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# Lived experiences of people with intellectual disabilities during the COVID-19 pandemic from a crip time perspective

# Expériences vécues par des personnes ayant une déficience intellectuelle pendant la pandémie de COVID-19 dans une perspective de temporalités *crip*

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## Abstract

The pandemic disrupted normative time for all and exposed systemic and societal inequalities affecting disabled people. This qualitative study, framed within crip time theory, explores how people with intellectual disabilities experienced the social restrictions imposed during the COVID-19 pandemic in Iceland. Conducted between 2021 and 2023, the research involved twenty adults with intellectual disabilities. Findings indicate that the pandemic perpetuated isolation for people with intellectual disabilities who were already excluded from many aspects of normative spaces. The pandemic highlighted the precarity of the disability service system, revealing sub-standard support, lack of control over personal time, and feelings of intense loneliness among participants. To protect the disability service system, people with intellectual disabilities faced stricter and longer social restrictions compared to others. Despite this, they were not prioritised for vaccinations, and many felt neglected by authorities. The pandemic serves as a harsh reminder of the ongoing struggle for full social inclusion for people with intellectual disabilities. The article calls for a post-pandemic future that is better than the past, demanding a revaluation of societal attitudes and policies to ensure a more inclusive future.

## Résumé

La pandémie a perturbé le temps normatif pour tout le monde. Elle a également mis en lumière les inégalités systémiques et sociétales qui touchent les personnes handicapées. Cette étude qualitative, soutenue par la théorie des temporalités crip, explore la manière dont les personnes ayant une déficience intellectuelle ont vécu les restrictions sociales imposées pendant la pandémie de COVID-19 en Islande. Menée entre 2021 et 2023, la recherche a porté sur vingt adultes ayant une déficience intellectuelle. Les résultats indiquent que la pandémie a perpétué l'isolement des personnes ayant une déficience intellectuelle qui étaient déjà exclues des espaces normatifs de plusieurs façons. La pandémie a mis en évidence la précarité du système de services aux personnes handicapées, révélant un soutien de qualité inférieure, un manque de contrôle sur le temps personnel et des sentiments de solitude intense chez les personnes participantes. Pour protéger le système de services aux personnes handicapées, les personnes ayant une déficience intellectuelle ont été confrontées à des restrictions sociales plus strictes et plus longues que les autres. Malgré cela, elles n'ont pas reçu le vaccin en priorité et beaucoup se sont senties négligées par les autorités. La pandémie sert de rappel brutal du fait que la lutte continue pour une pleine inclusion sociale des personnes ayant une déficience intellectuelle. L'article appelle à améliorer l’avenir post-pandémique et à assurer un futur plus inclusif en exigeant une réévaluation des attitudes et des politiques sociétales.

**Keywords:**
Intellectual disabilities; COVID-19, Crip Futurity; Crip Time; Iceland
**Mots-clés :**
Déficience intellectuelle; COVID-19; futurité crip; temporalités crip; Islande

## Introduction

In her book *Feminist, Queer, Crip*, Alison Kafer explores how time is experienced differently by disabled people, challenging normative temporal frameworks and emphasizing the need for a more flexible, accommodating approach to time that considers the diverse temporalities of disabled bodies and lives. She explains how people have been predicting her future for years, ‘Of fortune cookies and tarot cards they have no need: my wheelchair, burn scars, and gnarled hands apparently tell them all they need to know. My future is written on my body’ (Kafer, 2013, p.1). Although the future is by definition unknown, ableist constructions of normative life stages are used to forecast limited and marginalized futures for disabled people (Ljuslinder et al., 2020).

The COVID-19 pandemic caused much uncertainty about the future. At the onset, nobody could have predicted the transformation of the social and temporal landscape over the next two years. Pandemic time turned out to be non-linear and unpredictable; it was ‘not easy’, ‘not fair’, and ‘could not be reasoned with’, a perception that disabled people are all too familiar with (Samuels & Freeman, 2021p. 247). The pandemic highlighted the systemic and societal inequalities faced by disabled people, particularly in access to healthcare, social support, and employment (Scherer et al., 2022; Snæfríðar- og Gunnarsdóttir et al., 2023; Tryggvadóttir et al., 2021).

There is no statistical information available about hospital admission and death from COVID-19 among disabled people in Iceland. However, compared to non-disabled people, they experienced more financial hardship and lacked access to resources such as medicine and food during the pandemic (Tryggvadóttir et al., 2021). Additionally, research found a widespread reduction in social care and support for people with intellectual disabilities during the pandemic.

These adverse circumstances led to a sense of loss and increased loneliness among people with intellectual disabilities (Kim et al., 2021; Scherer et al., 2022), which needs to be addressed.

