

COVID-19 infection control measures - Cross-pressure between the right to work and the right to health

## **-A Norwegian case study of service provision to persons with cognitive disabilities**

### **ABSTRACT:**

Work participation and work facilitation represent basic human rights for everyone. Work represents an important platform for welfare and well-being, but compared to the general workforce in Norway, persons with cognitive disabilities are severely under-represented. When workplaces locked down under the first COVID-19 outbreak spring 2020, some people were made redundant whilst many continued their work from home. The lockdown affected persons with cognitive disabilities through lockdown of workplaces, vocational training centres and even day activity centers. The scheme of working from home was not as obvious or facilitated for this group, as for other employees. When also visits were banned and common areas for socialization were locked down, the consequences of these lockdowns were exacerbated. In this chapter we have examined and discussed the COVID-19 restrictions in Norway and how they affected the basic human rights of persons with cognitive disabilities, and also how such rights can be promoted through legislation, governance and service provision.

### **KEYWORDS:**

Cognitive disabilities, work, human rights, COVID-19, lockdown, infection control measures

## 1. Introduction

“Everyone has the right to work”, (UN Universal Declaration of Human Rights of 1948, article 23). The right to work, as well as the right to non-discrimination is also stated in the European Convention on Human Rights (1950) (ECHR) article 14, and in the International Covenant on Economic, Social and Cultural Rights (1966) (ESC) articles 6 and 2. Persons with cognitive disabilities are to be secured all human rights on the same level as others, and their rights to work and to non-discrimination are further protected through the Convention on the Rights of Persons with Disabilities (2006) (CRPD), articles 27 and 12.

According to the Norwegian Constitution (1814, article 110), authorities must facilitate work and work inclusion for their citizens. The Constitution further states that all interventions from authorities must be founded in legislation (1814, article 113), and interventions through infection control measures were founded in the Norwegian Infection Control Act (1994).

The individuals’ right to equality and non-discrimination can be interpreted as being equally treated according to legislation (formal equality). However, to redress individuals’ risk of

disadvantage due to stereotypes and prejudice for instance, equality must be facilitated through participation and accommodation of differences (substantive equality) (Fredman, 2016, p. 282). Due to their impairment, persons with cognitive disabilities may require such accommodation to have their individual rights secured. As part of securing participation, Kane & Köhler-Olsen (2018) emphasize the importance of inclusion and point out how the right to participation of CRPD requires close consultation and active involvement of persons with disabilities in policies related to disability.

During the Norwegian lockdown following the outbreak of the Coronavirus in the spring of 2020, many employees were laid off from their jobs, and many workplaces were closed or reduced. Work represents a source of income, but also an important platform for people's quality of life, psychological wellbeing, and autonomy (Jahoda et.al., 2008), as well as for being included in mainstream society and for forming ideas about democracy, equality, and participation (Kane & Spjelkavik, 2021). Having a job essentially seems to have the same positive impact on the quality of life of persons with cognitive disabilities as of people in general, for example work enhances the experience of mastery and social belonging (Brun & Melbøe, 2021). Although persons with cognitive disabilities in Norway have secure income through disability benefits, their participation in work life or regular work-related activities still represents an important platform for welfare and wellbeing.

While the conception of work in today's society is perceived as synonymous with paid employment, other types of activities are often questioned as to whether they can be called work (Heen, 2008). According to Wadel (1977, p. 387), work should be understood as more than employment activities: "Work is something we all do also outside of working life, and outside work hours and workplace". Wadel (1977, p. 407) also suggests defining work as: "Human activities which can be seen as maintaining, establishing or changing valued social institutions", meaning human interaction in a wider perspective than merely source of income. In this perspective, vocational and other regular day activities for persons with cognitive disabilities can be defined as work, regardless of receiving disability benefits.

While the lockdown has affected the citizens' right to work, this measure as well as other infection control measures also represented governance of their right to the highest attainable standard of health through "the prevention, treatment and control of epidemic, endemic, occupational and other diseases" (ESC article 12, CRPD article 25). During the Coronavirus

outbreak, this right has been important for persons with cognitive disabilities, as they seem to have a slightly higher risk of getting infected with COVID-19 than others. This is due to social circumstances such as relying on support from other people and services and living close to others in care facilities (Tummers et al., 2020), physical health problems (O’Leary et al., 2018) and challenges in understanding and implementing health measures to protect themselves from the Coronavirus (Courtenay & Perera, 2020).

