# 8 Affective citizenship

Social exclusion of families with disabled children during the COVID-19 pandemic

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#### Introduction

What are the affective ramifications of being excluded from social services and healthcare that people have the right to? More specifically, how did families with disabled children in Norway experience social exclusion during the pandemic? These questions constitute the focal point of this chapter as we explore the affective consequences of exclusion among families with disabled children in Norway during the COVID-19 pandemic. Through an analysis of qualitative interviews with parents of children with disabilities, carried out in 2021, we shed light on how families with disabled children experienced social services and healthcare at the height of the pandemic. To do so, we draw on theories on affective citizenship, which invite us to move beyond the rational paradigm of much citizenship research, exploring how citizenship is deeply intertwined with affect (Di Gregorio & Merolli, 2016; Fortier, 2016; Mookherjee, 2005). As such, our analysis adds to a growing field of research on citizenship, affect and emotions (Ho, 2009; Vilas et al., 2016). We study the affective consequences of social exclusion, both personally and socially, along with how particular modes of governing through affect are operative in welfare institutions, which only allow certain emotional articulations. Instead of excluding feelings from the conceptual and methodological apparatus, a turn to affective citizenship, coupled with qualitative interviews where people can elaborate on their emotional experiences, provides a deeper understanding of how citizenship matters and feels for people.

To understand how children with disabilities and their families can partake as full members in Norwegian society, some background knowledge is crucial. In the next sections, we outline the context of our study, the conceptual framework related to theories of citizenship, and describe our use of methods and data. In the end, we summarise our findings and discuss the implications of the presented arguments for future research.

## Implementing the UN CRPD and being disabled during the pandemic

Since the mid-1960s, it has been an undisputed ideal in the Nordic countries that disabled children should grow up at home with their families (Tøssebro, 2015). The explicit policy goal is to offer families with disabled children coordinated and

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flexible services to accommodate their needs and enable them to live as equal citizens, that is, provide for full participation and inclusion in society (Tøssebro, 2015). Particular notions of citizenship and inclusion are integrated as key components of the Norwegian welfare state and of the Norwegian social democratic society at large. After Norway ratified the Convention on the Rights of Persons with Disabilities (UNCRPD) in 2013, it has become even more pressing to organise Norwegian society and social policies of different kinds in ways that enhance autonomy, influence and participation for persons with disabilities. In short, the UNCRPD reminds us of the importance of developing policies and measures that enable persons with disabilities to exercise active citizenship on equal grounds.

COVID-19 and the subsequent shutdown of welfare services and educational institutions in Norway and elsewhere complicated the nation's relationship with the UN Convention of the Rights of Persons with Disabilities (UNCRPD). According to the Norwegian National Human Rights Institution (NIM, 2020), the shutdown of educational institutions following the outbreak of the pandemic disrupted Norway's ongoing commitment to these crucial human rights. In April 2020, NIM warned officials about the potential negative consequences of the country's various infection control measures and its closure of several welfare services (including schools and other established structures within the educational system). Other agencies underscored the related threat to key values of the Norwegian Education Act and the national educational curriculum (Bøhler, 2021). Although the Norwegian Prime Minister at the time and other politicians kept insisting that the measures should not disproportionately impact marginalised or vulnerable people, researchers and disability organisations have drawn attention to the subsequent systematic neglect of children with disabilities (Bossy & Hervie, 2021; Funksjonshemmedes Fellesorganisasjon, 2021). One report (Bøhler & Ugreninov, 2021) has suggested that children with disabilities were marginalised in complex ways during the pandemic because of the prohibition of physical contact with their personal assistants, educators trained in special education and physiotherapists. Overall, the shutdown of educational institutions and welfare services undercut Norway's commitment to offering "varied forms of assessment, learning resources, learning arenas, and learning activities so that everyone gets the best possible benefit from the education" (The Directorate of Education, 2022). In the interest of unpacking this difficult situation, we next elaborate on how theories on citizenship offer a conceptual frame to examine the extent to which families with disabled children could live a life according to their values and visions during the pandemic.

