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# Social class, disability, and institutional interactions: the case of families with disabled children in the welfare state

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## ABSTRACT

Research on families with disabled children has highlighted how such families experience frustration in their encounters with health and welfare services. However, less attention has been given to how these encounters are linked to social class. This article explores whether levels of cultural capital and family resources influence communication with professionals among parents of disabled children. To this end, I draw upon a longitudinal qualitative dataset of fieldwork and interview data from families in Norway. The findings show that middle-class parents could utilize experts, keep communication smooth, and persist in trying to secure services for their children without any real sense of achievement to a higher degree than working-class parents. However, neither working-class nor middle-class parents thrived in navigating these bureaucracies. This study has clear implications for policy and professionals in acknowledging how levels of cultural capital and other family resources influence the ability to endure and navigate welfare institutions.

## ARTICLE HISTORY

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## KEYWORDS

Cultural capital; disability; health and welfare services; parents; social class

## Points of interest

- To understand the situation of families with disabled children it is important to find out under which circumstances these families try to obtain public services for their children.
- The paper examines the significance of social class on how parents with disabled children manage welfare services for their children in Norway.
- The research uses interviews with parents and practitioners and observation of meetings.
- All parents fight for services for their children and find it frustrating.
- Working-class and middle-class parents differ in how they communicate with professionals and how they deal with frustration.

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## Introduction

Families with disabled children have extensive contact with public agencies. Paradoxically, public agencies designed to support and lessen the burden of extensive care are often experienced as a heavy burden by these families (Green 2007; Runswick-Cole 2007; Kittelsaa and Tøssebro 2014; Thomas 2021). However, little is known about how these encounters are linked to social class, as the intersection of disability and social class has not been well explored in previous research (Jenkins 1991; Shakespeare 2011; Chatzitheochari, Velthuis, and Connelly 2022). Exploring this intersection is essential to understanding how social class shapes the lives of families with disabled children and to further comprehend how social class is related to institutional encounters. This is particularly interesting to explore in the context of Norway, where social welfare is high and less dependent on financial resources.

This article explores the ways in which class-based cultural repertoires are utilized in interactional processes in institutional encounters by using a longitudinal qualitative study of families with disabled children and their public service coordinators in Norway. I use Bourdieu's (1986, 1989) concept of cultural capital to explore how agents may exploit cultural capital in their communication with welfare services. I ask: How is cultural capital mobilized and utilized by parents in their interactions with professionals in welfare services? By exploring this, the article attempts to make a twofold contribution to the existing literature. First, to contribute to the research on families with disabled children and disability studies, it draws on theories on social reproduction and social class to address how social inequalities contextualize the settings in which these families navigate complex bureaucracies to facilitate services for their children. Second, regarding the literature on classed involvement in social institutions, it highlights how families that are highly involved with and constantly dependent on welfare services endure and navigate these settings and how disability influences the context for involvement in welfare bureaucracies.

## Families with disabled children and welfare services

Since the mid-1960s, it has been an uncontested principle in the Nordic countries that disabled children should grow up with their families (Tøssebro 2014). Through public support, social policy aims to enable these families to live an ordinary family life (Tøssebro 2015). From a comparative perspective, Norway has a generous support system for families. In the Norwegian welfare system, a variety of health- and care-related benefits and services are available to families with disabled children (The Norwegian Directorate of Health 2018). These families can apply for cash benefits provided by the state (basic benefits and attendance benefits) and welfare services provided by municipalities (e.g.

support personnel, relief, and personal assistance). Moreover, people with impairments are covered by a specific health and rehabilitation regulation stating that services should be (1) based on a user perspective, (2) in or close to the user's accustomed environment, (3) coordinated and interdisciplinary, and (4) experienced as meaningful for the user (Ministry of Health and Care services 2011).

In Norway, families with comprehensive and long-lasting services are to be appointed a public service coordinator (e.g. a nurse or physiotherapist) by the municipality. There is no official definition of comprehensive and long-lasting services and families must themselves apply for a coordinator. The appointed coordinator is mandated to secure user participation and give the families holistic, coordinated, and individual services (The Norwegian Directorate of Health 2018). In addition to securing cooperation between families and different services, the coordinator organizes interdisciplinary coordination group meetings, usually twice a year. The meetings gather parents and professionals (e.g. teachers, physiotherapists, general practitioners, and specialists from hospitals or advisory units) involved in the child's life in different ways. In the meetings, the participants usually discuss what has happened during the last 6 months and set aims for the next period.

