How Did Children With Disabilities Experience Education and Social Welfare During Covid-19?

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Submitted: 10 June 2022 | Accepted: 12 September 2022 | Published: in press

Abstract
Research suggests that children with disabilities have been systemically marginalised during the Covid-19 pandemic as contamination measures complicated some social policies. School closure, quarantine, and the increased use of social media in remote schooling have placed children with disabilities in a vulnerable situation. This article explores the subjective consequences of such processes through the analysis of qualitative interviews with parents who had children with disabilities. To contextualise our analysis, we also draw on expert interviews with bureaucrats and social workers and data from a survey that was sent out to parents who had children with disabilities. Taken together, these data sources provide a rich empirical context to study how the pandemic influenced the access of children with disabilities to education and social services in Norway. We also pay attention to how the pandemic influenced parents’ perception of social welfare in Norway and discuss how issues of race, class, and socio-economic background were reflected in their experiences. Both interview data and survey data were gathered during the pandemic. Conceptually we take inspiration from the capability approach with a particular focus on theoretical work on “conversion factors.” These theoretical perspectives invite us to identify and analyse specific mechanisms that prevented and/or enabled children with disabilities to live a life according to their own visions and values during the pandemic. Through this study of how children with disabilities experienced education and social welfare in Norway during the pandemic, we shed new light on how one of the world’s most advanced welfare states operates during a time of crisis.

Keywords
capability; children with disability; education; Norway; pandemic; social welfare

1. Introduction
Research suggests that children with disabilities have been systemically marginalised during the Covid-19 pandemic as contamination measures complicated some social policies (Asbury et al., 2021; Ferguson, 2021; Nøkleby et al., 2021; Orsander et al., 2020). School closure, quarantine, and increased use of social media in remote schooling have placed children with disabilities in a vulnerable situation (Orsander et al., 2020). This article explores the subjective consequences of such processes through the analysis of qualitative interviews with parents who had children with disabilities in Norway. To contextualise our analysis, we also draw on expert interviews with social workers and welfare bureaucrats working in the field. In addition, we analyse data from a survey...
welfare in Norway during the pandemic, we hope to shed light on how one of the world's most advanced welfare states operates during a time of crisis. Together with Iceland, Norway had the lowest Covid-related mortality rates in Europe during the pandemic and among the lowest mortality rates in the world (Karlinsky & Kobak, 2021; Wang et al., 2022). While changes in mortality rates are the product of complex processes, some studies suggest that pre-existing healthcare policies in Norway, and the aforementioned mitigation measures (e.g., lockdown, social distance, focus on hygiene), contributed to a general decrease in influenza, infections and other illnesses which influence mortality on an annual basis (Helgeland et al., 2021; Juul et al., 2022). The influenza virus alone is an important driver of mortality rates in Norway (Gran et al., 2010; Hauge et al., 2019) and internationally (Schanzer et al., 2007; Karlinsky & Kobak, 2021; Wang et al., 2022).

During a press conference on 12 March 2020, Norwegian Prime Minister Erna Solberg argued: “Today the Norwegian government will announce the strongest and most intrusive measures we have ever made in Norway during times of peace. However, these measures are necessary to fight the spread of the virus” (Regjeringen, 2020). All welfare services which involved physical contact between people, and which did not have a critical function for society at large, were shut down to prevent the spread of the virus. As a consequence, the Norwegian Directorate of Health decided to close kindergartens, schools, and educational institutions. Only some healthcare services and institutions, which the government defined as having “critical societal functions,” were allowed to run normally. The prime minister argued that marginalised youth and children, and people with disabilities more broadly, should receive an adequate offer of educational and social services despite the shutdown of large sectors of Norwegian society. However, this was not how NIM, the Norwegian Human Rights Institution, perceived the closure of education and social welfare following the pandemic. In a letter written to the Ministry of Health and Care Services, the Ministry of Modernization, the Norwegian Directorate of Health, and the National Institute of Public Health on 6 April 2020, NIM warned officials about the potential negative consequences of various infection-control measures. They argued that the closure of important social welfare services jeopardised Norway’s social and political commitment to persons with disabilities according to the UNCRPD, which had been signed and ratified by the Norwegian government. Following the convention, Norway was committed to ensuring that people with disabilities enjoy “all human rights and fundamental freedoms.” While Solberg and other politicians kept insisting that the measures should not disproportionately impact marginalised or vulnerable people (Regjeringen, 2021), researchers, disability organisations, and activists have identified a systematic neglect of children with disabilities during the pandemic (Bøhler, 2021; Bossy & Hervie, 2021). One report (Bøhler & Ugreninov, 2021) suggests that children with disabilities were marginalised in multiple ways as contamination measures complicated physical contact with their personal assistants, educators trained in special education, and physiotherapists. Taken together, the shutdown of educational institutions and welfare services complicated 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” (UDIR, 2022). People with disabilities, both young and adult, experienced several barriers that placed restrictions on their ability to partake in society on equal ground with their non-disabled peers.