In this study, using Kafer's (2013) crip time theory, I explore how people with intellectual disabilities experienced the social restrictions put in place to reduce COVID-19 transmission rates in Iceland. Crip time, as defined by Kafer (2013), challenges the conventional ideas about time and productivity, which often do not align with the realities of disabled people. The pandemic has further disrupted these expectations, highlighting existing disparities. Such disruption creates space for the re-evaluation of the future. A feminist crip theory offers a radical and critical perspective that provides a nuanced understanding of temporalities of disability. This approach can open new avenues of critique against ableist power dynamics by challenging normative ideas about the past, present, and the future.

## Crip Time and Critical Disability Studies

Kafer (2013) criticizes disability studies and disability movements for not being inclusive, and she points out that little attention has been paid to the experiences of people with intellectual disabilities. She calls for solidarity and inclusion, 'If disability studies is going to take seriously the criticism that we have focused on physical disabilities to the exclusion of all else, then we need to start experimenting with different ways of talking about and conceptualising our projects' (Kafer, 2013, p. 16). Disability scholars on both sides of the Atlantic have echoed this sentiment, criticizing the marginalization of people with intellectual disabilities within the social and minority models of disability (Erevelles, 2002; Goodley & Runswick-Cole, 2016). However, the lives of people with intellectual disabilities have received considerable attention within the field of disability studies in the Nordic countries, including

Iceland (Bjarnason, 2004; Sigurjónsdóttir & Rice, 2023). Nordic disability studies approach disability as relational, based on complex interactions between the individual, environment, and society (Traustadóttir, 2006). Such understanding resonates well with Kafer's (2013) call for a more political/relational model of disability:

> [O]ne that builds on social and minority model frameworks but reads them through feminist and queer critiques of identity. My concern with imagining disability futures differently frames my overview of each model; thinking about the kinds of futures imagined or implicit in each definition provides a useful lens for examining the assumptions and implications of these frameworks. (p. 4)

There is a notable shift in theorizing beyond the social and minority model frameworks (Goodley, 2013; Meekosha & Shuttleworth, 2009). Kafer (2013) aligns her theory with McRuer's (2006) crip theory, which argues for the re-imagination of time and space away from societies' demand for abled-bodiedness. She combines 'references to bodies with references to minds' and pairs compulsory able-bodiedness with compulsory able-mindedness (p. 16).

Kafer's ideas fit well within critical disability studies (CDS), which draw on diverse critical perspectives and explore and challenge the intersecting social, cultural, and political structures that perpetuate the discrimination and exclusion of disabled people. CDS has proven meaningful for people with intellectual disabilities (Goodley et al., 2019) and offers a framework for understanding how societal structures contribute to individuals with intellectual disabilities experiencing feelings of abnormality, dependency, and exclusion (Peddogrew, 2023, p. 146). CDS also addresses the ableist assumptions and norms that underlie society's discriminatory practices (Goodley, 2013; Meekosha & Shuttleworth, 2009). Ableism, which refers to the systemic discrimination and oppression of disabled people, is a central concept in CDS. It is manifested in various forms, including inaccessible spaces, damaging discriminatory policies, and attitudes that view disabled people as inferior or abnormal (Bogart & Dunn, 2019). Kafer (2013) argues that the normative, linear concept of time is inherently ableist, emphasising that it does not accommodate the varied experiences of disabled people which can be unpredictable and polyrhythmic (Kafer, 2021). She argues,

> These shifts in timing and pacing can of necessity and by design lead to departures from ‘straight’ time, whether straight time means a firm delineation between past/present/future or an expectation of a linear development from dependent childhood to independent reproductive adulthood. (Kafer, 2013, p. 34).

Normative developmental timelines often do not apply to people with intellectual disabilities (Ingimarsdóttir et al., 2024), but Kafer’s (2013) conceptualizations recognise how learning and development can be non-linear. Although some people with intellectual disabilities might benefit from more time for some tasks, Kafer (2021) warns us about narrowing crip time to more time, ‘as a way of mobilizing disabled people into productivity rather than transforming systems’ (p. 421). Crip time challenges normative expectations and advocates for policies and practices that recognize and support diverse temporal experiences, reducing the pressure on disabled people to conform to normative timelines (Kafer, 2013, 2021; Samuels, 2017; Samuels & Freeman, 2021).