Raising a disabled child is an overwhelming experience for many parents (Gundersen 2012; Runswick-Cole and Ryan 2019). A key takeaway from previous research, both from Norway and internationally, is that the challenges and frustrations these families experience often stem from dealing with welfare services, not from their children's impairments per se (Runswick-Cole 2007; Nowak, Broberg, and Starke 2013; Barr, Duncan, and Dally 2021). Parents are often frustrated that the professionals who are supposed to help them act as rigid gatekeepers for welfare services (Albertini Früh, Lidén, and Kvarme 2017). In a large research project on families with disabled children in Norway, Kittelsaa and Tøssebro (2014) found that parents are frustrated by the lack of access to information concerning available support, the fragmentation of public services, and the way in which support depends on the civil servants they encounter. A recent report from the Office of the Auditor General of Norway (2021) also stated that the coordination of services is largely left to families themselves, despite the initiative of appointing public service coordinators. Gundersen (2012) argued that in the Nordic context, the contradiction between parents' expectations of the welfare state and the everyday reality they experience leaves them feeling that the state is working against them. The discrepancy between policy and practice provokes resentment connected to unrealized expectations regarding the generosity of the Norwegian welfare state (Gundersen 2012).

Furthermore, the process of service acquisition has often been found to be gendered, following a traditional gendered division of labor between unpaid

care work and paid work outside the home (Traustadottir 1991; Reisel, Nadim, and Brekke 2021). The intensified care work that is needed to provide for disabled children have a traditionalizing effect (Syrda 2023) in the way that it often becomes the mothers' responsibility. Blum (2015) argued that it makes little sense to talk about the parental involvement of families with disabled children in institutions in gender-neutral terms. Wondemu et al. (2022) found that having a disabled child in Norway had a significantly negative effect on mothers' labor market participation, working hours, and labor income. In a time of growing austerity in Europe and of 'neoliberal-ableism' (Goodley 2014), Thomas (2021) illustrated that parents highlight exhausting experiences with institutions as part of a wider hostility toward disability that forces them into a series of fights and battles. Kibria and Becerra (2021) argued that in the neoliberal era, access to public entitlements among families with disabled children is individualized and that children's success is tied to the level of their parents' advocacy. Mladenov and Dimitrova (2022) argued that parents of disabled children are constantly undermined and deprived as epistemic peers (i.e. suffer epistemic injustices) in meetings with professionals by having their statements understood as less credible than statements of other professionals.

### **Cultural capital in institutional encounters**

Following the 'cultural turn' in class analysis (see, e.g. Weininger 2005; Reay 2011), social class may matter not only for its relationship to social or economic resources but also for the cultural resources (e.g. knowledge, skills, and competencies) it provides. How social class shapes social processes, interactions, and institutional encounters has nevertheless been given less attention (Lareau and Calarco 2012; Elstad 2018). Norway is generally perceived as an egalitarian country with a high degree of universal welfare services and a low degree of privatization. Although these factors are associated with less inequality, Norway may be a particularly interesting case for exploring social inequalities in institutional interactions, since everyone must go through the same channels to access welfare services. Previous research has also shown the arbitrariness of some welfare services by, for instance, highlighting that much depends on the public employee one encounters (Kittelsaa and Tøssebro 2014).

To understand class, this article draws on Bourdieu's (1986, 1989) notion of cultural capital. Cultural capital is a somewhat challenged concept often associated with prestigious 'highbrow' aesthetic pursuits and attitudes, as well as with the mastery of elements of a prestigious status culture (Dimaggio 1982, p. 191). However, in line with Lareau and Weininger (2003), I argue for a broader conceptualization of cultural capital—one in which it is defined as 'the micro-interactional processes through which individuals comply (or fail

to comply) with evaluative standards of dominant institutions' (p. 53). This can be actualized, for instance, through language use or bodily practices, and specific elements may include cognitive, communicational, attitudinal, and behavioral capacities—skills that can be used as resources in institutional encounters. These resources are linked to social class position, and society is perceived as a hierarchical, ordered, and as a social space. Imagining capital as a scarce resource, Bourdieu (1987) showed how forms of capital can be converted and how they are central to the social reproduction of social life. Cultural capital is context-specific—meaning that both what functions as resources in institutional encounters and the standards of dominant institutions vary across space and time—and must be explored empirically. Furthermore, a fundamental aspect of cultural capital theory is its emphasis on relationality. This means that cultural capital is utilized in interactions; the families and institutional agents (street-level bureaucrats) in interaction with each other are what matter for understanding how cultural capital works. Shim (2010) argued that this allows researchers to highlight both the critical role of institutional agents as evaluative actors and the interactive and symbolic give-and-take of these encounters.

