worries concerning both the virus itself, how to contract it, and how to spread it to others, are found to have negative affect on the emotional well-being of people with intellectual disabilities (Doody & Keenan, 2021; Embregts et al., 2022; Lake et al., 2021). Therefore, carers withholding information, based on good intentions, can also be seen as securing the individual's right to be protected from information which may cause disproportionately more harm than good (Patient- and User Rights Act, 1999, § 3–2). The main aim for the right to information is to benefit the individual, for example, to make informed decisions, not to harm the individual. However, the right to protection from potentially harmful information is waived when such information is "determined in or pursuant to law" (Patient and User Rights Act, 1999, § 3–2(2)). The Covid-19 restrictions aimed at protecting individuals from being infected by a disease which, during the first lockdown spring 2020, was perceived as particularly dangerous and referred to as such through authoritative statements as well as national and international media. The option to withhold information was therefore challenged by the general fear of, and need for protection against, a potentially deadly virus. For residents with intellectual disabilities, adequate and adapted information, enabling and

motivating them to comply with infection control measures, was crucial for their right to protection and self-determination.

A handful of our informants did describe examples of good practices in residential settings, such as the use of animated videos, adapted information material and physical demonstrations on how to use infection control equipment. Such group-based and/or individual facilitation are examples of what Bigby et al. (2019) describe as tailored communication, an important part of providing decision support. However, which and how much information carers offered the residents varied, partly justified by their wish to reduce risk. This reflects the findings of Bigby et al. (2019), highlighting how “perceptions” of risk, especially around health issues, influence the nature of carers' decision support.

4.2 | Supported decision-making: A prerequisite for equal citizenship

Regarding the introduction and implementation of infection control measures, our informants have described how the residents with short notice had to stay in their homes all day, restricted from contact with family, friends, and work colleagues. Residents also had other measures implemented within their homes without their consent.

Although the infection control measures challenged the citizenship of all Norwegians (Graver, 2020), many of the residents in our study experienced extra limitation in the realisation of their citizenship. First, measures in their own homes were more restrictive than in private homes in general (Norwegian Health Authority, 2021). Second, measures which were only advisory for the general population, were imposed as mandatory to them. Residents had no or very little influence on implementation of different measures in their everyday life. Thirdly, persons with intellectual disability were also excluded from national or local political processes regarding infection-control, the latter subsequently being demanded by United Nations (2020). Thus, several of Halvorsen et al.'s (2018) criteria of active citizenship, such as exercising social rights, enjoying autonomy and political participation, were clearly challenged.

While our informants have stated national and local regulations as the reason to why residents generally had not been involved in the implementation of measures, the lacking involvement of residents with severe and profound intellectual disability was justified by cognitive capacity. However, as underlined by Bigby et al. (2019) article 12 in CRPD have been interpreted as asserting that everyone has the right to self-determination irrespective of cognitive abilities. As discussed by Watson (2016) everyone can assert self-determination with support, as a person's “will and preference” can be communicated in many ways, including non-verbally. Thus, even though residents might not be able to understand information about Covid-19 or measures, carers could have facilitated supported decision making by interpreting and responding to these residents' non-verbal signals expressed when being exposed to measures. However, as found by Demic et al. (2023) the facilitation of supported-decision making for people with

intellectual disabilities receiving home-based municipal health- and care services “has fallen short.” Communicating resistance represents an important part of people acting self-determined (Nicholson et al., 2021), and providing decision support could lead to changes or adjustments of measures, based on residents' negative non-verbal responses.

Another example of stereotyping on group level is seen in our data regarding how both national and local authorities, and most service providers, seem to have acted from an idea of viewing people as what Davidson et al. (2015, p. 16) refer to as “either globally capable or incapable” of making decisions. It is important to highlight how the carers who actually involved residents in implementing measures, did so based on individual assessments. These carers offered facilitated information about Covid-19 to residents who had been assessed as “capable of complying with measures” and involved them in informal everyday decisions such as going shopping, using public transport and visiting family. Such practice is in line with what Bigby and Frawley (2010) describe as informal decision support, thus enabling residents to exercise what Halvorsen et al. (2018) define as active citizenship, realising social rights and enjoying possibility of choice. Such practice also illustrates how citizenship constitutes a relational practice (Lister, 2007), where residents during a pandemic, rely even more on carers than usual to uphold their rights.

4.3 | “Othering”: A hindrance for equality on macro-, meso- and micro-levels

Our data has revealed that persons with intellectual disabilities were inflicted far heavier restrictions both formally and practically, based on instructions from both national, municipal, and residential regulations (macro-, meso- and micro-levels), resulting in limited self-determination within health protection. Hence, our study reveals how, as stressed by Abery and Anderson (2020), opportunities for self-determination within the healthcare context depends on relationships with both large and small systems, and individuals. Norwegian national health authorities introduced a total lockdown 12th of March 2020, stricter in health- and care residential settings than for citizens in general. Some municipal doctors re-defined such residential settings to institutions, while carers in residential settings introduced visiting protocols, taped separating borders on the floors, and so forth.