Of particular importance to my research is Kafer’s (2013) ‘politics of crip futurity’ (p. 3). She positions her ideas about crip time alongside critical futurity, explaining how the anticipated future has historically placed disabled people out of time or as an obstacle to progress. People with intellectual disabilities often fall outside of normative and linear assumptions of time (Ljuslinder et al., 2020), leading to barriers in social institutions such as education, employment, and family life (Ingimarsdóttir et al., 2024; Pacheco et al., 2024). The imagined or anticipated future shapes our perception of the present, and grim or limited futures often justify sub-standard support and services. Societies privilege able-bodiedness and able-mindedness, often perceiving people with intellectual disabilities as vulnerable, in need of care and oversight, or as eternal children (Björnsdóttir et al., 2015). Instead of viewing them as 'abnormally asynchronous,' Kafer (2013, p. 68) invites us to disrupt the notion of linear time and consider how we can do things and develop less straightforwardly – maybe a bit queerly. The notion of crip time, therefore, urges us to reject ideas about ominous and limited futures for disabled people and instead imagine more bright futures filled with opportunities.

Pandemic time was crip time for all (Samuels & Freeman, 2021). Restrictions were lifted and reinstated; people had to adjust to everchanging and unpredictable responses from authorities who struggled with managing the risks of the pandemic. Many activities moved online, and students and workers were quickly offered the same accommodations that disabled people had long called for (Hankerson & Brown, 2021; Samuels & Freeman, 2021). Although many disabled people benefitted from an increased level of digitalisation and flexibility regarding work and education, these circumstances exacerbated existing structural disparities for others, especially people with intellectual disabilities (Hankerson & Brown, 2021; Scanlan, 2022). The pandemic disrupted everyone's daily routines, but many people with intellectual disabilities also experienced loss of services and felt isolated and lonely (Kim et al., 2021). Reports worldwide indicated an increased risk of hospital admission and death from COVID-19 among people with intellectual disabilities (Scherer et al., 2022). Hence, the pandemic time was imbued with worries about what the future might bring. When we look at the post-pandemic future, we need to ensure that people with intellectual disabilities have equal rights to recovery and that their experiences and wishes have place in the discourse about 'accessible' and 'tractable futures' (Kafer, 2013).

## Materials and Context

The present study aims to explore how people with intellectual disabilities experienced the social restrictions put in place to reduce COVID-19 transmission rates. I draw these data from a larger mixed-methods research project that focuses on the experiences, health, and well-being of disabled people during the COVID-19 pandemic in Iceland. The research was funded by the Icelandic Research Fund. At the onset of the pandemic in 2020, the population was only 364,000 people. Iceland provides universal healthcare, and disabled people are entitled to general services and assistance (Digital Iceland, n.d.). Compared to many other European countries, Iceland had high numbers of tests and confirmed cases but low death rates and relatively mild restrictions (The Directorate of Health & The Department of Civil Protection and Emergency Management, n.d.).

### *Participants*

A total of 20 participants (10 women, 8 men, and 2 non-binary persons) were recruited for this research through self-advocacy groups and educational institutions. The participants were selected through purposeful sampling, an intentional selection of participants and sites (Creswell & Creswell, 2018). The selection criteria were as follows: 1) people having intellectual disabilities, 2) with at least 18 years of age, and 3) interested in sharing their pandemic experiences.

The participants were 22 – 46 years old. Five participants lived in their own homes, ten still lived with their parents in family homes, and five in residential care, usually provided in small group homes or clusters of flats with shared support staff. Seven participants worked at sheltered workshops; eleven had part-time jobs in the open labour market, while two men were unemployed and seeking jobs.

### *Data Collection and Analysis*

Data were collected from three focus groups held at the University of Iceland and involved 16 participants (8 female, 7 male, and 1 non-binary person), aged 22-40. The purpose of conducting focus groups was to create an environment conducive to participant interaction and to facilitate conversations about their pandemic experiences. Focus groups provide much research data in a relatively short time and can generate diverse and sometimes conflicting information (Creswell & Creswell, 2018).

Traditional research methods can be inaccessible to people with intellectual disabilities. Therefore, we adapted the length of the interviews to the wishes and needs of the participants, who found it challenging to participate in long sessions. One group lasted 20 minutes and two groups little over 40 minutes. To ensure that the findings were meaningful to the participants, I engaged in individual meetings with them to help validate the findings. The first two focus groups were held in November 2021 when social restrictions had been lifted but soon after there were surges in infection rates and we could not access the participants until January 2023. The focus groups were conducted by the author and two doctoral students, Hrafnhildur Snæfríðar- og Gunnarsdóttir og Tinna Ólafsdóttir, at the University of Iceland.

Four people—one non-binary, two female, and one male—who could not attend the focus groups because of work were interviewed individually; they were 25–46 years old. The purpose of the semi-structured interviews was to get the research participants to describe their perspectives, values, and experiences in their own words (Creswell & Creswell, 2018). The interviews were conducted by the author. All interviews and focus group discussions were in Icelandic, recorded and transcribed word for word.