At a more general level, the present study may be considered a stress test of how Nordic social welfare states, modelled on universalism (Esping-Andersen et al., 2002), work during times of crisis. Through a study of how children with disabilities experienced education and social welfare in Norway during the pandemic, we hope to shed new light on how one of the world’s most advanced welfare states operates during a time of crisis.


During a press conference on 12 March 2020, Norwegian Prime Minister Erna Solberg argued: “Today the Norwegian government will announce the strongest and most intrusive measures we have ever made in Norway during times of peace. However, these measures are necessary to fight the spread of the virus” (Regjeringen, 2020). All welfare services which involved physical contact between people, and which did not have a critical function for society at large, were shut down to prevent the spread of the virus. As a consequence, the Norwegian Directorate of Health decided to close kindergartens, schools, and educational institutions. Only some healthcare services and institutions, which the government defined as having “critical societal functions,” were

(N = 150) that was posted online on the website of key disability organisations in Norway. Taken together, these data sources provide a rich empirical context through which to study how the pandemic influenced the access of children with disabilities to education and social services in Norway. In interpreting these data, we pay particular attention to how the pandemic influenced parents’ perception of social welfare in Norway and discuss how issues of race, class, and socio-economic background were reflected in their experiences. Both interview data and survey data were gathered during the pandemic in 2021.

Conceptually we take inspiration from the capability approach (Sen, 1992, 1993, 2009) with a particular focus on theoretical work on “conversion factors” (Assmann et al., 2021; Bøhler, 2021; Hvinden & Halvorsen, 2018; Robeyns, 2005). These theoretical perspectives invite us to identify and analyse specific mechanisms that prevented and/or enabled children with disabilities to live a life according to their own visions and values during the pandemic. Both the 2006 UN Convention on the Rights of Persons with Disabilities (UNCRPD) and the 1989 UN Convention on the Rights of the Child (United Nations, 1989, 2006) underscore the importance of such theoretical arguments as they draw attention to the importance of organising society in ways that allow persons with disabilities to partake on equal grounds. We argue that the capability approach offers a useful theoretical frame with which to study how children with disabilities experienced education and social welfare during the pandemic as it provides new insights into factors that hampered and/or facilitated structures of social inclusion and exclusion. At a more general level, the present study may be considered a stress test of how Nordic social welfare states, modelled on universalism (Esping-Andersen et al., 2002), work during times of crisis. Through a study of how children with disabilities experienced education and social welfare in Norway during the pandemic, we hope to shed new light on how one of the world’s most advanced welfare states operates during a time of crisis.


Together with Iceland, Norway had the lowest Covid-related mortality rates in Europe during the pandemic and among the lowest mortality rates in the world (Karlinsky & Kobak, 2021; Wang et al., 2022). While changes in mortality rates are the product of complex processes, some studies suggest that pre-existing healthcare policies in Norway, and the aforementioned mitigation measures (e.g., lockdown, social distance, focus on hygiene), contributed to a general decrease in influenza, infections and other illnesses which influence mortality on an annual basis (Helgeland et al., 2021; Juul et al., 2022). The influenza virus alone is an important driver of mortality rates in Norway (Gran et al., 2010; Hauge et al., 2019) and internationally (Schanzer et al., 2007; Karlinsky & Kobak, 2021; Wang et al., 2022).
Simonsen, 1999), and the decrease in influenza during the pandemic may partly explain the low mortality rates in 2020. However, even if mortality rates were low, the socio-psychological costs were high for both marginalised groups (Nesset et al., 2021) and the population at large (von Soest et al., 2022). Several recent studies have elaborated on the contribution of the lockdown and social distancing to an increase in mental illness and loneliness in Norway during the pandemic (Blix et al., 2021; Hoffart et al., 2020; Reme et al., 2022).