Regarding this book’s aim to highlight how COVID-19 have affected social practises in Welfare Disability Policies in Europe and how such changes can promote or challenge the rights of people with disabilities, this chapter addresses how COVID-19 in Norway affected their human rights regarding work participation. When persons with cognitive disabilities were restricted from attending their work and/or work-related activities during the lockdown in the spring of 2020 to prevent them from infection of the Coronavirus, these human rights were set under a cross-pressure. Based on our research question: ***COVID-19 lockdown – implications for the individual right to work?*** our aim is to identify and discuss different implications of the Norwegian governance of protection of the right to health, by restricting work and work-related activities for persons with cognitive disabilities. From this, we will discuss how COVID-19 restrictions changed social practices considering participation in work and regular day activities, and how different changes have impacted on the individual rights of the service users.

## 2. Background

### 2.1 Welfare services in Norway – framework, organization and policy

Welfare service for persons with cognitive disabilities in Norway is divided between several National Acts. Disability benefits are regulated in the National Insurance Act of 1997, whereas home care services are regulated in the Municipal Health and Welfare Service Act of 2011. Both acts have the legal aims of promoting social security, contributing to equal rights, and of ensuring the individual’s right to independent, active, meaningful and social lives, integrity and dignity. The state is responsible for governing National Insurances such as disability benefits, whereas municipalities are responsible for providing home care services such as personal assistance, practical support, and day activities, as well as housing providing such services. As these services are mostly public, they are equally accessible to all citizens (Stamsø, 2009).

From the 1950s Norway mainly provided residential services to persons with cognitive disabilities through large institutions. As stressed by Meyer (2003) these institutions had a lot in common with what Goffman (1961) defines as total institutions, as these were a place for both residence and work for a great number of similarly situated people, and where the residents were cut off from the wider society. Due to critique of the living conditions at these institutions, the normalization concept evolved, focusing on having the possibility to live in the community on the same basis as everyone else. Based on normalization principles such as access to a normal daily pace, normal routines of life (for example living in one place and working somewhere else), self-determination (Nirje1996) and so on, the institutions were replaced by community care in the period 1991 to 1995 (Tøssebro, 2016). Since then, the municipalities have been responsible for the delivery of primary health care and social services to persons with cognitive disabilities just like to other Norwegian citizens. Today, persons with cognitive disabilities in general live in individual housing, most in group homes, and some in individual homes. Moreover, the focus on normalization has also had consequences for work, leading to an expectation of people with disabilities participating in work, and not only mainstream employment, but also work-related activities within segregated settings. Thus, several Official Norwegian Reports and White papers stress the importance of work inclusion for persons with cognitive disabilities (Gjertsen et.al. 2021b).

Just like CRPD, Norwegian disability policy today is based on a relational understanding of disability (Skarstad 2019). In a relational model, disability is defined as a mismatch between individual abilities and the requirements of the environment. Thus, meaning that disability is situational to the environment and relative (Tøssebro 2000), occurring at the intersection between the individual and the specific context. For example, a wheelchair user will be disabled when encountering a set of stairs to enter a building, but not when a ramp is encountered. The relational model replaced a medical understanding of disability in Scandinavia during the 1970s. In the medical perspective one assumes that disability is caused by defects in the individual, and where the goal of interventions is to “cure” the person through rehabilitation, medical treatment etc. (Goodley 2011). Some perceive the relational model as a variation of the social model (Skarstad, 2019). According to the social model people with impairments are disabled/ oppressed by society through socially constructed barriers that prevent access, integration, and inclusion to all parts of society (Goodley 2011). Thus, the disability is caused solely by the environment, and a consequence is that society is not adapted to all people. From

this perspective “the political challenge is to change the environment in order to create equal opportunities for larger portions of the human variation - to recreate the environment in order to 'fit' more people” (Tøssebro 2000:4). Moreover, while the medical model is based on paternalism, where patients are expected to avail themselves to treatment offered by professionals, the social model is based on autonomy and the slogan “Nothing about us without us” (Goodley 2011).

## 2.2 COVID-19–infection control measures in Norway

The first case of COVID-19 was confirmed in Norway 26 February 2020, and on 12th March 2020 national lockdown measures were announced. In the following section, we will present the infection control measures throughout the pandemic, as described in the Official Norwegian Reports (NOU 2021:6 and NOU 2022:5). To maintain physical distance, all educational institutions were physically closed, and digital teaching was introduced. Employees were advised to work from home, cultural and sports events and gatherings were banned, visiting vulnerable groups living in institutions was not allowed, people were encouraged to limit their social interaction, and establishments in the hospitality industry not serving food were closed and so on. During early summer 2020, the community gradually reopened. However, in the autumn the number of infected increased substantially. With this second wave of the Coronavirus, at the end of October and beginning of November, authorities reintroduced many of the original infection control measures, such as working from home at a national level. In addition to the national measures, more comprehensive local measures were implemented in municipalities with high infection pressure, such as digital teaching. The authorities barely managed to ease these measures before the third wave of infection hit in March 2021.