## Citizenship in theory: from rights and duties to affective citizenship

Discussions of citizenship have been at the heart of social and political theory for over two millennia (Aristotle, 1996; Collins, 2006; Heater, 2004). Citizenship has served as a starting point for broader debates on how political participation should be organised (Arendt, 2013) and inspired more specific discussions related to equality, freedom and autonomy (Bohman & Rehg, 1997; Fraser, 2009; Rawls, 1997). After the Second World War, theories of citizenship have inspired different

right claims among various marginalised groups within and across national contexts, often in dialogue with identity politics entangled with race, class, gender and postcolonial matters (Crane, 2002; Fitzgerald, 2017; Sadiq, 2017; Volpp 2017). Understood along these lines, citizenship is a complex and dynamic concept defined by context and various social factors. However, at a more general level, it may also be understood as a particular relationship between an individual and a state (see also Chapters 1 and 13 in this book), where the former's responsibility includes allegiance, paying taxes and military service in exchange for protection from the latter (e.g., social security and protection by law; Dwyer, 2010). Along these lines, it is common to distinguish between citizenship in the liberal, republican, and social traditions (Dagger, 2002; Delanty, 1997; Honohan, 2017; Turner, 1993a). In the liberal tradition, citizenship is often understood as a legal status that aims to ensure equal opportunities for all citizens (Johansson & Hvinden, 2007, p. 33), and this is often linked to the emergence of modern nation-states (Turner, 1993b, pp. 7–9). This understanding has been particularly prominent in the United States. Republican understandings of citizenship build on key arguments in Rousseau's The Social Contract (1964) by focusing on people's sense of political agency through active participation in deliberation and decision-making (Miller, 2000, pp. 84–87). However, in Europe, citizenship is often understood as a more comprehensive and holistic concept associated with Marshall's social interpretation of the term in the classic essay "Citizenship & Social Class" (1950). Here and in other essays, Marshall theorised citizenship in light of the rise of social rights among working-class people in the UK during the twentieth century (Marshall, 1950; Turner, 1992). Marshall was concerned with citizenship as a right for all citizens and defined it as composed of three different categories, which he called civil rights, political rights and social rights. Civil rights are those rights that are necessary to enhance individual freedom, equality and a sense of justice (Marshall, 1950). Political rights, on the other hand, are defined as rights necessary to exercise political power, such as voting and participation in politics. However, it is the third category, social rights, that has received the most attention from scholars because this interpretation draws attention to people's sense of social and economic security and their ability to participate in society on equal grounds (Edmiston, 2017; Friendly, 2020; Seemann, 2021; Walker, 2016).

Although citizenship is an indispensable concept when trying to understand how politics and social inclusion work, the aforementioned definitions have been criticised for paying little attention to how social citizenship is also conditioned upon emotional and affective structures (Ayata, 2019; Di Gregorio & Merolli, 2016; Fortier, 2016). In the past decade, scholars have criticised citizenship theory for focusing too much on rational arguments and abstract calculations (Di Gregorio & Merolli, 2016; Fortier, 2016). Instead, they have suggested that feelings, emotions and affective engagements are crucial when citizens claim a voice and the appearance of a new subject (Johnson, 2010; May, 2010). One example is Zembylas, who coined the term "affective citizenship" as a concept to study "which emotional relationships between citizens are recognized and endorsed or rejected, and how citizens are encouraged to feel about themselves and others" (2013, p. 6). In another

study, Keegan argued that affective citizenship forces us to move beyond rational analysis of the distribution of rights and duties and focus on "the very boundaries of citizenship that determine who belong in particular places" (2019, p. 348). Following Mookherjee, a turn to affective citizenship simultaneously demands a focus on the emotional mechanisms that enable recognition and voice, or "action," through wooing in the Arendtian tradition (Arendt in Behabib, 2012, p. 54). Mookherjee wrote the following:

Yet absolute contrasts between reason and rights, on the one side, and emotion and affectivity, on the other, have been resisted by influential feminist thinkers, who have convincingly established the interdependence between these categories. . . . Affective citizenship follows their lead by insisting that emotional connections and dispositions support citizens' most important reasons for action . . ., affective citizenship presumes that citizens' structural autonomy is formed not through just one set of affective bonds, but rather through commitments to multiple, intersecting communities.