Other studies have addressed how these policies hampered the economy, both in Norway and internationally (Ibn-Mohammed et al., 2021). Importantly, we are still recovering from the pandemic as well, and some of its consequences remain to be seen. Therefore, more research is required here.

One of the marginalised groups which were influenced by the mitigation measures consists of children with disabilities (Bøhler, 2021; Bøhler & Ugreninov, 2021). Below, we develop a conceptual framework inspired by capability theory to investigate the extent to which children with disabilities were able to live a life according to their own interests during the pandemic. Such a conceptual framework can shed light on whether the shutdown of important social welfare services jeopardised Norway’s social and political commitment to people with disabilities following the UNCRPD.

4. Capability as a Theoretical Framework

Amartya Sen’s capability theory starts from the premise that every individual should be able to live a life in line with their own needs (Sen, 1992, 1993, 2009). The theory draws attention to a person’s relative freedom and possibilities to live a life according to his or her visions and values in specific contexts. To study how capability operates in practice, Sen (1992, p. 40) developed the related concepts of “functionings,” which are different realisations of one’s sense of capability in specific contexts. Functionings can vary over time and may be influenced by a wide range of what Sen (1981, pp. 26–30) calls “conversion factors.” Conversion factors refer to how people can convert the characteristics of their resources to improve their capability set (Robeyns, 2005, p. 99). In short, conversion factors are the contextual features which shape a person’s sense of capability in practice, and they may be social, personal, material, or made up of other dynamics, depending on the context. The concept refers to the specific interactions between a subject and their environment, as well as the ways in which these interactions influence that subject’s ability to realise their capability. Recent elaborations upon this concept have addressed the fact that conversion factors may both be negative and positive concerning the realisation of capability (Halvorsen & Bøhler, 2017; Hvinden & Halvorsen, 2018).

In recent decades, capability theory has been used widely in the interdisciplinary field of disability studies to underscore the importance of developing educational tools and policies which allow people with disabilities to partake in society as equal citizens (Halvorsen & Bøhler, 2017; Halvorsen et al., 2017; Hvinden et al., 2017)—work often inspired by the UNCRPD, as described above (Sépulchre et al., 2017). Sen himself has often used people with disabilities as an illustrative case when arguing for the importance of developing special educational policies and practices, as well as different forms of social security and welfare services (Nussbaum & Sen, 1993; Sen, 1994). Universal design, for example, improves the sense of capability for persons with mobility impairments and allows them to participate in society on equal terms with their non-disabled fellow citizens.

In the following analysis of qualitative interviews and survey data, we draw on capability theory as a conceptual frame to look at how positive and negative conversion factors facilitated or hampered social welfare and education for children with disabilities during the pandemic. First, however, we will outline data sources and methods which were used in the present study.

5. Methods and Data

Our data sources consist of eight semi-structured qualitative interviews with parents who had children with disabilities (8–15 years old) and 28 expert interviews organized as semi-structured, together with a survey (N = 150) posted online on the websites of important disability organisations in Norway. The survey was designed for parents of children with disabilities and 150 people responded.