In addition to strict local measures in municipalities with high infection pressure, national guidelines requested employees who had the chance to work from home. Throughout the spring the authorities gradually reopened the country, easing the infection measures. However, a fourth wave of COVID-19 at the beginning of September led to a postponement of further reopening, and regions with high infection were subject to the imposition of containment measures. At the end of September almost all restrictions were lifted. A fifth wave of COVID-19 at the end of November 2021 led to new stricter national infection control measures, but almost all these were lifted in January 2022.

Geographically, Norway is long stretched, and has 5,4 million inhabitants (SNL, 2022). While the country holds 17 inhabitants per square kilometer, our more densely populated cities and areas hold 2000 (SSB, 2022). These differences have naturally impacted the infection pressure throughout the pandemic, and the consequences of the lockdown have therefore been quite different for the inhabitants. Those living in regions with high infection pressure have experienced quite intrusive infection control measures throughout the whole pandemic. For example, in the capitol Oslo, many have worked from home, and leisure activities for adults have been closed for almost the entire period. By contrast, inhabitants in rural areas with little infection for extended periods have been able to live almost normal lives. Furthermore, inhabitants who depend on various services to function in everyday life, like people with disabilities, have experienced greater challenges than many others, as we will highlight in our case study, chapter 3.1.

## 3. Case study

### 3.1 Work life before and during the pandemic

Persons with cognitive disabilities in Norway have over time experienced restricted access to work life (Gjertsen et.al., 2021). Whilst the general employment rate in Norway is approximately 70 percent (Norwegian Directorate of Health, 2021), the employment rate for persons with cognitive disabilities in Norway is only 24,5 percent. Most of these work under adapted measures and in segregated settings, while some are employed in the regular work market. In addition, many attend day centres set up by the municipalities, even though there has been a decline of such centres in recent years (Engeland & Langballe 2017).

When Norway locked down due to the COVID-19 breakout, several hundred thousand employees started working from home (Confederation of Vocational Unions 2020). A key reason for this being possible, is that most Norwegians have internet service at home, and that a large proportion of the jobs by nature can be performed from home (Dingel & Neiman, 2020). However, for persons with cognitive disabilities, the situation was different. A report on the Coronavirus pandemic as experienced by persons with cognitive disabilities in Norway (Norwegian Health Inspectorate, 2021), shows that two thirds of the informants who had a job experienced the closure of their workplace, while all informants attending activity centres experienced closures. Moreover, some people were stopped from going to work because their

service providers feared that they could bring infection into the shared residence where they lived.

In addition to lockdown of all work-, daytime- and leisure activities, many persons with cognitive disabilities experienced strict infection control measures such as access control and bans on visits in their own homes (NOU 2022:5). Thus, many during the first lockdown experienced isolation and lack of freedom (Norwegian Health Inspectorate 2021), spending all their time in the group homes together with a limited group of staff. This triggered reactions such as anger, frustration, restlessness, sadness and/ or resignation (Melbøe et.al., 2021). The sum of infection control measures affected persons with cognitive disabilities even more so, which underlines the importance of access to work during this period.

### 3.2 Research methods

This chapter is based on the qualitative research project “Independent living and infection control – experiences with provision of home-based services for persons with cognitive disabilities under Corona measures” (Melbøe et.al., 2021; Gjørnum et.al., 2021). Approval of the study was granted by the Norwegian Centre for Research Data (no. 702777). Both authors have participated in preparing the research project, in designing interview guides, studying and analyzing the interview material, and in the writing process.

Our case study consists of two parts: 1) studies of national regulations and guidelines regarding the different infection control measures following the Coronavirus outbreak in Norway, and 2) interviews with service providers at municipal home care services in Norway.

#### **Document studies**

When applying document studies as a source for discussing a research problem, the documents must be interpreted within their actual context (Tjora, 2017). By studying documents, one can obtain an overview about incidents, actions, and grounds for actions in specific contexts. The aim of our document studies of national regulations and guidelines during the COVID-19 lockdown from March to June/July 2022 has been to provide an overview of how the Norwegian authorities described and founded their decisions regarding injunctions and prohibitions introduced to prevent spreading of the Coronavirus. Regulations restricting people’s privacy and autonomy must be founded in National legislation (ECHR art. 8), and these regulations were founded in the Norwegian Infection Control Act (1994). In addition, our

aim was to gather information on how the infection control injunctions were balanced with other relevant considerations and rights. For our studies of legal documents, we also applied a legal-dogmatic method, aiming to “systemize and describe the legal rules regarding a specific area within society at a given time” (Kjønstad et.al., 2017 p. 76). All named documents have been made public, and the national authorities presented restrictions and their aims on national TV, radio, and newspapers both in paper and online.