(2005, p. 37)

Other scholars have used the term to study how the state "govern through affect" (Ayata, 2019, p. 333), and some scholars have explored how different government agencies have developed affective communication strategies to improve dialogue with citizens when they implement new policies (De Wilde & Duyvendak, 2016; Johnson, 2010).

However, although affective citizenship has been used in multiple ways, our focus is mainly on how it enables an in-depth analysis of how citizenship is experienced as affective in subjective experience within the families of disabled children. This conceptual focus allows us to study how tears, anger, frustration and other affective ramifications may be triggered when people have a sense of citizenship hampered and no longer enjoy autonomy or equal societal participation. More importantly, a turn to affective citizenship suggests that such experiences are entangled in different social structures because it invites an analysis of how the affective ramifications described above may hamper other relationships within the family and between the users and providers of welfare services. In addition, an analysis informed by affective citizenship can illuminate what feelings and emotional articulations are accepted or not by gatekeepers in the welfare administration and how emotional self-regulation constitutes an important part of the everyday life of families with disabled children. Before we explore affective citizenship empirically through qualitative interviews, it is crucial to briefly describe our use of the data and methods.

#### Data and methods

This chapter draws on semistructured qualitative interviews carried out in January 2021 with eight self-recruited parents with children with disabilities. The interview data were produced as part of a commissioned research project that aimed to understand the consequences that the closure of welfare services during the pandemic had for families with disabled children (Bøhler & Ugreninov, 2021). The eight informants (three men and five women) included two parents with immigrant backgrounds and six native Norwegians. They covered a diverse socio-economic landscape, including high- and low-income families, and had varied academic experience and training. All eight informants signed informed consent forms before the interviews, which were carried out on Zoom, recorded and later fully transcribed. To ensure compliance with the research ethics guidelines, the consent form and interview guide were reviewed and approved by the Norwegian Centre for Research Data.

To enhance comparisons across the qualitative data, all the interviews followed a semistructured interview guide (Kvale, 2008) organised around key questions that examined the child's participation and everyday life during the pandemic. Although all interviews followed the same interview guide, they were also shaped by the internal dynamics of the social interaction between the interviewer (Bøhler) and informants and varied in length (some lasted an hour, others almost two hours). Here, we briefly introduce and describe the interviews subject to an indepth analysis.

In our analysis, we have focused on three interviews subject to in-depth analysis and interpretation that have been informed by our conceptual framework. We decided to focus on these four interviews because they highlight the affective ramifications of the pandemic in multiple ways.

The following is a short description of the three informants using pseudonyms:

- Jens was Thea's father. Both he and Thea's mother were home during the pandemic to assist Thea in her education and everyday life. Thea was 15 years old and had multiple disabilities.
- Turid was Therese's mother and lived with her husband and two other children. Therese was ten years old and had multiple disabilities.
- Stine was the mother of Jonas, who was 14 years old, and Margrete, who was eight years old; both children were disabled. Both Stine and her husband worked. Both Jonas and Margrete had significant disabilities.

Taken together, these informants provided rich data with which to explore how children with disabilities were impacted by the new educational environment of the pandemic. More importantly, an in-depth qualitative analysis of the affective causes and consequences they experienced with regarding citizenship during the pandemic sheds important new light on how social exclusion mattered during the pandemic. Here, we apply the presented theoretical arguments to analysis.

#### Affective ramifications: "Moses was better off in the desert"

One of our informants, Stine, argued that the pandemic had put the whole family in a precarious situation:

Those 40 days, from the 12 March to the 20 April 2020, were like being in hell. Moses was better off in the desert. Everything stopped. Special education for the children disappeared. Health services disappeared. Everything. . . . The digital competence of the main teacher was not present, so digital home-schooling did not work. It was chaos, and we were the ones who had to bear the cost.