The study was approved by the Norwegian Centre for Research Data (NSD) and follows all national requirements with regard to the handling of research data. Due to NSD regulations and the General Data Protection Regulation, we were not able to interview the children themselves, as the understandably extensive permission process was not possible to undertake within the timeframe of this study. It is also true, however, that some studies suggest that in-depth qualitative interviews with parents can still provide important insights into children’s educational experiences (Brett, 2002; Wiart et al., 2010). Parents provide the perspective of an adult “third person” and shed light on mechanisms and aspects of the educational experience which are difficult to grasp from the viewpoint of the children themselves. More importantly, the new home-school context propelled by the pandemic created new relationships between parents and children with disabilities that are important to explore in detail because many parents acted as teachers, mentors, and supervisors for their children. The eight informants (three men and five women) included two parents with immigrant backgrounds and six native Norwegians. They encompassed a diverse socio-economic landscape, including high- and low-income families, as well as a range of academic experience and training levels. Five of the
interviewees had pursued higher education and secured permanent employment. During the interviews, they gave the impression of being relatively well-off. Three of the interviewees had not completed higher education and had fewer resources. Two of the interviewees lived in a relationship where one parent or both parents stayed home to take care of the child. One interviewee was divorced and lived with his new girlfriend; another was a single mother. All informants self-recruited after we posted an invitation to participate in the research project on websites frequently visited by people with disabilities. They also signed an informed consent form before the interviews, which were carried out on Zoom, recorded, and later fully transcribed. To enhance comparisons across the qualitative data, all the interviews followed a semi-structured interview guide (Brinkmann & Kvale, 2018) organised around key questions that explored their experience with social welfare and education.

While all the interviews followed the same interview guide, they were also shaped by the internal dynamics of the social interaction between the researchers and the informants and varied considerably in length (some lasted an hour, others almost two hours). While capability theory did not inform the interview guide as such, we explored it both explicitly and implicitly through follow-up questions linked to that guide. Below, we briefly introduce the key informants and their children. In our analysis of the research data, we focus mainly on quotes and fragments from the interviews which shed light on how children with disabilities experienced social welfare and education during the pandemic. However, we also discuss how these experiences were intertwined with issues of race, class, and socio-economic background, and discuss parents’ perceptions of social policies during the pandemic. As part of our analytical strategy, we also paid attention to how capability theory, defined as the children’s ability to live a life in line with their own views, values, and visions during the pandemic, manifested during the interviews.

6. Characteristics of Key Informants, Sampling Criteria, and Analytical Strategies

In our analysis, we focus particularly on three interviews with parents of children with disabilities. To anonymise the informants, we use the following pseudonyms:

- Farah was Maria’s mother and was single. She had arrived in Norway from East Africa already pregnant and had very poor economic circumstances, relying on student loans and social support from the government while she studied to become a secretary. Maria was nine years old and went to a special school and had multiple disabilities (both physical and cognitive).
- Ada was Grete’s mother. Ada had been staying home to take care of her daughter since 2018 while her husband worked; the family was well-off. Grete was nine years old and had multiple disabilities (both physical and cognitive).
- Turid was Therese’s mother and lived together with her husband and two other non-disabled children; the family was well-off. Therese was 10 years old and had multiple disabilities, both physical and cognitive.

These informants represent three different socio-economic strata of Norwegian society. Ada is representative of upper-middle-class families, as her family enjoyed a good income which allowed for one parent to remain at home. Turid is representative of a typical middle-class family in which both parents work. Farah brings with her the experiences of economically marginalised single mothers with immigrant backgrounds who rely on support from the Norwegian welfare administration. By analysing and comparing these three narratives, we hope to gain insight into how class and socio-economic background were intertwined in how children with disabilities experienced education and social welfare during the pandemic. Such a perspective is important because a growing body of evidence suggests that differences in socio-economic background have increased in Norway (Hansen & Strømme, 2023; Hansen & Toft, 2021) and across the Nordic countries (Jonsson, 2004) in recent decades. In addition, new flows of migration and increased globalisation have placed Oslo among the fastest-growing cities in Europe, with an immigration rate which has increased from under 10 percent of the population in the 1990s to over 33 percent today. More importantly, some studies suggest that people with immigrant backgrounds face more economic hardship and discrimination in the labour market than Norwegians without immigrant backgrounds (Midtbøen, 2014; Reisel et al., 2019), thus adding evidence to theories about the interplay of race and class in modern societies. In addition, some studies suggest that socio-economic differences increased in Norway during the pandemic because vulnerable population groups which relied heavily on social welfare services found themselves yet further marginalised (Blikstad-Balas et al., 2022; Reme et al., 2022). In-depth interpretive analysis of the ways in which Ada’s, Turid’s, and Farah’s children experienced education and social welfare during the pandemic and the extent to which they were able to live a life according to their own visions can provide important insights into how children with disabilities experienced the pandemic.