## **Interviews**

For our interviews, participants were recruited through purposeful sampling, characterized by Creswell and Plano Clark (2011) such as identifying and selecting individuals with special knowledge and experience within a phenomenon of interest. Our participants were chosen because they 1) provided municipal home care services to persons with cognitive disabilities, from March to June 2020 (when large parts of Norway were locked down due to the outbreak of Coronavirus), 2) attained higher education in health and/or social work, and 3) worked in services in different parts of Norway, including both urban and rural areas.

Participants were recruited digitally through professional networks at competence centres, county governor's offices, head of health and social services and so forth. Additional recruitment was conducted by advertising the study on social media. Those willing to participate either contacted the researchers themselves, or the organization through which they had obtained information about the study passed on their contact information. 19 service providers gave their informed consent for participation in our study. The participants consisted of 13 women and six men between 21 and 67 years of age, employed in different care groups, and in total offering services to approximately 160 persons with cognitive disabilities. The infection pressure varied between the municipalities, and there had been Corona infection outbreaks at two of the group homes. The service users were between 20 and 90 years old. The interviews were recorded, and then transcribed verbatim and anonymized. In the text participants are anonymised by using pseudonyms.

The service providers were interviewed in June 2020 about their experiences with safeguarding infection control and independent everyday life for persons with cognitive disabilities during the first Corona lockdown in the spring of 2020. Our interview guide focused especially on work, daytime activities, leisure, social participation, and digitalization. Due to infection control reasons the semi structured interviews were primarily conducted digitally via Zoom or by phone, and only exceptionally face to face. Most of the interviews lasted around an hour.



The interviews were conducted by three researchers at the Institute of Social Education at UiT, the Arctic University of Norway. The first author of this chapter did not conduct interviews. Our interview material was analysed by means of thematic analysis (Braun & Clarke 2012), to systematically identify, organise and get insight into the patterns across our data set. After studying our transcriptions, we generated codes to identify data relevant to answer our research question, and then started searching for themes. Potential themes were identified and discussed actively among the two authors.

We have organized our findings in accordance with the following three overarching themes: 1) the lockdown of work and vocational activities, 2) facilitating work participation through innovative solutions, and 3) worklife and regular day activities after the re-opening.

## 4. Results

When presenting our results under the above-mentioned overarching themes, we first present our findings from our studies of official documents regulating the COVID-19 infection control measures in general, and work-related infection control measures in particular. We then proceed to presenting findings from our interviews with service providers.

### 4.1 The lockdown of work and vocational activities

On deciding the Norwegian lockdown 11th March 2020, the Norwegian Directorate of Health (DoH) (2020a) dispatched a letter to Norwegian employers 'organizations with a call for facilitation for home office and flexible working hours to curb the spread of infection. This to reduce the number of people traveling collectively and people working in the same room. Due to the higher risk of health problems related to Corona infection for persons with cognitive disabilities, DoH (2020b) thereafter presented guidelines regarding infection control measures in municipal home-based services, including lockdown of workplaces and day activities.

According to our informants, due to official guidelines, almost all activities were closed for their service users, regardless of whether they worked in ordinary jobs, vocational training centres or participated in work-related activities such as firewood production, assembly, or craftwork. One informant exemplified how two service users who were employees in grocery stores, continued their work as these stores did not close. Thus, to most service users the

lockdown meant extensive changes. Many of our informants pointed out that no regular alternative daytime activities were organized, and that each service provider was responsible for "finding out what to do today". They described how this for many of the service users resulted in long quiet days at home inside their own apartment, mainly being offered leisure-like activities like going for a walk, playing games, listening to music, watching tv and so on.

Informants illustrated how finding alternative activities for service users who no longer could attend their regular vocational activities, was left to each service providers' individual initiative and implementation. As our informant Anne described it: "It has been up to us! To be – not exactly avocational training center, but to fill their time with something nice and productive! /.../ She has not had the chance to saw and pack firewood /.../ but we have done what we could do!". In addition, regular "out of home" activities, representing meaningful daily life inclusion, were for some service users exchanged with more passive activities, or no activities. According to the informants most of the service users did not experience any digitalization at all, and those who did mainly used digital equipment (for example Snap or Facetime) to keep in touch with family, leisure activities (such as digital Zumba or drumming-rehearsals) or to practical everyday tasks such as using apps to order groceries. However, none of the service users seemed to experience digital work solutions. One of the informants, Jon, attributed the limited digitalization to a lack of equipment. As he pointed out: "Group homes are sort of old-fashioned using pen and paper...".

## 4.2 Facilitating work participation through innovative solutions

According to the first Official Norwegian Report on the authorities' handling of the pandemic, executed by the Norwegian Corona Commission (NOU 2021:6), approximately half of all employees in Norway worked digitally from home in March 2020. However, the subsequent Official Report from the Corona Commission (NOU 2022:5), showed that digital solutions as a means for working from home were far less used by people with disabilities.