Recent U.S. contributions have highlighted how parents use their cultural capital in interactions with schools (Lareau 2011; Calarco 2018). Lareau and Calarco (2012) argued that institutional processes are not class-neutral and found that middle-class parents align their strategies with institutional expectations in institutional encounters more than working-class families. Lareau and Calarco (2012) also discussed how socioemotional strategies differ according to social class and how middle-class parents are often better suited to dealing with the complex and often unarticulated standards of schools. Research also shows that middle-class parents' educational resources increase their vocabulary and understanding of legal and educational jargon, while working-class parents have difficulty understanding key terms used by professionals (Ong-Dean, Daly, and Park 2011; Lareau 2011). Moreover, middle-class parents have better knowledge of when and how to intervene in institutions outside the home. They view professionals as equals and have the confidence to criticize them. In contrast, working-class parents view professionals as social superiors and display greater respect for authorities (Lareau 2011). The sense of entitlement displayed among middle-class families is key for familial communication with experts.

The mechanisms identified in research on interactions between parents and schools have provided important insights into how cultural capital is linked to institutional interactions. I argue that this theme should also be explored in health and welfare institutions. Like schools, health and welfare institutions require parental involvement. In the same way as teachers, the central persons in these institutions are professionals with higher education (i.e. middle-class persons). However, the services and institutions surrounding

disabled children and their families are often more specialized than schools and are administered by those with expert knowledge. McKeever and Miller (2004) argued that families with disabled children enter a new, highly specialized field and that they must 'learn the rules of the game' and adapt their strategies to align with professionals. Ong-Dean (2009) showed that, in the United States, middle-class parents of disabled children draw on the medical model of disability (understanding disability as a medical issue rather than a social construct) to a higher degree; he argued that privileged parents may use a medical construction of their children's needs in pursuit of valuable services and accommodations that might not otherwise be available. Blum (2015) argued that privileged mothers of disabled children in the United States internalized a sense of entitlement that helped them work with highly credentialed specialists. However, these privileged families could call on little authority of their own to confront authoritative discourse and specialists in the educational and medical systems (Malacrida 2003; Blum 2015). Chatzitheochari and Butler-Rees (2022) used an intersectional analysis of stigmatisation of disabled young people and found that those from high- and middle-class backgrounds had benefitted from distinctive parental advantages in navigating welfare institutions (p.7). Building on cultural capital theory and the existing literature, my article aims to contribute by providing an analysis of institutional navigation among parents with disabled children. Disability and class are understood as socially constructed categories and used as theoretical concepts. Disability is understood as social and occurring from a person-environment mismatch as well as being situational or contextual and relative (Traustadóttir and Ytterhus 2015: 22).

## Data and methods

This article uses data produced between September 2021 and October 2022. The study was designed as a comparative case study with 12 cases consisting of parents of disabled children and their coordinators in different parts of Norway. Of the parents we followed, all except one were mothers. The fieldwork and interviews were carried out by the author and three other researchers involved in the project. In the presentation of the findings, I will use the pronoun we when describing field visits. In the discussion I will continue to use the pronoun I. The eligibility criteria were that the participants be parents of a child using comprehensive services and have a public service coordinator. This meant that the types of impairments in the sample varied. It was common for the children in the families we interviewed to have multiple diagnoses. Although services vary according to diagnosis and type of disability, this is not highlighted in the analysis. The focus of this article is on the common experiences of navigating welfare institutions, regardless of the child's type of impairment. The project

passed evaluation by the Norwegian Centre for Research Data, who reviewed interview guides and consent forms.

At the start of the project, participants were invited to take part in a face-to-face semi-structured interview which lasted between 50 min and 2 h. We informed the participants that they could withdraw at any time, stop the audio recorder at any moment, and avoid answering certain questions. Furthermore, we followed the families (by observing them in coordination group meetings and keeping in touch) for a year before conducting a final interview.

Passive observations in coordination group meetings were carried out throughout the year. In some cases, meetings were recorded with the consent of the participants; in other cases, we relied on field notes because the meetings were not recorded (because of a lack of consent to record). Pseudonyms are used throughout this article, and necessary precautions have been taken to ensure that the participants' identities cannot be recognized.

After the meetings, we recorded debriefing interviews with parents and coordinators separately and asked them how they experienced the meetings. Throughout the study, we covered topics such as experiences dealing with services, relationships with the parents' coordinators, ideal welfare services, and strategies for acquiring services. The families were recruited with help from the coordinators and the municipality. In total, we conducted 27 individual interviews with parents, 21 interviews with coordinators, and observed 17 in-meeting sessions.