7. Additional Data from Expert Interviews and Survey

While these three interviews constitute the primary focus for our analysis, we also rely on other data sources, such as survey data and additional expert interviews, that help to contextualize our interpretation and provide a deeper understanding of the situation. One of these was an expert interview with Fakhra Salimi, the Pakistani-Norwegian activist and expert on minority politics, black
feminism, and social exclusion. Salimi was awarded the Ossietzky Prize of PEN (poets, essayists and novelists) from Norway in 2005 and the prestigious St. Halvards medal in 2015 for her ground-breaking work on the rights of women with immigrant backgrounds and black feminism more generally. She is a prominent and outspoken intellectual in the public sphere in Norway and presently leads the MiRA Center: Resource Center for Black, Immigrant and Refugee Women. Our discussion of the key interviews with Salimi inspired important additional interpretations which we include below. We also analyse an interview with Aiden, who worked in the implementation of social services for the Norwegian Welfare Administration during the pandemic. This interview brought nuance to our analysis by providing insights into the complex factors that influenced the management and allocation of social welfare services in practice.

One challenge with qualitative interviews is that they offer limited possibilities for generalisation as interpretations are often based upon a small number of in-depth observations. One way to overcome this is to combine in-depth qualitative interviews with the analysis of survey data (Woolley, 2009). We, therefore, complemented the aforementioned qualitative interviews with a survey sent to crucial disability organisations in Norway which posted the survey on their websites and, in some cases, sent it out through email lists. The survey arose from a pilot study, a critical review of the literature and discussions with experts in the field. The target group consisted of parents who had children with disabilities; respondents had to be over 18 years old. In all, 150 respondents completed the survey, most of whom (87 percent) identified as Norwegian with no immigrant background. In addition, 71 percent of the respondents were mothers of children with a functional impairment, and only 9 percent were fathers. Twenty-six percent of the respondents had children with disabilities in kindergarten, 41 percent had children in primary school, and 31 percent had children in secondary school. The survey consisted of 20 questions concerning how the pandemic influenced the access of children with disabilities to social services. In our analysis of the survey data below, we focus particularly on questions exploring parents’ experiences with access to social services before and after the pandemic, respectively.

Because we have gathered and analysed both quantitative and qualitative data (with a focus on the latter), our research design is firmly situated within the growing field of mixed-method research (Hesse-Biber, 2010).

8. Social Welfare Programs Were Shut Down Due to the Pandemic

The survey clearly revealed that children with disabilities experienced decreased access to social welfare programs after the pandemic. Figure 1 shows how many parents who argued that their children’s access to social services was severely hampered by infection-control measures:

Further inquiry clarified the ways in which the pandemic complicated the access of children with disabilities to personal assistance, care assistance, support at school, physiotherapy, home care support, and other social services (see Figure 2).

As illustrated in Figure 2, some social welfare programs were almost completely shut down during the pandemic (e.g., care assistance, which went from 28 percent to 0.7 percent), whereas others were substantially reduced (home care assistance, which went from 21 to 2.7 percent). Overall, the trend was toward less access to everything.

The qualitative interviews indicated this same trend, as in the following quote by Turid, Therese’s mother:

Therese was surrounded by a great network prior to the pandemic. She had a speech therapist, a physical therapist, an occupational therapist, and an assistant who helped out. In addition, various physicians were involved. But then all of this collapsed on March 13 [2020]. It was very hard. The pandemic made our situation chaotic….The specialised teacher tried to organise teaching online through digital platforms, but it didn’t work. Because our life became so difficult,

Figure 1. Parents of children with disabilities who experienced severely hampered access to social services during the pandemic (N = 150).
we asked NAV [the Norwegian Labour and Welfare Administration] if we could have an assistant, but NAV responded: “No, you cannot, because your jobs are not critical to society.” When we asked again, they said: “Would you really expose the assistant to the risk of getting the virus?” Covid was the most important thing. Our children were neglected. It felt like we were putting the lives of others at risk every time we asked for the support that we needed. We were not seen nor heard. Our needs were of secondary importance. It almost makes me cry when I talk about this. It was very hard [she cries for a bit, and we take a short break from the interview]. We were to a large extent left to ourselves. It would have ended badly if we didn’t have a good relationship [referring to Turid and her husband]. We argued a lot about who should sit where. All four of us had to stay at home, under the same roof, and the apartment is not very big. And me and my husband constantly discussed who should skip today’s work meeting. Stress, stress, stress, and stress. It was too much!