Regarding participation in work related daily activities, the Official Report (NOU 2022:5), highlights that although vital basic needs were met during the lockdowns, many persons with disabilities have experienced reduced access to facilitated work and work-related daytime activities during the pandemic, as well as to other services. The report also emphasizes that several service providers have made efforts for facilitations, far beyond what anyone could expect of them.

While many of our informants referred to the lockdown as a necessary collective infection control measure, some emphasized making individual assessments. Through creative solutions, for some service users they combined necessary infection control measures with facilitating *working from home*. For example, at one group home they collected the knitting machines that three of the women usually used to create fabrics at an activity center so that they could continue knitting from home. In another group home, they transported lots of firewood and the familiar wood chopping machine outside the home of one of the service users, so that he could keep up his ordinary job from home. In one group home the service providers transported the paper shredder from the activity center and established a workstation at their office, this so that one of the women living there could continue her well-known work tasks. A couple of informants also described the inventive facilitation of *alternative work*. For example, the service providers at two group homes involved some of the residents in gardening, such as mowing the lawn or growing vegetables. At another place, two of the residents who usually attended an activity center, were involved in outdoor activities such as clearing beaches for plastic and the like. One of the informants, Linda, stressed the importance of the service providers showing creativity in the facilitation for alternative activities, she pointed that “They (the service users) do not possess a big bank of ideas! Often, we must make suggestions”.

Here, our interview material implies that the service providers emphasized their service users’ right to health protection by staying at home. The examples of bringing work/activity equipment to homes indicate an important proportionality assessment by the professionals, where the protection of both physical and mental health and wellbeing was regarded as the more important consideration.

Some informants pointed out how a few of the service users were anxious about being infected by COVID-19, and therefore were pleased to stay at home instead of going to work as this made them feel safe. However, informants described how the closed workplaces caused most of the service users to express anger, sadness, restlessness, and resignation, through expressions like: “I do not want corona!», «This must stop now!”, “I want to go to work”. Observing the service users’ reactions on being excluded from work has also made an impact on the service providers, as exemplified by our informant Anne: “It has been heartbreaking! It has not been easy to be at work!”. Informants explained these reactions as consequences of missing social contact with colleagues, boredom due to lack of activities, and change of daily routines. One informant, Linda, stressed that: “Work is an arena for mastery where you feel that you are valuable and that you contribute to society /.../ The job is a big part of the identity”, and another

informant, Rita, underlined how she found work just as important for the employers with cognitive disabilities as for others, maybe even more.

In these and similar statements, our interviewees showed different areas where the service users' welfare and rights are set under cross pressure. Being unable to participate in regular daily activities, the service users were deprived of their platform for community, active everyday life, safe routines, identity, and mastery. At the same time, absence from activities also provided safety for service users fearing infection. This illustrates how the right to the highest attainable standard of health also includes mental health and wellbeing.

### 4.3 Work life and regular day activities after the re-opening

The Official Norwegian Report (NOU 2022:5) regarding the handling of the COVID-19 pandemic, states that many people with disabilities did not re-attend their regular daily activities after the first re-opening due to being anxious about getting infected. Also, activities which had been locked down due to the first COVID-19 outbreak, did not re-open. According to the report, more than half of the service users reported that their services were reduced compared to before the pandemic, and that welfare services took a long time to get back to normal.

Our informants described how, although workplaces, vocational training centres and activity centres gradually re-opened, this did not mean that the service users automatically could re-attend. The informants referred to how before returning to centres, they conducted various assessments, such as whether the employees themselves or their co-residents had a higher risk of severe illness from COVID-19, and whether the employees were able to understand and comply to infection control measures such as keeping distance to others and carrying out proper hand hygiene. As one informant, Kristin, commented regarding those service users who were the first to go back to work: "Those who sit still get offers more often! So, it matters how they behave". In addition, one consequence of the distance requirements was limitations in the number who could attend work at the same time, which meant that most were asked to work fewer weekdays than before.

In these descriptions, the informants illustrate other examples of health protective measures for the service users. As well as respecting the service users' hesitation to participate in work and other daily activities, they also show how they carry out their own professional assessments

and weighing in the cross-pressure between each person's right to health protection and right to participation in work and regular day activities also after the lockdown was eased. For example, one informant, Linda, described how they had to make the service users feel safe when the centre re-opened, for example by being patient and give them enough time. According to these service users before the pandemic: "... (they) used to be very independent, but they have lost it! They really want to (go back to work), but they do not want to leave home. It is the fear of COVID-19".

## 5. Discussion

In our case presentation, we have described how Norwegian authorities imposed and/or advised closing of workplaces and day activities for persons with cognitive disabilities as measures for infection control at the COVID-19 outbreak. We have also presented interview material from service providers regarding impacts for the service users.