Stine's daughter, Margaret, was ten years old and had multiple disabilities. The pandemic turned her life upside down and put pressure on the family because special education, physiotherapy and other social services were placed on hold because of contamination measures. Stine's argument that "Moses was better off in the desert" and her description of the first 40 days as a "nightmare" illustrate the affective costs of the pandemic. Feelings of stress and anxiety made Stine insecure about the future, and this added further to the burden. The lack of support during this time led to feelings of resentment towards the state because she felt socially excluded by the Norwegian welfare apparatus. Similar stories were found among the informants. Another example is Turid, who argued the following:

Therese [Turid's daughter] had a very nice network around her [prior to the pandemic]. She had a speech therapist, physiotherapist, occupational therapist, assistants who helped and various doctors and specialists who contributed. But then, it all fell apart on the 13th of March. . . . It felt a bit like Norway panicked. Life and health were paramount for everyone. . . . We asked if we could get an assistant, but then NAV [the Norwegian Welfare Administration] said, "No, you won't get that, you are not two parents who are in a critical social function." When we asked about the assistant again, they said by email, "Do you really want to expose the assistant to this risk of infection?" It was COVID that mattered. Our children were of low priority. It was as if every time we asked about something, we were ruining the goal of "saving lives." We were not met with understanding. There was constant talk about the critical functions of society. We are not seen or heard. Our needs are secondary. It makes me cry, just talking about this. It is very heavy. [She cries a little, and we take a short break in the interview]. We were very much left to ourselves. If we hadn't had a good relationship, it would have gone badly. My husband and I argued a lot about where we should sit in the apartment. All four needed to be at home under the same roof, and the apartment is not that big. My husband and I also constantly had discussions about who should drop out of today's work meeting. Stress, stress, stress and stress. It was too much of a burden.

Turid's quote elaborates on Stine's arguments by underscoring the feedback loops between the social and affective costs of the pandemic. According to Turid, the system that provided and coordinated different social services, which used to work well, showed no understanding or empathy for Turid when she asked for additional help. In her own words, "It was all about saving lives, [...our] children were not

prioritized." Those experiences were emotionally difficult to handle and were part of the reason why Turid started crying during the interview as she recalled a very difficult time. In short, the precarious situation Turid was in generated further anxiety about the well-being of the family at large and instigated arguments between Turid and her husband. The repetition of the word "stress" at the end of the quote encapsulates these affective costs. "Stress, stress, stress, stress." As Turid's story illustrates, stress was both personal *and* socially mediated. The stress she felt came from both the wider shutdown of social institutions and the particular emotional situation of their family. As such, this illuminates how her sense of precarious citizenship was part of a broader "political economy of affect" (Fortier, 2016) and the product of multiple "affective bonds" (Mookherjee, 2005, p. 37) that interacted in feedback loops and hampered the well-being of Turid and her family. Turid's narrative illuminates how perceptions of affective citizenship are socially mediated by multiple factors. These interactions added further to the burden. However, Turid was not alone.

All the informants reported strong emotional costs related to the lack of services and what many regarded as systemic neglect by the welfare apparatus. However, these affective experiences had to be articulated in particular ways; if not, you would not get support, as Jens, one of our informants, argued. According to Jens, you had to be able to manage your sentiments when talking with welfare service providers:

We are very cooperative. We must be. I have an angry friend who has a disabled daughter. He gets angry. But you won't get anywhere if you're angry. You can cry, but you can't get angry. The welfare administration accepts tears but not anger. You can't get mad. Then, you don't get anything.