Turid’s quote illustrates the social and affective costs of the pandemic, before which she felt that her family had been taken care of by the Norwegian state and its various social welfare programs. Turid’s sense of the pre-pandemic system is echoed by the many studies that point to high levels of satisfaction with the social welfare programs in Norway as opposed to other states (Andress & Heien, 2001; Esping-Andersen et al., 2002), and to a general sense of social trust between citizens and the state (Christensen & Lægreid, 2005; Miller & Listhaug, 1990). For Turid, at least, this all changed during the pandemic, when she felt that her daughter was “neglected” by the system and that her family’s needs “were of secondary importance.” This difficult situation generated anxiety about the wellbeing of the family as a whole and even started arguments between Turid and her husband. The repetition of the word “stress” at the end of the quote captures these affective costs, as Therese, Turid, and their family could no longer live a life they had reason to value.

9. Interviews With Social Workers Reveal New Complexities

Professionals working in the field such as Aiden echoed Turid’s argument:

Researcher: How do you think the lockdown affected families with children with disabilities? Did they get the support they needed?
Ana’s observation that all children were affected by the pandemic has been borne out by recent studies in education (Azevedo et al., 2021; Blikstad-Balas & Klette, 2020; Bubb & Jones, 2020) and childhood research (Bryant et al., 2020). Other studies likewise indicate that children with disabilities suffered the most because the social services on which they relied were no longer available (Bøhler, 2021; Bøhler & Ugreninov, 2021; Greenway & Eaton-Thomas, 2020). More importantly, the increased use of social media during pandemic-driven home-schooling placed children with disabilities in a particularly vulnerable position by enabling new social hierarchies and forms of exclusion, as Turid points out:

One problem seemed to be that the teacher was not able to organise and handle the new digital classroom—for example, both socialisation after class and talking in class were very chaotic. They organized a “class chat” [klassechat] with the aim that everybody should talk with each other. But it was complete chaos. The teacher struggled with this concept. She tried to say to the children: “Everybody has to talk to each other, and everybody should be included.” However, it became clear that the most popular children dominated the conversation. In this context, Therese struggled and was excluded. Therese struggles to understand the social codes of social media—she posted things that others didn’t understand, or that they disliked, and she was sad and disappointed. We, as parents, would like to have some guidance with regard to how children with disabilities like Therese can use these social media platforms, [so as to] avoid social exclusion. What digital social codes do you have to follow as a nine-year-old kid on Facebook? And what should be done so that children with disabilities can participate on social media and avoid exclusion? What does she need to know socially, on social media, to be part of the class? There are several great digital platforms available, but we should also have some guidance with regard to the use of such platforms. If not, these new digital social spaces can be new spaces for bullying and social exclusion. I miss more guidance from the school.

Toward these important ends, public institutions should develop guidelines, policies, and models for teachers so that they can create a socially open and healthy environment online. Teachers must also establish a sense of order and ethics related to children’s interactions on social media platforms to avoid chaos and social exclusion. Several studies have elaborated on how social media, and digital technology more generally, can lead to new forms of social exclusion of people with disabilities (Bøhler & Giannoumis, 2017; Bøhler & Ugreninov, 2021). In light of capability theory, such conditions may be theorised as negative conversion factors because they hinder the ability of people with disabilities to participate fully in society. More importantly, these conditions complicate
the implementation of the UNCRPD (The Convention on the Rights of Persons with Disabilities) and the UNCRC (The United Nations Convention on the Rights of the Child), both of which underscore the importance of organising society in ways that enable the full recognition and integration of children with disabilities at all levels.