From our gathered data we will derive three areas for discussion regarding the securing of substantive equality in the cross-pressure between rights: 1) COVID-19 – consequences on social practices and rights regarding work participation, 2) The understanding of work as a measure of individual rights, and 3) The facilitating of work participation through individual assessments.

### 5.1 COVID-19 – consequences on social practices and rights regarding work participation

In chapter section 2.1, we have described how Norwegian authorities should aim to promote and secure participation in all areas of society for all inhabitants, including work. Our case study has illustrated how the COVID-19 lockdown has restricted such participation for persons with cognitive disabilities, regarding both ordinary work and work-related day activities.

Because of the first lockdown and other infection control restrictions, this group seems to have spent the majority of their time in their homes, largely in isolation with only service providers. Thus, a COVID-19 consequence on social practices among persons with cognitive disabilities in Norway seems to be a shift back in the direction of the institutionalization that

characterized Norwegian disability policy for the four decades before 1990. Hence lacking work or work-related activities has meant that many have lost their normal daily and general routines and pace, both of which are major aspects of the normalization principle (Nirje 1996). Moreover, the new reality also represents a move in the direction of what Goffman (2006) described as total institutions. Firstly, as many have experienced being cut off from work and the wider society, or not being allowed to reside in other places than at home (except for staying outdoors). Secondly, those who have been given the chance to work from home have then had to adapt to home as being a place of work as well as their personal space.

The strict infection control measures imposed on several people in their own homes (NOU 2022:5), might have reinforced an experience of their homes as total institutions. Not surprisingly, it was these restrictions which caused different organizations to strongly protest in public against the infection measures. The Norwegian Association for Persons with Intellectual Disabilities protested fiercely against the introduction of what they described as both “visit prohibition, entry prohibition and curfew” in group homes for persons with cognitive disabilities (Gitlesen, 2020). Furthermore, they raised a discussion about how such restriction were an expression of the fact that the homes of persons with cognitive disabilities are still regarded as institutions. The Norwegian Equality and Anti-Discrimination Ombud Hanne Bjurstrøm for example warned against the extra stress many persons with cognitive disability experienced due to the breach of their daily routines. She also argued that “It is completely unacceptable that a group of people are subject to far stricter restrictions, for no other reason than having a disability” (Kvistum,2020). The independent public body Norwegian National Human Rights Institution (NIM), in a critical letter to the authorities, especially criticized the banning of visits and the imposition of a curfew and stressed that human rights and the constitution must be followed also during the COVID-19 pandemic (NIM 04.04.2020).

The case received a lot of attention in the media and led to the case being discussed in the Norwegian Parliament. The Official Report on the Authorities’ handling of the Pandemic (NOU 2021:6, p. 286) describes how fewer than 10% of municipalities introducing or considering curfews during the first wave of COVID-19 had consulted personnel with legal qualifications, and also points out that the Norwegian Directory of Health should have clarified that general curfews were not legal. Consequently, the authorities changed the official guidelines which embedded these restrictions. With the exception of this change, the institutions’ protests do not seem to have led to other major changes in policies or services for

persons with cognitive disabilities. However, the rather massive public attention in the media on the violation of the human rights of this group, could help to promote changes in attitudinal barriers which impede the protection of the rights of this group, including their right to work. Departing from a relational understanding of disability (Tøssebro 2000), reducing such barriers could limit the gap between demands imposed by society (working life) and the capacity of the individuals. However, the results presented in the Official Reports regarding restrictions lacking legal basis can raise general awareness about justice within governance. Intrusive decisions made by national, regional and local authorities must be made within the legal framework of national law and also basic, individual human rights.

## 5.2 The understanding of work as a measure of individual rights

Some of our informants have described how they have regarded participation in work and work-related activities as important for the service users, and also exemplified different ways of facilitating such participation during the COVID-19 lockdown, such as by bringing work equipment home and creating alternative work tasks in the domestic setting.

Based on Wadel's (1977) broader understanding of "Work" as all "human activities which can be seen as maintaining, establishing or changing valued social institutions", through maintaining participation, establishing practice with a wider understanding of work, Heggebo (2020) argues the importance of not narrowing work to merely income, and also points out how people receiving benefits can perform various activities which are also beneficial for society, such as volunteering. This inspires us to further widen this horizon by acknowledging participation in daily activities for persons with cognitive disabilities as equally beneficial to society. According to our informants, some service users worked with firewood production, paper shredding and the sewing of garments. This illustrates how they work with both production and service provision, which customers pay for. Interviewees have also described how their service users seem to have perceived their participation in work activities and other regular daily activities as "work" and have described their reactions from being locked out of their activities similarly to how other citizens have experienced being locked out from work. What the informants in this study describe as negative consequences of the closure of regular day-time activities, largely coincide with the impacts Jahoda (1981) attributes to unemployment in general on people's social and psychological health, such as deprivation of time structure, social contact, collective purpose, identity, and regular activity.