Braun and Clarke's (2022) six-step approach to reflexive thematic analysis was employed to identify and interpret 'patterns of meaning' in the data (p. 33). The first stage of this analysis involved familiarizing myself with the data. Initial coding and theme generation were carried out as part of phases two and three. Building on the previous stages, phase four necessitated further theme development and review. Subsequently, phase five entailed theme refinement and expansion. Thematic analysis can be applied across a range of frameworks and is well suited for the 'critical' interrogation of data patterns (Braun and Clarke, 2022). In the sixth stage, the analysis centred on crip time theory (Kafer, 2013) and critical disability studies (Meekosha & Shuttleworth, 2009) to examine the social structures and processes that shaped the participants' experience of social restrictions during the pandemic. In the final phase, I wrote the findings and translated the direct quotes from Icelandic to English.

## Ethical Considerations

I consider reflexivity vital in my analysis and strive to understand and recognize my privileged perspectives as a non-disabled researcher. Throughout the study, I adhered to ethical research practices. The research proposal was reviewed by the Research Ethics Committee for Public Higher Education Institutions (SHV2021-009), as recommended when interviewing people belonging to a marginalized group. The participants were informed of the study's nature and purpose, and their right to withdraw and terminate their participation at any time. This information was presented in an easy-to-read format, and care was taken to ensure each participant's opportunities to raise questions and discuss their participation. For example, we made ground rules about respect and taking turns speaking, and encouraged silent participators to join in. We found it helpful to conduct the focus groups in pairs where one would lead the discussion, but the other would monitor it and intervene if some participants would dominate the conversation or to follow up with prompts and feedback. Due to the geographical location of this study and the small population, it is almost impossible to promise anonymity to the extent that a person will never be traceable from the data presented about them (Saunders et al., 2014). To protect the participants' anonymity, identifiable background information was omitted, both in the analysis phase and in the published findings.

## Findings

The findings are divided into three parts. First, I will explain how people with intellectual disabilities had to adhere to longer and greater social restrictions as compared to other people in Iceland. Next, I will describe their pandemic temporal experiences and how people with intellectual disabilities felt isolated and lonely. Finally, I will focus on the presumed able-bodiedness and abled-mindedness in the authorities' responses to the pandemic, highlighting how people with intellectual disabilities felt overlooked or neglected by authorities during times of social restrictions.

## Stuck In "The Time of Waiting"

The concept of time was central to authorities' responses to the pandemic. As infection rates soared, the urgency to protect society intensified, making it crucial to protect people who were at risk of severe outcomes. The Chief Epistemologist in Iceland did not classify people with intellectual disabilities at greater risk for serious COVID-19 illness or prioritize them regarding vaccination (Kristjánsdóttir, 2021). His decisions contradicted the recommendations of the World Health Organization (WHO), which considered disabled people at greater risk of being impacted more significantly by COVID-19, and people with intellectual disabilities were identified as a group that needed consideration (World Health Organization, 2020). This contradiction placed significant strain on people with intellectual disabilities and the disability service providers who were unprepared. The service providers needed to protect the support staff, the service user, and the already fragile social service system. Hence, they urged or demanded that people with intellectual disabilities would shield, and some of the participants conformed to these restrictions for almost two years. These restrictions affected the participants' lives at home and work and their participation in education and leisure. The service providers addressed and justified the strict and long-lasting restrictions in temporal terms as *urgent*, *unprecedented*, and *temporary*.

Although the impact of disasters on the disabled population is well documented (McDermott et al., 2016; Priestley & Hemingway, 2007), the service providers did not have response plans to mitigate the pandemic for service users (Björnsdóttir & Jóhannsdóttir, 2021). The unpreparedness created urgency in responses because support staff and service users were falling ill with COVID, isolated, and quarantined. The urgency also meant that, in some cases, the responses were not in the best interest of the service users. For example, the temporary strain on the residential care system led three participants to return home to their parents. A person in their late twenties said, 'The staff needed a break, so I moved in with my parents. After a few days I had enough and wanted to go back home [to their flat].' They stayed with their parents for a few weeks and were relieved when they were allowed to move out again. Although the crisis brought unprecedented challenges for social services and society, this was not the first time this participant had moved back home to give 'the staff a break.' It was a common practice as a response to staff shortages. A man in his early thirties also moved back home with his parents and stayed with them for several months, said,

> We decided it would be best for me to move back home with my parents because they [parents] wanted me to shield. But it did not take long for me becoming their baby again. It was unhealthy, and it turned out to be a bad idea.