To include both working-class and middle-class families in our study, we asked the municipality to help recruit a wide range of families. At the beginning of the interviews, several background questions were asked. Throughout the study, information regarding family background and occupational and educational histories was gathered. Occupational history was important, as many of the participants had changed their occupations due to their children, and several relied on disability benefits as their main source of income. Social class was operationalized by educational and occupational history. Those having received a bachelor's degree or higher were characterized as middle-class, while those with no higher education were characterized as working-class. The rationale for using the participants' education instead of their current occupation is that, although many of the participants were now out of work, their education and occupational history gave them resources they could draw on. Although a simplistic class scheme is used to categorize participants (working-class and middle-class), I understand class more as a continuum rather than dichotomous categories. The focus is on levels of cultural capital and other resources the families possess rather than their position as working-class or middle-class families. Nevertheless, these categories act as a point of departure to understanding social class differences in the material. The sample consists of eight working-class parents (five with



primary school education and three with upper-secondary education), and four middle-class parents (three with bachelor's degrees and one with a master's degree). Four of the parents had immigrated to Norway and among them, three were fluent in Norwegian while one interview was conducted with a translator. Five of the parents were single mothers while the rest of the sample was living with a partner. At the time of the interviews, six of the parents were on some sort of disability benefit or not currently in work, while the rest were employed.

The analysis consisted of multiple steps. First, repeated readings of the separate cases were conducted to understand the participants' situations, involvement in welfare services, and strategies used to communicate with professionals. After drawing up each case, I began to compare the cases with each other. I then started to sort the data into broad thematic codes, focusing on how the families dealt with institutions. The main themes were *information* (gathering it, lacking it, and receiving it) and *communication* (initiation of contact, support or lack of support, recognition, sense of entitlement, and resignation).

Throughout the fieldwork and analysis of the data, I drew inspiration from the extended case method, which is defined as theoretically driven ethnography (Burawoy 1998). Using this approach, I took Lareau's (2011) work on class-based childrearing and how families deal with social institutions as a point of departure. In the following sections, I use detailed accounts of two cases, the Olsen family and the Dahl family, as illustrative examples. These were the families we followed most extensively during the fieldwork. For both families, we conducted four individual interviews and participated in three meeting observations each. The families also provided good points of departure for discussing social class, as they could be placed on either side of the spectrum in terms of their level of resources and were the most ideal typical cases in the sample. This allowed me to explore and explain 'from below' (MacDonald et al. 2005) the everyday experiences of two families whose lives were contextualized by levels of capital. In the next sections, these cases will be presented in depth, with the aim of providing theoretical insights rather than generalizations of social patterns. Other cases are also used in the analysis to substantiate my arguments.

### **You should watch your step: The Olsen family as an example of a working-class family**

Yvonne Olsen was a working-class, single mother with a primary school education living on benefits. She lived in an apartment with her son, who had just turned 18. Her son had several mental diagnoses and attended upper secondary school.

Ms. Olsen argued that raising a disabled child could be described as a 'full-time job with overtime and no vacation.' She argued that the

combination of caring for your child while trying to facilitate and coordinate the related services as best as possible was exhausting. Ms. Olsen also had health issues, causing her to often struggle to remember appointments and deadlines. Moreover, she had a limited network and only a few kin living close by.

In the interviews with Ms. Olsen, a recurring topic was her experience of being mistrusted by professionals. She argued that the behaviour of several professionals was 'based on what they have learned by reading all the books they have read, and a lot of them were a bit 'world champions' referring to that many of the professionals felt that they knew better than her what was best for her son. Throughout her child's upbringing, she found it hard to be heard and felt that 'All the time there is someone that tells you that you don't know anything, because 'I have an education.' She often felt that her observations and opinions regarding her son's social and medical issues were not taken seriously. For instance, during the time we were in contact, Ms. Olsen's son's dosage of medication was decreased, which led to him acting out. Their doctor later increased the dosage again, and Ms. Olsen shared in a later interview:

Some doctors and other people in the system are a bit stubborn [referring to the increase in his medical dosage] due to the fact that they are the doctor and not you. However, time and time again, it turns out that they should have listened to me.

She had tried to protest the decision to decrease her son's medication but felt ignored by the doctor. Earlier, she described a previous teacher of her son, who constantly dismissed her complaints due to the teacher's professional expertise, which drove Ms. Olsen's son to several years of selective mutism. According to Ms. Olsen, the teacher isolated her son away from his classmates for several years which led to him becoming depressed and eventually stopping talking and refusing to participate in activities. We asked her if it was possible to fight back against professionals. She answered that it was impossible and that you must beware and subordinate yourself. She linked this to the risk of being reported to child protective services and argued that people were not hesitant to do so. Another working-class mother, Mrs. Berg, had a complaint filed against her with child protective services. She told us that the complaint was done as revenge for her threatening to submit a formal complaint against her son's school. The complaint ended up being disregarded, but it left Mrs. Berg's relationship with her son's school in shambles. Mrs. Berg constantly expressed anger and frustration in her stories. This frustration was often directed toward individuals, and she regularly confronted professionals.