How the authorities perceive the status of “work” also influences how various types of “work” for citizens representing a diversity of people can be protected as a human right. The suspension of all regular daily activities for persons with cognitive disabilities illustrates how such activities seem to have been perceived as merely services, which is narrower than an understanding of how regular daily activities for this group can be perceived as work. This would imply a key difference, since defining regular daily activities as merely services means that the users in this context are defined as merely “passive recipients of services” rather than “active contributors to society”. Based on the social model perspective of disability, such a rethinking of the work concept could contribute to reducing barriers described by Barnes and Mercer (2009) as cultural images and stereotypes. Providing access to the valued role as a worker would challenge the traditional perception of disabled people, based on the medical model perspective of disability; “(...) have been treated as objects of pity and as burdens on their families and societies” (Kayess & French, 2008, p. 5).

The individual right to work, as stated in human rights conventions, must be secured by national authorities, through legislation, governance, and service provision. Securing this right for persons with cognitive disability requires accommodation of differences in order to obtain substantive equality (Fredman, 2016). Because rights are equal and people are different regarding resources and needs for instance, we broaden the need to consider “work” in a wider sense than merely a source of income. Thereby one can understand how regular daily activities, where people maintain a daily rhythm, performing work-related activities, often with other colleagues, can be as important as paid work. Following the thought of substantive equality, the right to work-related regular day activities for this group should be seen as closer to the right to work, than merely the right to welfare services.

### 5.3 The facilitation of work participation through individual assessments

Our informants have described how most service users who worked or regularly attended daily activities were inhibited due to the lockdown, and the facilitation of alternative activities was left to each service provider.

In Norway, work with preparedness and social security is based on the proximity principle, which means that from an organisation point of view, crises should be handled at the lowest possible level (Official Norwegian Report 2021:6). Thus, in pandemic preparedness, municipalities are responsible for infection control in the event of local outbreaks. For example,



the decision to close work- and activity centres was made locally by the municipal board and municipal doctor, even though the decision was based on national recommendations.

However, the lowest level of infection control was implemented by those providing services in the homes of persons with cognitive disabilities. These service providers' leeway for safeguarding the service users' right to work was limited by the closure of work- and activity centres. Even so, to be prepared for future crises, including pandemics, we can learn from some of the actions presented by several of the creative service providers in our interviews. Based on individual assessments they facilitated work and work activities within the framework of safe infection control measures. This facilitation was performed by simulating the frequently used measure from ordinary working life, that is making it possible to work from home. Thus, this would reduce the number of people the service users would meet in everyday life, as they avoided using public transport and interacting with colleagues face-to-face. Two different strategies were used to enable work from home. Some service providers moved the service users' original work tasks, including the necessary equipment, from work- and activity centres to their homes. However, some work tasks were impossible to move and/or to carry out from home, and therefore some service providers invented new and alternative work tasks which could be done from home. In our view, informants describing their facilitation of “working from home” and other important work tasks, demonstrate *ingenuity* considering maintaining work activities, as well as an *attitude* of equal treatment. To succeed with this type of facilitation, one should also have a dialogue with the service users themselves. A two-way dialogue about tasks and changes can bring out alternatives the staff and managers have not thought of (Norwegian Health Inspectorate, 2021b, p. 49).

A real interesting finding though, is that while approximately half of all employees in Norway worked digitally from home in March 2020 (NOU 2021:6), none of the service users in our study did. One reason for this obviously is that many of them performed practical work tasks such as chopping wood or sewing for example. However, according to Fuglerud et.al. (2021) a challenge for work inclusion in general is also that digital solutions often lack accessibility and universal solutions, which creates barriers to persons with cognitive and other disabilities. Moreover, there are also differences in digital infrastructure and the digital competence of the service providers (Holte& Strand 2021). For instance, some described lacking equipment in the group homes in our study. Thus, the situation that digital solutions rarely seem to be used to promote work inclusion of people with disabilities (Gulliksen et.al. 2021), does not seem to be a unique situation for the service users in our study or in times of the pandemic. From a

social model perspective on disability (Goodley 2011) these findings are noteworthy, as they illustrate how digital barriers seems to be an obstacle for persons with cognitive disabilities to continue their work specifically during the pandemic, but also for work inclusion in general.