Previous research has demonstrated that parents often struggle to relinquish control when their children with intellectual disabilities approach adulthood (Mill et al., 2010; Strnadová et al., 2021). These participants who stayed with their parents did not follow linear time; they moved back in time and were forced to renegotiate their independence while their parents did not want to let them go. The parents and service providers needed time, which left the participants in 'the time of waiting' for the pandemic to end and for them to regain their independence (Kafer, 2021, p. 421).

Their employment situations further compounded the urgency to protect the support staff and service users from the coronavirus. While remote work provided certain normalcy for many people during the pandemic, most of the participants were frontline workers, such as grocery clerks, library staff, and cleaners, or worked at sheltered workshops. These jobs often have precarious work arrangements, and most participants could not work from home. Furthermore, there was little for them to do at home, except for watching TV. Only three participants were able to work remotely. A man in his thirties said, 'It was nice to be able to log on and we even met [on Zoom] for happy hour.' Another man described his remote work as challenging. He worked at an after-school club for teenagers, and they used social media applications to keep the group occupied and active during the pandemic. He used temporal terms to describe his experience,

> We decided to transfer the club to Messenger on Facebook, which was clever, but it was challenging sitting in front of the computer for four or five hours with short breaks. We chatted online and we had to be resourceful to figure out what to do and one time we baked together using video calls and we were talking to each other. I baked a Betty Crocker cake and the others something else … We swapped groups every two weeks so we would not get bored, but it was difficult not being allowed to show up for work.

His use of temporal terms emphasizes the creativity and difficulties he encountered during social restrictions. Samuels and Freeman (2021) argue that the COVID-19 pandemic revealed that despite reasonable accommodation disabled people need to put much time and effort to be able to use online platforms which makes the 'space of crip time' often 'time-consuming' and 'frustrating' (p. 247).

Adhering to unpredictable and everchanging social restrictions was also frustrating and not achievable to some of the participants. For example, mask mandates were difficult for some participants who could not wear masks for various reasons. One man quit his job when the authorities imposed a mask mandate. He said,

> I could not wear a mask. I called them [employer] and explained. Also, because they did not seem to know how to handle the pandemic. I was relieved I quit when I heard somebody got COVID there the next week. I have not been back. It is difficult getting back out there.

Other participants in the focus groups also shared their discomfort with using masks, which interfered with their ability to participate in work and leisure. A young man said, ‘It felt like I was suffocating. I got claustrophobic. But then I got used to it and was able to work.’

The restrictions at home and work also disrupted other aspects of the participants’ lives. For example, people who were in care and/or worked at sheltered workshops had to drop out of continuing education classes even though some centres were able to organize their classes with fewer students and obey the social distancing rules. Participants who were in residential care or worked at sheltered workshops stopped going to on-site classes because the service providers did not allow their users to participate in any activities outside home/work because of the risk of contracting infection. A woman in her forties—living alone, receiving no formal support, and worked at a local supermarket—was considered an essential worker. In contrast, her colleague was in residential care, which meant an unexpected workload for her because he needed to shield. She said,

> I was not worried about getting COVID … I had a mask on and gloves … I think I worked even more during the pandemic. At one point I took so many extra shifts I worked every day for a week because the guy who was supposed to work the other shift had to quarantine and got COVID [laughs] … but the computer class I was taking was cancelled.

Since her colleague was in residential care, he was not allowed to work at the supermarket when the infection rates were high because he would put his housemates and support staff at risk—which, in turn, created more work hours for her. The service providers did not put the same restrictions on the support staff and professionals, only service users with intellectual disabilities. These unprecedented and urgent restrictions were temporary but burdensome for people with intellectual disabilities and ableist in nature (Bogart & Dunn, 2019). The participants shielded for weeks, some for months or even years, effectively becoming stuck in ‘the time of waiting’ (Kafer, 2021, p. 421). This temporary shielding lasted a long time for the participants forcing them to adhere to greater and more prolonged restrictions compared to most other Icelanders. While there might have been an emphasis to return to ‘normal’, pre-pandemic times (Abrams & Orsini, 2022), this urgency did not include people with intellectual disabilities. They were supposed to continue waiting.

## Pandemic Temporal Experiences

The restrictions authorities enforced to mitigate the spread of COVID-19 affected all aspect of society and disrupted people’s social and temporal experiences. During the two years of the pandemic, social restrictions were imposed and lifted in response to the fluctuating waves of infections. People with intellectual disabilities are a heterogeneous group, and the abrupt change to their daily lives was experienced differently by the participants depending on their circumstances. However, I could identify three trends in their experiences. First, the social restrictions revealed *a continuity of isolation* for some participants because, prior to the pandemic, they had few opportunities for social engagement. There was not a drastic change in their level of social participation, so the temporal disruption caused by the pandemic was less pronounced to them. Participants explained that they spent most of their time at home even before the pandemic and did not have much work or social life. One man in his twenties recalled staying at home with his mother during the first wave of the pandemic,

> When we had to quarantine, my mom said: ´This is no difference for you, home alone and watching your movies´. And it is true, I am always alone. And because of that I could protect myself [against the virus] really well.