In a coordination group meeting we observed, Ms. Olsen stated that she had spoken with a person at the rehabilitation unit who had explained that her son needed to attend smaller groups during school hours. During the

observation session, the school representative rejected this proposal by claiming that they did not want to separate him from the rest of the class, as this would make him lonely. Ms. Olsen did not protest this. Later in the meeting, we observed that the representative from the rehabilitation unit supported Ms. Olsen by arguing that, in line with his diagnosis, it would be useful for the boy to have the possibility of being in smaller groups and taking a timeout. The teacher then agreed with the professional consultant but argued that the son must indicate himself when he needs a breather. Ms. Olsen responded that her son struggles to express when he needs a timeout; however, the teacher again rejected this and said that the boy must find a way to manage. Again, Ms. Olsen did not protest. Straight after the meeting, Ms. Olsen told us:

It is a stupid thing that is everywhere in his childhood, that there is always someone who feels that their observation during the last 2 months surpasses what you know about your child. The teacher experienced that my son's feelings of loneliness came when they separated him from the rest of the group during classes. However, he has explained to me, as best as he can, that the feeling of loneliness comes during recess because he feels he is not included socially.

We observed that this was not mentioned by Ms. Olsen in the meeting. When asked about it she told us that she felt that the teacher would not hear her out because the teacher had interrupted her and was not interested in listening. Ms. Olsen felt that the teacher several times had an impression of the situation at school that differed from her own.

During the time we were in contact, Ms. Olsen was working on appointing a legal guardian for her son. However, the process stopped during her attempt to acquire the correct forms to submit to the public office. We asked what had happened, and Ms. Olsen replied:

My doctor gave me an application form that turned out to be wrong, according to my coordinator. So, when I returned to him to explain the situation, he got angry at me because he meant that could not be the case. So I sat there and got iatrophobia. So now I am just waiting until he retires so I can return to the doctor's office. Because he got really, really irritated with me.

She had started the process before her son turned 18, but the process was abandoned because, as told by Ms. Olsen, she was reprimanded by the doctor. Other working-class mothers also reported that the processes they tried to start often stagnated after they were discussed with professionals. For instance, we observed a coordination group meeting in which Mrs. Hussain raised the problem of low flexibility in some services, and it was promised that this would be fixed. However, several months after the meeting, we spoke to Mrs. Hussain about the progress of the issues, and she told us that nothing had happened, and that she had received no updates about the issues.

## **You shouldn't sit idly by: The Dahl family as an example of middle-class family**

Marianne Dahl was married to Nikolaj Dahl. Mrs. Dahl, a middle-class mother, was originally educated in a creative profession but worked in a primary school to accommodate the care work she did for her son. Mr. Dahl had completed several years of university education and had worked in different jobs on and off during the last few years. Their son attended upper secondary school and lived at home with his mother, father, and sister. They were a close-knit family who spent a great deal of time together.

Mrs. Dahl's son had an invisible disability, and she explained that she usually had to attend several rounds with professionals to get them to recognize her son's disability. Mrs. Dahl described the process of obtaining services as a struggle and emphasized the need for constant repetitions of her son's needs in dealing with services. A formative experience for Mrs. Dahl was meeting a family that was in a similar situation to her own but who received more comprehensive services than her son had. She then realized that how you navigate the system has an impact on what treatment your child receives and reflected on this throughout the interviews. She described how she tried to be 'objective' in dealing with the services and how she learned not to have too high expectations about what could be achieved. Mrs. Eriksen, another middle-class mother told us:

I am very attentive to making sure she has her assistant there in class. I know from experience that the bitchy mother who calls and emails all the time is the one who gets things through. I know you can't just stand by and do nothing.

She explained that she had to monitor the situation constantly to make sure that things went according to plan. Her approach was, however, more mellow than aggressive.

In our first interviews, Mrs. Dahl spoke about how one should be stubborn and not 'sit idly by,' but she also stressed that one must at the same time be 'diplomatic,' as parents can easily be overruled by specialists. On a specific occasion, she was discontented because the physical education teacher did not notice that her son had a disability, which led her son to refuse to participate in the classes. However, she told us:

I didn't think that I could talk to the physical education teacher directly, because the situation can easily go from the frying pan and into the fire when you, as a non-professional, start to lecture a teacher.

Mrs. Dahl's strategy was not to directly confront the physical education teacher, as she thought that this could make the situation worse. Instead, she contacted her coordinator (who was also their physiotherapist), who delivered the message to the physical education teacher and solved the issue.

We observed that Mrs. Smith, another middle-class mother, often used small talk after coordination group meetings to discuss services she knew would be needed in the future. When we asked her if this was a deliberate strategy, she told us that this was a conscious strategy on her part because she experienced the professionals as insufficiently proactive, so she wanted to take an early initiative in future situations.