11. Intersectional Capabilities During Home-Schooling: Race, Class, and Socio-Economic Background

The interviews also indicated that white ethnic Norwegian couples with middle-class backgrounds in which only one of the partners worked were able to dedicate more time to the educational support of their children than couples of other races, classes, or socio-economic backgrounds. The following quote by Ada, who had been out of work since 2018 to help her disabled daughter while her husband continued to work, captures this situation:

You know, we have been living quite isolated for two and a half years now [since she quit her job], so, in a sense, we were used to this situation of the pandemic. But all this was only possible because I was at home and could dedicate time and care to our daughter, while my husband worked. We could afford it. I could assist her in home-schooling....In the beginning, it was very difficult, but then we started to structure our own school at home. We often started with two classes in Norwegian. Then one class in English. After every class, which lasted 45 minutes, we had a 15-minute break and a longer break during lunch. It was just like the school. First one more class in mathematics. Afterward, we had a class for physical exercise, followed by [classes in] science and social science education. We used the timer on the smartphone to organise the day. We tried to follow the teaching plan provided by the school. In our home-school the bell rang for break-out time [smiles]....In retrospect, I actually think Grete learned more during this period of home-schooling than at the ordinary public school. In mathematics, we were able to go through all the curriculum for the second grade and even spent some time on the third-grade curriculum. We were also able to get quite far in the science and social science curriculums. I think we were very creative. But there was one cost. I had to dedicate all my time to following up. For example, sometimes we followed the teaching plan provided by the school, and other times I had to be creative and rearrange and organise the teaching material in new ways....However, we got little support from the school and the teachers. I am very glad I had the time and energy to act as a substitute teacher. If not, I think Grete would have struggled a lot during this period.

Here, we see that the physical school itself, as well as the support from assistants and special education teachers, were not part of Grete’s life due to infection-control measures. Thanks to her circumstances, however, Ada was able to serve as Grete’s “substitute teacher” while both were stuck at home. While this may have been to Grete’s advantage in the end, this was not an option many families enjoyed during this time, and, indeed, studies have pointed to the complex ways in which socio-economic background can shape learning outcomes even outside of pandemic conditions (Holmes-Smith, 2006; Tieben & Wolbers, 2010; Perry, 2012). In families where both parents worked, for example, it was much harder to adapt to pandemic-driven restrictions to educational resources and life in general, as we see in Turid’s tears and emphasis on “stress, stress, stress, stress.”

As a native Norwegian, however, Turid was at least able to voice her frustrations with the system and communicate with representatives of the welfare apparatus and school in her mother tongue. She also knew how the system worked and what she was entitled to, and she could file a complaint when necessary. For Farah, who was black and had arrived in Norway as a single mother and refugee from East Africa, it was more difficult to contend with such circumstances. Farah had lived most of her adult life in East Africa and was less familiar with the Norwegian welfare state and school system as the pandemic brought about its changes in her daughter’s education:

Everything became very difficult because of the shutdown of public transportation and the school and all of it. For me, it was particularly difficult, as I am in the process of learning Norwegian, and it is difficult for me to communicate with NAV and the school system. I am very grateful for the support I get, and I think the special school for my daughter [who has disabilities] is amazing, but during the pandemic much of this was placed on hold. Also, I am alone, and I must take care of my daughter even though we live on a student loan and with support from NAV....When the school closed, I had to do everything. But I am no teacher. I am a single mother. I study Norwegian and [study] to become a secretary....It was difficult. The home-schooling had a strong impact on Maria [her daughter]. She loves her school, and she loves her friends there. Maria enjoys the music classes, the social interaction, and all of that. But she hates social media, iPads, and computers. She wants physical contact with teachers and students. Social interaction. It was very hard for me to deal with all of this. Most of the assignments they gave us from school did not work. However, some did, particularly the ones that were more practical. For example, yesterday we got the assignment of going out in the woods to find a beautiful flower that we should take a picture of and then learn about. That was very enriching. However, the pandemic-school situation made everything unstable. First it was this,
then it was that. It was hard to deal with for Maria, as she needs stability. It is part of her diagnosis. She hates disruptions.