Although he had gotten used to such isolation, it did not mean he would have chosen solitude. It had been forced upon him and some other participants long before the pandemic. 'The normative structuring of time is … highly centered on labour and productivity' (Ljuslinder et al., 2020, p. 35). Participants' pace of life was not normative, and the continuity of isolation was, for some, an exacerbation of existing conditions where they had to wait even longer for work, housing/residential care, and other opportunities.

The second trend was *limited control over time and schedules*. The five participants in residential care shared support staff with other residents, described how every activity of their daily lives, before the pandemic, was carefully scheduled around the assistance they received at home, transportation services, rehabilitation services, work, and various leisure activities. Time was central to their service plans, which were supposed to be individualized, but were not in practice, and did not allow for flexibility to their schedule. Their bodies and minds had been bent to meet the 'normative and normalizing expectations of pace and scheduling' (Kafer, 2013, p. 27). The constraints of the service providers shaped their schedules. When the participants went about their days, for example, going to school or work, they had to allow for the same things that non-disabled people do. However, they also had to consider various disability-related matters that were most often out of their control (Katzman et al., 2020). This rigidity often caused them to show up late for events, and they also missed out of opportunities, highlighting a significant gap between the intended and actual practice of individualized support.

The pandemic showed us that it was possible to crip time. When everybody was forced out of linearity in pandemic time, there was suddenly a space for alternative ways of moving through life (Abrams & Orsini, 2022). The pandemic provided flexibility regarding education and work and some participants welcomed this shift. A man in his thirties who was in residential care, used a wheelchair, and shared support staff with four other people described pandemic time as better than pre-covid time. He was in his second year of college at the start of the pandemic, but before the social restrictions he had often missed classes because the support staff did not prioritize his education. His situation changed considerably during the pandemic,

> I liked taking classes on Zoom … I got help at home to log on … I could be online wherever I was. I even went online in the car [on his phone], and I still could participate from the car. And I got better grades when I was online.

Online education offered flexibility since he did not have to worry about showing up at a particular location and time. However, flexibility was irrelevant if they did not get appropriate support. For example, the participants who required more intensive support in their daily lives did not participate in online classes during the pandemic, especially those in residential care, because support staff were forced to prioritize basic care. The residential care system was not prepared for people staying at home during the day, and most care homes were already understaffed, which caused even more problems when staff members were quarantined or isolated and could not show up for work.

Furthermore, crip time is not standardized, it is not the same for all disabled people, and although some participants welcomed the flexibility introduced during pandemic time, not all enjoyed this change. Several participants described how they missed interacting with people in person. A woman in her twenties said, ‘I hated not being able to meet my friends. And when I had to log on [Zoom] for classes it was a reminder of not being allowed to meet in real life.' Online classes disrupted what she considered normality; therefore, she opted out and consequently missed out on valuable learning time and social interactions.

The third trend I identified was *a temporal disturbance* leading to increased loneliness among the participants during the pandemic. All participants experienced loss of services and struggled to maintain contact with family and friends. People with intellectual disabilities were less likely to use technology such as communication platforms and social media to interact with others during the pandemic (Tryggvadóttir et al., 2021). A young woman living with her parents missed her friends and her daily routine, stated, 'I became totally closed off and did not talk to anybody during the pandemic.' She was among few participants who stopped using social media during the pandemic.

The prolonged social restrictions contributed to temporal disturbance. A man in his thirties who had worked in the open labour market shielded for almost two years described his unbearable experience of staying home, feeling distressed, and needing professional help. He remarked, 'I felt like I was doing something wrong because I did not show up for work … I became distressed and … had to talk to a psychiatrist about this.' He furthermore described how impossible and never-ending the pandemic felt to him, as if time stood still. Many participants described this kind of time expansion, especially when they were bored or lonely. One young man said in this regard, 'I felt like this pandemic was never going to end.'

Most participants had contracted COVID-19, but none became seriously ill. When the participants in residential care got infected, they simultaneously experienced time expansion, feeling sick and fed up with the pandemic, and the time pressure of hurrying to get back to health to reduce the strain on the service provider. There were not enough support staff in their homes during the day to care for residents who had fallen ill and to support those who were home because their workplaces had closed.

The findings suggest that previously active people had more difficulty adapting to COVID-19 restrictions, but all participants experienced temporal disturbance and loneliness, which can partly be explained by the more stringent and prolonged restrictions imposed by disability service providers.