In the meetings we observed, Mrs. Dahl and the other middle-class mothers maintained a good relationship with their coordinators. Mrs. Dahl's coordinator described the family as:

A very grateful family to work with, because they are so positive and try to work out solutions, and that is not always the case [with families with disabled children]. The Dahls are grateful, and although they have been through some tough processes, they are still happy for the help they receive and don't take these things for granted. The first contact I had with them was when they submitted a complaint to get more help, but there was still no anger or frustration, and I think they are great to work with.

The description of Mrs. Dahl given by the coordinator fits well with how she wanted to be perceived by professionals. Moreover, the coordinator contrasted this family with other families, who are harder to cooperate with because they are more frustrated and less grateful.

Throughout the time we followed Mrs. Dahl, she was involved in trying to get her son's school to facilitate the provision of an assistive listening device for his use, as he struggled to access communication in difficult listening situations (e.g. situations with significant background noise or group discussions). This issue was raised several times by Mrs. Dahl during the year we followed her. In the last coordination group meeting we observed, the school representative apologized for the concern still not being resolved but watched him argue that this is not something they can fix, as the state building commissioner who owns the building needs to solve the issue. We observed Mrs. Dahl argue in the meeting that:

I think that the increase in seizures lately can be connected to him getting tired (from not being able to focus properly); this is also the opinion of his doctor (at a national specialized hospital).

Mrs. Dahl used two arguments to support her cause: the principle of universal design (which is a part of the Norwegian law on equality and discrimination) and the knowledge of a doctor at a specialized hospital.

### **Cultural capital in the context of institutional interactions**

Families with disabled children constantly face problems related to institutions. However, as argued, institutional interactions are not class-neutral. Cultural capital in the form of knowledge about accepted ways of expressing

oneself is vital in facilitating continuous interactions with professionals and navigating bureaucracies. In this section, I discuss institutional navigation through a cultural capital lens.

Navigating complex and dense institutions without any real sense of achievement was a typical narrative among the participants. Frustration related to the experience of not attaining the services they needed was common among all parents. This aligns with the narrative of 'fighting' against bureaucracy that is found in previous research on families with disabled children (Gundersen 2012; Thomas 2021). My findings suggest that parents deployed different strategies to cope with this frustration in institutional encounters. The informants aimed not to direct this fighting rhetoric toward the welfare professionals, as doing so was regarded as a hopeless strategy. Aggressive outbursts are usually not accepted by public services. A grim example of this is Ms. Berg, who got into an aggressive confrontation with the school because of a formal complaint made against her to child protective services. This eventually led to her terminating the coordination group and limiting her contact with the municipality to a minimum. A negative bias against displaying frustration was also identified among several of the coordinators interviewed in the study. Like McKeever and Miller (2004), I found that more assertive maternal practices were typically discouraged, curtailed, and/or pathologized. However, behavior that was too submissive led to topics that were important to the parents disappearing from the meetings.

In complying with institutional standards, it is vital to have the cultural competence to keep communication light and airy while avoiding being submissive. Mrs. Dahl and other middle-class mothers seemed to reflect on and balance this frustration in their interactions to a higher degree than the working-class mothers. Working-class families sometimes reflected on this tightrope, but they seemed to struggle more in aligning their strategies than their middle-class peers.

Ms. Olsen often resigned herself to the services. She lacked a sense of entitlement to speak her mind against professionals, and in some cases, she showed unease with authorities. She linked this to the potential threat of being reported to child protective services. In Norway, families with a low socioeconomic background are much likelier to be in contact with child protective services (Kojan and Fauske 2011). Moreover, Kojan (2010) found that Norwegian child protective services struggle to deal with high-status families insofar as the social workers enter an 'underdog position' and believe they are going to lose against these families, while the opposite is the case for their dealings with low-status families. However, Ms. Olsen's unease with the authorities was also linked to being constantly dismissed when she tried to share her concerns. She lacked a sense of entitlement to continue fighting the services and often 'watched her step' in dealing with experts. Everyday life was about getting by and trying to make the most of the services they already had.

Continuous bumps in the road led to her withdrawing from trying to expand the services her son received and instead sticking to the services they had.

Despite continuous bumps in the road, Mrs. Dahl continued to maneuver, although slowly, to customize her son's services. Her strategy was to avoid confrontation while remaining involved and trying to follow the norms of the institutions with which she interacted. This was also common among other middle-class families. Mrs. Dahl's cultural knowledge expanded to when and how to intervene with different professionals. She argued, 'You have to be diplomatic, because they are experts in their subject areas, so you have to watch your step and know that I want something else than they do.' She recognized that this sensitivity to interpersonal dynamics and respect for professionals' authority are key to maintaining harmonious communication with professionals. Although she often acted mildly and avoided confrontation, she displayed a sense of entitlement when needed. She could be persistent in meetings and continue to argue her case when dismissed; however, she did this in a delicate or easygoing way.