Moreover, local authorities have something to learn, namely to ensure that infection control measures are in line with human rights, such as the right to work, as well as the right to freedom of speech and freedom of unlawful interventions. According to our interviewees, local authorities in many municipalities closed all work- and activity centres for persons with cognitive disabilities. This appears to be a decision on behalf of an entire group within the population, rather than on behalf of individuals, based on individual assessments of vulnerability to infection, ability to comply with infection control measures or the individual effects of such restrictions. The latter is important as not all persons with cognitive disabilities are at higher risk, even though they as a group are over-represented regarding health problems. Risk is therefore not linked to their cognitive disability, but to each person's individual health situation. For instance, O'Leary et al (2018) highlights how respiratory conditions are the leading cause of death amongst people with Down Syndrome. In the event of possible future crisis, individual assessments and facilitation could counteract universal severe and invasive decisions at a group level. The authorities lacking involvement of the service users in the introduction of infection control measures might be perceived as the perpetuation of the medical perspective on disability in the mindset of the municipalities. Hence the perception within this perspective of professionals as controlling interventions (Goodley 2011), can explain the imposition of restrictions. This contradicts the fact that disability policy is officially based on a relational perspective of disability and self-determination (Official Norwegian Reports 2016:17).

Considering that persons with cognitive disabilities both in Norway (Gjertsen et.al., 2021) and internationally (Lysaght et.al., 2012) have limited access to work life, we emphasize the importance of protecting and facilitating their right to work also during times of crisis. As stressed by Lysaght et.al. (2017) the loss of work and daytime activity may have a considerable impact on persons with cognitive disability, as many may experience a lack of meaningful activities in everyday life. For example, a Dutch study examining the experiences of people with mild cognitive disability during the lockdown period, reveals how they missed social contact and faced difficulties with being housebound (Embregts et.al., 2020). Moreover, the Norwegian Board of Health (2021) based on a qualitative study, reports that the quality of life and health of persons with cognitive disabilities are at risk of being more negatively affected

by the lockdown than the population in general. The Official Norwegian report (NOU 2022:5) confirmed how many have experienced reduced access to facilitated work and work-related daytime activities during the lockdown, and that it took a long time to get these services back to normal. This illustrates how large crises such as the COVID-19 restrictions cause higher vulnerability and risk of exclusion from mainstream work and work-related activities. It also illustrates the need for individual assessments and measures for securing health protection, to prevent instrumental restrictions which can have counterproductive consequences.

## 6. What can we learn?

Our empirical material from spring/early summer 2020 must be understood in its context. The Corona pandemic had just entered Norway, authorities and the public had little knowledge of its impact but expressed the need for protective measures at both group and individual levels. The infection control measures affecting the citizens' right to work was implemented with the aim of safeguarding the citizens' right to the highest attainable standard of health, and therefore represented a cross-pressure between rights. Our hindsight from the lockdown spring 2020 can nevertheless provide some insight into how citizens' welfare and rights can be safeguarded in the event of other large crises. According to The Official Report (NOU 2021:6), authorities' infection control measures, in the first phase of the pandemic, seem to have been more invasive than human rights and the Norwegian Constitution gave leeway for. Further, the report describes how neither national, nor local authorities sufficiently weighed the infection control measures against human rights.

In the future, to secure the individual right to work for persons with cognitive disabilities, we call for an understanding of work in a wider sense, so that their regular daily activities can be safeguarded as work also in times of health crises. To obtain such equality between citizens, discrimination between this group and mainstream employees should be counteracted, and participation facilitated through accommodation of differences at both individual and group levels regarding both work participation and health protection. Such facilitation should take place in several areas, such as the forming, interpretation, and application of legal framework. National legislation could give clearer safeguarding of the right to day activities, interpreted as a right to work in a wider sense, as well as the duty to facilitate participation through targeted health protective measures. In future crises, when formulating regulations and guidelines, the right to work and regular daily activities for this group could further be secured through

authorities' rights-oriented interpretation and application of human rights. Furthermore, by founding national legislation and authorities' regulations and guidelines on human rights, the individual rights to both work and health could be promoted through service provision securing participation.

Still in May 2022, working from home is regularly discussed in Norwegian media. Employers experience good productivity and continue to facilitate for employees to work from home part time, employees emphasize the importance of flexibility regarding travel time and caring for children, and authorities highlight the importance of less travelling with regards to the environment. If we analyze this, we can also consider that sick leave from work can be reduced by employees being able to do their work, or parts of it, from home, depending on their health situation. In a wider sense, we highlight how the option of working from home can promote more people obtaining access to work, maintaining work, and returning to work after absences regardless of health-related, social or cognitive impairments.

In summary, we aim to highlight the importance of community perspectives, and individual rights orientation as mainstream thinking, also during times of crisis. Although our research question has mainly focused on participation in work and vocational activities, our informants have described how the aim of infection control measures also led to many service users spending all their time in and around their homes. We therefore raise awareness about the risk of setting back the aims of normalisation, inclusion and participation, by considering the risk of future crisis situations such as Covid-19 leading to total institutions.

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