## Overlooked and (Still) Waiting

During the first waves of the pandemic, the Department of Civil Protection and Emergency Management held daily press conferences with the Chief Epidemiologist, the Director of Health, and the Chief Constable of the Civil Protection Department. These broadcasts provided structure for the disrupted days of many of the participants. The three officials soon became known to everyone in Iceland, and some of the participants described them as friends. However, early on during the pandemic, it became apparent that the Department of Civil Protection and Emergency Management did not emphasize the circumstances of disabled people during these meetings, they had not involved disabled people in any emergency planning, and disabled people's organizations did not have a defined role in the emergency operations (Björnsdóttir & Jóhannsdóttir, 2021). These meetings presumed abled-bodiedness and able-mindedness and most safety advice introduced was not available in easy-read language and did not resonate with the participants. The three men who used wheelchairs burst out laughing when asked if sinks were physically accessible to them. One of them said, 'It can be tricky when you are supposed to wash your hands to be safe.' Also, the Department of Civil Protection and Emergency Management (n.d.) emphasized 'individual infection control' of, for example, social distancing, using masks, and handwashing and sanitizing. All of this is incredibly difficult when one relies on personal assistance and move about in a world that has an ableist design.

Some of the participants did not want to talk about getting sick from COVID-19, and some admitted that they were embarrassed for not being able to ‘stay safe’ and follow the advice properly that was introduced in the press conferences. The Chief Epidemiologist had urged everyone who was ‘vulnerable’ to shield during the pandemic. Although he could not force anyone to shield, he hoped people would be ‘responsible and not cause strain on the health care system,’ which was an important factor in the campaign for the aforementioned individual infection control (Gunnarsdóttir, 2020). If disabled people would have been obligated to shield, the state would have guaranteed them payment of wages while shielding (Prime Minister's Office, 2020). Instead, they were encouraged to shield, which put the responsibility of staying safe on the individual, keeping the stress off the healthcare system. As mentioned above, many of the research participants had shielded, missed out on activities and social events, and had done everything asked off them, but they still contracted the virus. Therefore, some became afraid of how other people would react to their failure of staying safe and felt as if they had let their three new friends (the Chief Epidemiologist, the Director of Health, and the Chief Constable) down by contracting the virus.

The Covid-19 fatality rate among disabled people in Iceland is unknown, but according to Statistic Iceland (n.d.) several people died from various non-life-threatening conditions such as autism, cerebral palsy, and Down syndrome during the pandemic. However, if we examine the situation in other countries, it is likely that individuals with intellectual disabilities have also succumbed to COVID-19 in Iceland. High death rates due to COVID-19 among people with intellectual disabilities allowed them to be prioritized for vaccination in some countries, such as the UK and some states in the U.S. (Kuper & Scherer, 2023), but this was not the case in Iceland. Ambiguity and unpredictability surrounded the information provision of the vaccination process and the management of implementing the vaccinations. The Ministry of Health published regulations regarding prioritizing COVID-19 vaccination, which stipulated vaccinating healthcare workers and people living in nursing homes for the elderly and geriatric hospital wards (Ministry of Health, 2020). Disabled people were not considered a priority group in Iceland unless they had underlying medical conditions. Vaccination implementation for the priority groups seemed unpredictable, and several people claimed they were forgotten or left out of the priority group despite meeting the criteria for prioritization. A woman in her forties said,

I have a rare disease and I should have been among the first to get vaccinated. But I was among the last. Later than my [non-disabled] siblings. I was just told they [health centre] were sorry because they forgot about me.

Only five participants were allowed earlier vaccinations on the request of their service providers. Since the residential care system was under strain during the pandemic, people who received such assistance or had independent living contracts with the municipalities were moved forward in line for vaccination. People who still lived with their parents or on their own or who had direct payment contracts were not prioritized. Many of them were at greater risk of contracting COVID-19 for many of the reasons that WHO (2020) identified, such as difficulty in enacting social distancing because of additional support needs or the need to touch things for physical support.

The participants described how the wait for the vaccination was difficult and they found themselves yet again in ‘the time of waiting’ (Kafer, 2021, p. 421). Not knowing where they were placed in the line for vaccination caused great concerns for many participants and exacerbated an already protracted and tiresome situation. A woman in her thirties who lived in her own flat said,

> I had to call the health centre and ask where I was in the vaccination queue. It is important for disabled people to know when they are supposed to be vaccinated and what it's like. Everybody is saying that they forgot about disabled people when prioritizing.

In the end, vaccinations were made open to all who required them, and booster shots were readily available. The participants stated that they had high hopes regarding vaccinations and thought it would end the pandemic. It was disappointing when new variants kept occurring, and the wait for the world to return to past normal was not over.