While the pandemic clearly hampered her daughter’s ability to cope with the world, Farah still saw the value (literal and figurative) of the Norwegian welfare apparatus, which perhaps provided her with better social services than what she was used to in East Africa. In contrast, both Ada and Turid criticised what they saw as the systematic neglect of children with disabilities in Norway during the pandemic. When we discussed this discrepancy with Fakhra Salimia, a leading activist in the field, she framed Farah’s perspective within what she called the “depth of gratitude” one often encountered among mothers with immigrant backgrounds:

I think many immigrant and refugee families often express a strong sense of “depth of gratitude” [takknelemhetsgjeld] because they compare the Norwegian system with their countries of origin—for example, Pakistan, Somalia, or elsewhere—where the social welfare benefits are almost non-existent. Therefore, many tend to be very grateful in terms of what they receive here. However, this is problematic, because we know that, in order to get a number of welfare benefits, you often have to struggle [first] and prove that you are entitled to these benefits. The “depth of gratitude” sometimes prevents many from applying, or fighting, for their genuine welfare rights. In addition, many immigrant and refugee women have limited knowledge about the benefits provided by the Norwegian welfare state and the school system, so they don’t know what to expect. Norway is a welfare state and compared to many other countries we have generous welfare benefits. This became very clear during the pandemic. It is therefore very important that all citizens have access to the same benefits regardless of their immigrant or refugee status. There are many women who do not get adequate help and we are working daily to help these women in accessing their rights within the welfare system. I think that it is very important to make it clear that equal rights are not some charity [that] the government is doing for us immigrants. The person in your interview [Farah] is overwhelmed by this depth of gratitude and is not aware of the fact that these are her rights. I meet many women like her through my work, and it is our responsibility to inform them that they are Norwegian citizens and thereby eligible for equal rights.

While it is difficult to find strong empirical evidence for this “depth of gratitude” hypothesis, research carried out by the MiRA Centre where Salimi (2004) works, as well as several other studies (Hagelund, 2005; Næss & Moen, 2015), suggest that immigrants indeed know less about the welfare rights to which they are entitled than native Norwegians. Translated into capability theory, we can say that proficiency with the Norwegian language and familiarity with the Norwegian educational system and welfare state are perhaps the most important conversion factors hindering Farah and Maria from living a life following their own needs, values, and visions during the pandemic. If the Norwegian welfare state, including its educational structures, is most accessible to the white native-Norwegian middle class and less accessible to Norway’s most vulnerable citizens (for example, black immigrant single mothers with children with disabilities), this represents a racial bias that is important to address in future studies and policy development. In any case, we can see that race, education, language, and economic resources contribute as conversion factors to a negative feedback loop that constrains the sense of capability in, for example, a black Norwegian woman and her child with disabilities.

12. Conclusion

The aim of this study was to explore how children with disabilities were influenced during the pandemic, with a particular focus on social welfare and education. We focused on the in-depth analysis of semi-structured interviews carried out with parents who had children with disabilities. Findings from our analysis suggest that pandemic home-schooling impacted families differently depending upon their socio-economic and ethnic backgrounds. Well-off families which could afford to have one parent stay at home were less affected than those who had to work and help their children with disabilities at the same time. The virtual schooling situation was also particularly challenging for parents with immigrant backgrounds who might find it hard to communicate with the school and teachers, as well as the relevant parts of the welfare system. Scarce economic resources probably added further to these parents’ burdens. This placed single mothers and parents with few resources and/or immigrant backgrounds in a vulnerable situation as they struggled to make ends meet while simultaneously taking on the new responsibilities of home-schooling. Another finding from our study was that the new virtual classroom was seen as chaotic by many, and this further marginalised children with disabilities, who experienced trouble in terms of handling social codes online. In short, digital schooling created new forms of social exclusion that need to be studied more deeply and systematically.

Acknowledgments

We would like to thank the editors of this thematic issue, as well as the three anonymous reviewers who have commented on and provided well-founded and constructive critiques of an earlier draft. This has allowed us to substantially improve the article. Our sincere thanks also go to Norwegian Social Research (NOVA) and OsloMet for giving substantial support throughout the research.
process. We want to give a special thanks to Janikke Solstad Vedeler, section leader at NOVA, as she has provided substantial support throughout the process. We also want to thank the Norwegian Directorate for Children, Youth and Family Affairs for funding the initial research, including the data-gathering, as this empirical material and initial interpretations serve as the basis for this article. Lastly, we want to thank our informants who have shared difficult stories during a challenging time. This study would not have been possible without your participation.

Conflict of Interests

The authors declare no conflict of interest.

References


J. Tøssebro, & A. Waldschmidt (Eds.), *Understanding the lived experiences of persons with disabilities in nine countries: Active citizenship and disability in Europe* (pp. 174–191). Routledge.


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