Like Ms. Olsen, Mrs. Dahl argued that you must beware in interacting with professionals. However, her statement was not related to the fear of being reported to child protective services—a fear that was nonexistent among the middle-class families. When child protective services were mentioned, they were framed as more of a collaborative partner than as a risk. The way in which one must beware was instead framed as related to keeping communication with professionals pleasant. Furthermore, the alternation between intervening and refraining from intervening (or waiting until the small talk after a meeting to discuss issues) was more common among the middle-class families in the sample. This was an explicit strategy used to ease communication and maintain good relationships with professionals. These unarticulated institutional standards were better interpreted by middle-class parents. However, the more reactive involvement demonstrated by working-class parents must be understood in a wider context. Several of the parents in the sample were single mothers and/or struggling with health issues related to their extensive care burdens. Making the extra effort to be more proactive in dealing with services may rely more on health, social support, and economic capital than cultural capital. Especially the single working-class mothers seemed to be caught in a spiral in which low levels of dominant cultural capital, economic capital, and social capital all made it relatively difficult to endure these constant struggles.

Furthermore, with the realization that they have little authority themselves, the utilization of experts and expert knowledge is vital for families. Most parents in the sample recognized that when their statements were backed by experts' documents or by experts themselves, their claims were taken more seriously. A common strategy, therefore, was to bring authorities to meetings and acquire written documentation from specialists. There was also a clear hierarchy

among different professionals: the more specialized professionals at national institutions were on top, while the generalists in municipal organizations, such as schools, were lower down. In the meetings we attended, the participants seemed to listen more attentively when needs were uttered by specialized professionals rather than by parents. Most parents recognized this strategy.

In the case of Mrs. Dahl, she regularly utilized experts to communicate information she wanted to express to professionals. For instance, she utilized her coordinator to convey a message to her son's physical education teacher, as she did not want to confront the teacher herself out of fear that this might worsen the situation. She realized that arguing with professionals would lead to no good; however, she used a conscious strategy to tackle the situation. She contacted a relevant professional and got that professional to intervene in her place, although this meant that she and her son had to endure several weeks of suboptimal treatment. Mrs. Dahl tried as best as she could to explain the situation to her son but felt this was an emotionally challenging period.

Ms. Olsen also shared that activating professionals, such as specialists or one's coordinator, could be a useful strategy for managing other professionals. However, she argued that this was quite difficult to achieve, saying, 'I have tried but have been ignored.' Her advice was to instead team up with other parents to acquire information about their rights and to tread carefully in dealing with the school because of the potential of being reported to child protective services.

## Discussion

In the section above, I have discussed how social class is at stake in interactions between families with disabled children and professionals in highly specialized welfare institutions. I have argued that middle-class parents display the cultural competencies to keep communication smooth and keep going without any real sense of achievement to a higher degree than working-class parents. In this section, I discuss the differences between families of different classes further by outlining the specific challenges these families face and the limitations of cultural capital theory.

I investigated how cultural capital was played out in health and welfare services. I explored how the middle-class mother, Mrs. Dahl, aligned her socioemotional strategies with institutional expectations more than the working-class mother, Ms. Olsen. However, the cultural norms and institutional standards related to families with disabled children in this study differed from Lareau's (2011) findings. Lareau argued that having a sense of entitlement gave middle-class children and adults advantages in institutions by making it easier for them to voice their opinions against institutions. The middle-class mother, Mrs. Dahl, continuously displayed a greater sense of entitlement toward professionals than the working-class mother, Ms. Olsen.



However, more important than having this sense of entitlement was knowing when to step back and when to use it.

Furthermore, encounters between parents and professionals are infused with invisible epistemic injustices (Carel and Kidd 2014, Mladenov and Dimitrova 2022). The findings show how the opinions of professionals constantly were preferred over parents. Ms. Olsen is dismissed time and time again by professionals in her assessment of what is best for her child. Moreover, Mrs. Dahl is also hesitant to contact professionals directly with her opinion as she argues that the opinion of other professionals is taken more seriously. So, in line with Malacrida (2003) and Blum (2015), I conclude that even families with large class advantages have little authority to confront authoritative discourse and specialists in the educational and medical systems. Highly specialized institutions seem to be closed off to the assessments of 'non-experts' to a higher degree than ordinary schools. In these settings, knowing how to keep communication pleasant and utilize experts to one's advantage may be more important than displaying a sense of entitlement. This created a lot of frustration among all the families in this study, regardless of social class. As McKeever and Miller (2004) found, mothers with higher levels of capital were as likely as others to report frustration in relation to professionals. However, unlike their study, I found that the middle-class mothers seemed to endure these situations to a higher degree than working-class mothers by being proactive and highly involved throughout their children's upbringing.