## Discussion and Concluding Remarks

These findings demonstrate the precarious position of people with intellectual disabilities during the distress phase of the COVID-19 pandemic. It is helpful to draw from Kafer's (2013) ideas about crip time and futurity. In short, the findings demonstrate how people with intellectual disabilities find themselves continually in 'the time of waiting' within an ableist society. The disruptions caused by the pandemic revealed several important issues regarding the lives of people with intellectual disabilities. First, the level of rigidity in their daily schedules is astonishing. Most of the participants had to comply with the routines and needs of the service providers, and for many, this way of living had become the norm. It is a testimony of substandard services available to people with intellectual disabilities and how they have no control over their own time. It did not happen during the pandemic (Björnsdóttir et al., 2015), but was exaggerated during social restrictions.

Second, disabled people had, for a long time, called for more flexibility regarding education and work, which suddenly became possible during the pandemic when it benefitted business owners and employers (Hankerson & Brown, 2021; Samuels & Freeman, 2021). A flexible approach to work and education aligns well with the demands of crip time (Kafer, 2013; Samuels, 2017). However, while remote working and learning create flexibility regarding time and mobility, it is far from a suitable solution for all disabled people. Only some participants had jobs that allowed remote work. Since people with intellectual disabilities often receive substandard support (Björnsdóttir et al., 2015), they are not likely to be able to take on remote work and participate in online activities. People in residential care were least likely to use technology during the pandemic for social interactions (Tryggvadóttir et al., 2021), which is surprising since they should have around-the-clock support. Deinstitutionalization has perhaps not promised to be a solution to all social barriers in the lives of people with intellectual disabilities. However, the support quality in their community-based homes is disappointing and seems to have many institutional qualities.

Also, it is troublesome that pandemic time turned out to be a continuity of social isolation. When time slowed down for everyone during social restrictions, it was already moving at a slow pace for some of the participants. They needed to respect the service provider's schedules, with no control over their own time, but simultaneously needed to keep up with normative ableist ideas of linear time. When non-disabled people experienced temporary crip time during the pandemic, there was resistance to this tempo, and social isolation was not comfortable (Abrams & Orsini, 2022). However, this disruption was temporary for most people. The findings of this research suggest that social isolation and loneliness are not temporary for some people with intellectual disabilities, and this is an issue we need to address when we move forward toward a better post-pandemic future.

One of the reasons people with intellectual disabilities experienced social isolation and loneliness during the pandemic was the severe social restrictions placed on them. According to the state's officials, people with intellectual disabilities did not need considerations in terms of COVID-19 vaccinations or secured payment of wages during 'voluntary' shielding. However, they were conveniently categorized as vulnerable to protect the disability service providers. This ambiguity also turned them into time travellers, who, in some cases, moved back home to their elderly parents. Their adulthood was not delayed; it was cancelled. They were put in an impossible situation of having to renegotiate their independence. Similarly, those still living at home remained in the status of suspended youth.

The reasons provided for the severe restrictions are problematic. While the Chief Epidemiologist claimed a lockdown would cause 'enormous harm to society' (Árnason, 2020), socially restricting people with intellectual disabilities for over two years was not cause for concern. The authorities did not deem it appropriate or legal to put the same restrictions on non-disabled support staff. These are ableist double standards, which suggest that the lives of people with intellectual disabilities are less valuable. Perhaps the officials underestimated the need for people with intellectual disabilities to participate in society and connect with others since they do not follow the normative life path. Such an oversight would have been avoided if the Department of Civil Protection and Emergency Management had consulted the disabled people's organization before and during the pandemic.

In terms of crip futurity, the present amplifies what we know about the past (Kafer, 2013). It reminds us that people with intellectual disabilities are often left out, neglected and are expected to accept restricted realities. However, the present also indicates where we see their future. The pandemic highlighted how society prioritises able-bodiedness and able-mindedness. Kafer (2013) argued that society is based on a cure-driven future that ‘positions people with disabilities in a temporality that cannot exist fully in the present, one’s life is always on hold, in limbo, waiting for the cure to arrive’ (p. 44). When the pandemic slowed down the tempo of society, nobody could fully exist while waiting for the cure of COVID-19 to arrive. Since our vision for the future shapes the temporalities of waiting, it is worth asking what kind of future people with intellectual disabilities were waiting or hoping for. A post-covid future must be better than the past, but they have been waiting endlessly for full inclusion in society. It is of greatest importance that we spend the time between this COVID-19 pandemic and the next disaster wiselyl and, once and for all, stop the social exclusion of people with intellectual disabilities. I conclude by arguing for a post-pandemic future based on the politics of crip futurity, where disability is understood as ‘political, as valuable, as integral’ (Kafer, 2013, p. 3).

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