Jens' observation is thought-provoking. We know that families with disabled children have to work hard to get the support and services they need and are entitled to (e.g., Gundersen, 2012; Riksrevisjonen, 2021; StimuLab, 2021). Strong emotional costs are related to such battles. Along these lines, Jens' argument is intriguing. The welfare apparatus allows for crying but not anger. This shows how "individuals are affectively governed by others (e.g., the state, fellow citizens, social and political organizations) through the creation of particular emotional relationships" (Zembylas, 2013, p. 7). Jens' story illuminates how experiences of citizenship, or the lack of it, are always affective in practice because it entails "an economy of feelings where some forms of interaction are given more value than others" (Fortier, 2010, p. 20). Anger is a disqualifier, Jens argued: "If you show anger, you get nothing." However, "the welfare administration accepts tears," he argued. Although studies have suggested that tears may generate empathy and a sense of compassion among welfare service providers (Gibson & Martin III, 2019), research has suggested that anger is a less productive communicative strategy (Lareau & Calarco, 2012). In short, people seldom get what they want when they express anger in meetings with bureaucrats and social service providers. Still, feelings of anger are common reactions when people with disabilities and their families are in a constant fight with the system to get the services they are entitled to by law to exercise full citizenship (Halvorsen et al., 2017).

## Concluding remarks

The aim of this chapter was to explore the affective ramifications of being excluded from social services and healthcare during the pandemic through an analysis of interviews with parents of children with disabilities. We analysed the interview data through the lens of "affective citizenship", which draws attention to the emotional costs of social exclusion and their different social mediations. Three lessons can be learned from the study. First, the pandemic turned the life situation of families with disabled children upside down, as illustrated in Stine's words: "Moses was better off in the desert. . . . Those 40 days, from 12th of March to 20th of April 2020, was like being in hell." Stine's statement clearly shows the strong affective ramifications of being excluded from social services and education during the pandemic. It made an already difficult situation harder, and this emotional burden put further pressure on family work, logistics and social life, among other things. In a sense, the burden doubled. One aspect of this was not getting a service to which one was entitled. Another factor was the emotional stress, anger and feelings of abandonment that this exclusion generated. According to Stine, it placed families with disabled children in a state of emergency that hampered their sense of citizenship because they could no longer enjoy autonomy or participate in society on equal grounds.

Second, such affective ramifications were socially mediated in complex ways: Stine, Turid and Jens described how it influenced their relationship with their partner, their performance at work and the caring they were able to give to other children. Recalling these experiences less than a year after they happened was so troublesome that Turid started crying during the interview and repeated one word four times: "Stress, stress, stress, stress." Tears and stress were central in their story because they were situated in multiple "affective bonds" (Mookherjee, 2005, p. 37) during the pandemic (e.g., the aggregated affective causes of working from home, restrictions of public space, closed cafés and fear of the pandemic, among others).

Jens gave us a third lesson when he described the importance of emotional self-regulation when he met with welfare providers. He argued that you had to align your socio-emotional strategies with that of the welfare professionals to increase your chances of being granted services. Jens' argument illustrates how particular forms of affective governance are operative within the welfare apparatus, where crying is allowed, but not anger. However, feelings of anger are common reactions when marginalised individuals do not get the rights and services they are entitled to by law. More importantly, these individuals should be the key target of social welfare benefits and not excluded through tacit forms of affective governance that censor anger but accept crying.

All three lessons support the argument that citizenship should not be viewed exclusively as an allocation of rights and duties. Instead, our analysis reminds us that citizenship is a complex and dynamic concept defined by subjects, contexts and

various social factors, including affective ramifications of different kinds. When people are devoid of social services and healthcare, their experiences of exclusion are always affective. Still, frustration, tears, anger and sadness are usually not the topic of citizenship research, which tends to foreground (non-affective) rational actors, an analysis of legislation and social policy, broader social structures and the allocation of rights and duties, among others.

The presented findings – and the aforementioned concept of affective citizenship – are perhaps better understood in light of the recent "turn to affect" across the humanities and social sciences, which has created a renewed awareness of how affect shapes citizens, citizenship and politics more broadly (Fortier, 2016; Kim & Bianco, 2007). Our study adds to this trend and reminds us that barriers to citizenship are always affective for those who are involved.

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