Moreover, previous research on families with disabled children in the United States has speculated that working-class parents have difficulties understanding key terms used by professionals, while middle-class parents' proficiency in educational and medical jargon gives them an advantage in dealing with health and welfare services (Ong-Dean, Daly, and Park 2011). Throughout my study, I found only a few clear incidents indicating this, although the results might be different in researching written material because of the competencies formal education may provide working with texts. Although some middle-class parents referred to abstract concepts to a higher degree, this did not seem crucial in their communication with professionals. Moreover, working-class parents also mastered the diagnostic and educational jargon used by specialists regarding their children in both meetings and interviews. Finally, the language used in meetings was mostly related to everyday life and was not particularly specialized.

All parents gained knowledge of their children's impairments and welfare institutions. As McKeever and Miller (2004) pointed out, such families develop field-specific capital to navigate this new, unfamiliar field. Repeated interactions with professionals give these families experience in handling a range of different situations and interactions. However, my findings suggest that endurance and a sense of the unarticulated standards of institutions and the opinions of professionals were linked to the resources these families had

outside the field. These resources included economic resources, health, and social capital (in the sense of both Bourdieu and Coleman). Learning to navigate the system to acquire resources may depend on the resources one already has. Hence, these complex bureaucracies may reinforce already existing inequalities. This development of field-specific capital has a classed component. Related specifically to cultural capital, already having a sense of 'the rules of the game' regarding how institutions operate before entering these new and specialized welfare institutions can be understood as providing one with a better point of departure for learning what one must do in these institutional interactions, thus offering a better foundation for acquiring field-specific capital. However, as Mrs. Dahl pointed out, meeting other families in similar situations was also important in learning how to navigate this new field. User organizations, Facebook groups, and networks consisting of parents in similar situations may thus be important arenas for acquiring field-specific capital that can neutralize class differentials in cultural capital.

Furthermore, the fact that all except one of the participants were women underscores the gendered aspect of parental involvement among parents of disabled children. Most of the care work fell on the mothers as well as the involvement with professionals and coordination of services which relates to what Hochschild (1997) have coined 'third shift' to describe the planning and organisation of family time that is needed for parents who must juggle their responsibilities in the first shift (paid work) and the second shift (childcare). Moreover, the intensified labour done by mothers shows that acquiring cultural and field-specific capital to navigate these social institutions is a 'mothers' job'. The intersection of class and gender highlights how it can be easier for middle-class mothers than for working-class mothers to acquire this capital as it is dependent on the resources they already possess.

Moreover, I argue that there are clear limitations to adopting an overly narrow focus on cultural capital. There are topics that were not discussed in depth here, including one middle-class parent who failed to utilize her cultural capital because of fatigue related to caring for her children and coordinating welfare services. Ms. Solheim, a college-educated middle-class mother, regularly had to withdraw from meetings because of her child's impairment and her own health, hence failing to utilize her cultural capital in important settings. Thus, levels of cultural capital were not necessarily enough to facilitate cooperative communication; factors such as support from one's family and network, possessing economic and material resources, and having an involved coordinator were important for the everyday functioning of the families.

Finally, and perhaps most crucially, all the families struggled greatly. In keeping with previous research, the central finding of this study was the frustration and lack of achievement felt among all participants (Runswick-Cole 2007, Gundersen 2012, Barr, Duncan, and Dally 2021). This was the case regardless of social class. As both Thomas (2021) and Kibria and Becerra (2021) argue, in the

age of neo-liberal ableism, all families with disabled children face tough situations because of a lack of opportunities. There is a struggle both in entering into aggressive confrontations and in not engaging on behalf of your children, as some working-class mothers did. However, McKeever and Miller (2004) argued that 'knowing one's place' may contribute to mothers' social suffering and psychological distress, since 'justifiable anger toward an inadequate system of formal services is implicitly removed as an available and effective parental response' (as quoted in Ferguson, 2001, p. 380). This underlines the fact that neither working-class nor middle-class parents thrive in navigating these bureaucracies.

In this article, I have explored how cultural capital is mobilized and utilized by parents in their interactions with professionals in welfare services. Following Chatzitheochari and Butler-Rees (2022), I shift the attention beyond the importance of economic capital to explore parents of disabled children use of cultural capital in yielding advantages for their children. As Thomas (2021) speculated, my findings suggest that the fighting for accessing services and resources have a classed component. However, my findings suggest that although levels of cultural capital matter in institutional interactions, having a disabled child may put you in a disadvantaged position that outweighs whatever advantage cultural capital offers.

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