Stricter regulations implemented on group level can be interpreted as a form of “otherism,” “confirming a hierarchy between ‘us and them’, positioning *the others* or *them* as lesser” (Schäper, 2022, p. 125). Re-defining residents to “patients” is not only incorrect, but also creates a false and stereotypical illusion of disability as a health issue requiring medical treatment, rather than a result of barriers and discrimination (Shakespeare, 2012). These forms of otherism reflect findings by Mir et al. (2020), on how disadvantaged minority groups are more highly exposed to different exclusion mechanisms within public services. Thus, to secure the self-determination of people with intellectual disabilities also in future crisis, one must focus on all levels of the system.

5 | CLOSING REFLECTIONS ON BEST INTENTIONS

On all levels, authorities have a common duty of acting in line with both legal framework and codes of ethics.

On macro- and meso-levels, both governmental and municipal decisions and guidelines must be in line with both national and international legislation, protecting citizens' rights. Due to the gravity of the pandemic and haste to implement protective measures, several ethical dilemmas emerged regarding citizens' rights to privacy and self-determination. This article has unveiled such dilemmas regarding citizens with intellectual disabilities, and such and similar dilemmas are important to identify and address in future crises.

On micro-levels, carers should comply with value-based and rights-based professional codes of ethics, including values of the inherent dignity and inviolability of man and human rights promoting autonomy and equality of the individual. Ethics were challenged when carers implemented stricter restrictions than the national ones and also redefined homes to institutions and residents to patients. Our study indicates that the service providers' ethical duty to speak up when the rights of vulnerable citizens are at risk, was somewhat replaced with a strict obedience towards the infection control measures. Such obedience can be linked to citizens' great trust in national governance, a characteristic of Norway (OECD, 2022), despite Norwegian protective measures being more substantial than in many other countries (OECD/European Union, 2020). Such trust and adherence to authorities, combined with the sense of duty to protect residents from transmission of the virus, represented the carers' participation in what our government defined as a national "dugnad" – a Norwegian phenomenon for collective and joint efforts for the good of the community (Simon & Mobekk, 2019). Informants' concerns regarding lack of individual adaption of protective measures, due to staff meetings being cancelled under the same infection control regimes, represent another reason for limited deliberations between carers.

The carer's strong focus on protection can also reflect adherence to their legal duty to provide immediate care when such care is considered urgently needed (Health Personnel Act, 1999, § 7). Carers must act in a responsible manner, based on their qualifications and their assessment of a given situation (Health Personnel Act, 1999, § 4). Based on the situation and on the individual resident's manner of action, the carers might have interpreted that the individual resident was likely to accept the protective measures, through a tacit consent (Patient- and User Rights Act, 1999, § 4–2). The carers' protective practices can be seen as an exercise of paternalism, which can also be interpreted as an exercise of the "Bonus pater familias," a legal term describing "A diligent guardian of the rights and interests of his or her ward," for instance in governing the welfare and personal rights of the citizens (Oxford Reference, 2023a, 2023b). However, interpreting another individual's thoughts and wishes raises the risk of deciding on their behalf. This matter was highlighted by informant 4, who described a concern of residents falling back to decisions being made by their carers. As highlighted in Norwegian research (Sandvin &

Anvik, 2020; Tøssebro, 2019) counteracting such historical paternalistic traditions was one aim of the HVPU-reform, promoting independent living and self-determination for people with intellectual disabilities.

Though carers' strict implementations of protective measures reflect "good intentions" based on trust and adherence to national governance, "dugnad," ethics and legal obligations, their intentions have not prevented individual human rights of persons with intellectual disabilities being violated and challenged. In addition, these violations can cause ripple effects. A lengthy period of infection control measures might have taught not only residents, but also their carers, that people with intellectual disabilities in general are not "causal agents" in their own lives, as the development of self-determination is shaped by opportunities and support for such (Shogren, 2020).

Our findings illustrate the fine line between acting on what one – with the best intentions – assumes to be in the best interest of others – and exercising paternalism. We have discussed how a crisis such as the pandemic not only puts the health of people with intellectual disabilities at risk, but also challenges their hard-earned and fragile right to being self-determined. Our study thereby supports the findings of the study of Panocchia et al. (2021), stressing how in times of crisis, the interests of the individual might be sacrificed for the health and safety of others.

ACKNOWLEDGEMENTS

We sincerely thank the service providers who shared their work experiences during the first Covid-19 lockdown, and all those helping us in the recruitment process. We also thank Stina Hirsti and Rikke Gjørings Gjørings, our partners in the research project regarding independent living and infection control under Covid, on which the data in this paper is based.

FUNDING INFORMATION

The research leading to these results has received funding from UiT The Arctic University of Norway.

CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

DATA AVAILABILITY STATEMENT

The authors confirm that the data supporting the findings of this study are available within the article.

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How to cite this article: Melbøe, L., & Kane, A. A. (2024). With the best intentions: Implications on self-determination during Covid-19 restrictions. *Journal of Applied Research in Intellectual Disabilities*, 37(4), e13257. <https://doi.org/10.1111/jar.13257>