



Negotiating the Administrative Burden: The Navigation of Welfare Services by Parents with Disabled Children

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RESEARCH



ABSTRACT

Drawing on interviews with parents and coordinators, this paper explores the system for providing public service coordinators to parents with disabled children in Norway and how parents and coordinators understand and negotiate their roles in administering public services. Coordinators are service providers employed by municipalities to help families in need of long-lasting and comprehensive services. The findings reveal that parents carry an administrative burden, which involves learning about services, complying with rules and regulations, and managing psychological stress related to encounters with professionals. Coordinators vary in their interpretation of whether their role should go beyond providing information regarding services. Parents try to negotiate a higher degree of involvement from their coordinators, but coordinators often lack the necessary time and resources. The current state of the coordinator role may lead to inequalities and arbitrariness in the way families are supported while navigating welfare services.

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INTRODUCTION

In Norway, children who require long-lasting and comprehensive services can apply to receive the support of a public service coordinator. The coordinators are mandated to provide families with access to holistic, coordinated, and individualised services (Norwegian Directorate of Health 2018). Despite this regulation, the Office of the Auditor General of Norway (2021) recently stated that the coordination of services is left mainly to the families themselves. Previous research has also revealed that parents with disabled children frequently struggle and become frustrated when accessing and customising services for their children (Green 2007; Runswick-Cole 2007; McLaughlin 2019; Thomas 2021; Jacobsen & Bøhler 2023). These families face what Herd and Moynihan (2019) call an *administrative burden* in navigating welfare services. In the Norwegian welfare system, this burden is supposed limited by the help of coordinators. However, little is known about how coordinators and families work together to provide services and equal participation for disabled children.

Using a unique dataset consisting of interviews with public service coordinators and families with disabled children, this article explores how parents and professionals understand and negotiate their roles in administering public services. As recent contributions (Thomas 2022; Mladenov & Dimitrova 2022; McLaughlin 2023) have urged that there is a need for interdisciplinary approaches to understanding the situations of families with disabled children, this study aims to show how the social policy concepts of administrative burden and negotiated discretion can be valuable in understanding how parents with disabled children navigate welfare institutions. This study asks: How do parents and coordinators negotiate the administrative burden related to navigating welfare services?

COORDINATORS AND WELFARE SERVICES

Coordinators are service providers assigned to users who require long-lasting and comprehensive services (Norwegian Directorate of Health 2018). The coordinator system, which is regarded as a type of healthcare service, is part of the rehabilitation and habilitation services and is organised by municipalities. Each municipality has a 'coordinating unit' responsible for appointing, training, and supervising coordinators. Coordinators are supposed to be the closest collaborators to users, and their next of kin in ensuring that services are continuous and coordinated. The coordinators' prime task is to arrange coordination group meetings, which bring together parents and professionals involved in the child's life in different ways (e.g., teachers, physiotherapists, general practitioners and specialists from hospitals or advisory units). In the meetings, the participants usually discuss whatever happened during the previous six months and set aims for the next period. However, coordinators do not have any authority to grant services, as this is done by municipal case managers, specialist health services, or schools. Users and their families must apply for a coordinator.

Using the same dataset as this article, Albertini Früh et al. (2023) found that assigned municipal coordinators are usually professionals employed municipally as physiotherapists or school nurses. They perform their responsibilities as coordinators in addition to doing their regular full-time work. Coordinators argue that they often lack the time, resources, and competencies to provide equivalent and satisfactory services to families. Coordinators are often stretched between high demands and limited resources, and struggle to interpret their roles (Tveit & Cameron 2013; Albertini Früh et al. 2023). Bekken et al. (2021) found that a lack of time and resources requires other professionals in habilitation services to provide users with a 'realistic' understanding of what users can expect from public services. Nevertheless, there is limited knowledge of how the coordinator arrangement is implemented and experienced by parents of disabled children and coordinators in Norway.

FAMILIES WITH DISABLED CHILDREN AND WELFARE SERVICES

A growing body of research in disability studies suggests that the challenges and frustrations faced by parents (especially mothers) with disabled children stem from interactions with welfare services, rather than from their children's impairments (Runswick-Cole 2007; Nowak et al. 2013; Kittelsaa & Tøssebro 2014; Barr et al. 2021; Østerud & Anvik 2023). This seems to be the case across states and welfare regimes. 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 how support depends on the civil servants they encounter. Gundersen (2012) argued that the contradiction between parents' expectations of the welfare state and the everyday reality they encounter leaves parents feeling that the state is working against them. Skagestad et al. (2023) argued that in Norway, stigmatisation and marginalisation can pose challenges for disabled youth and their parents in dealing with services that other parents of children of the same age do not face.

Green (2007) found that mothers in the US described their 'burden of care' as relating to objective burdens (e.g., time-consuming contact with medical services) rather than emotional distress (e.g., embarrassment, guilt, resentment, entrapment, and emotional upset). She also found that perceived stigma towards individuals with disabilities, in general, was related to an increase in mothers reporting both higher objective burdens and emotional distress. Furthermore, Traustadottir (1991) in Iceland and Blum (2015) in the US showed that the caring role of mothers of disabled children involves advocating or acting as 'vigilantes' for their children in meetings with health and education professionals. Blum (2015) also argued that navigating welfare bureaucracies may be particularly hard for working-class single mothers and women of colour. However, she concluded that even families with considerable class advantages have little authority to confront authoritative discourse and specialists in educational and medical systems. In Norway, Jacobsen (2023) showed that levels of cultural capital matter in institutional interactions because it helps users know when and how to pick their battles. Mladenov and Dimitrova (2022) used the concept of *epistemic injustice* to show how parents of disabled children are constantly undermined and deprived as epistemic peers (i.e., they suffer epistemic injustices) in meetings with professionals by having their statements understood as less credible than the statements of professionals. Ryan and Runswick-Cole (2008) argued that parents of disabled children operate within a narrow and inflexible system of benefits, allowances, and access to resources. This system enforces perceptions of disability as negative and undesired, which, in turn, mirrors the dominant views of disability within society.

CONCEPTUAL FRAMEWORK

In summary, a body of research has focused on parents' (especially mothers') exhausting experiences and objective burdens in facilitating services for their children. In this article, I wish to build upon previous research and continue to theorise this 'objective burden'. I argue that the high involvement of parents in acquiring and customising services for their children mirrors what Herd and Moynihan (2019) termed an *administrative burden*. This notion enables us to conceptualise and distinguish between the costs of dealing with bureaucracies. Herd and Moynihan (2019) argued that dealing with bureaucracies comes with different costs arising from individual experiences of interacting with the government. First, learning costs arise from engaging in processes to collect information regarding public services, such as which services are available and what the associated eligibility criteria are. Second, compliance costs are the material burdens associated with following administrative rules—which require filling in forms or providing documentation—and the time lost in meetings and waiting for services. Third, psychological costs include a sense of loss of personal power or autonomy in interactions with the state or the stress and frustrations of dealing with administrative processes (Herd & Moynihan 2019).

In Norway, the state has acknowledged that parents face an administrative burden by implementing the coordinator arrangement. Parents' costs related to the coordination of services should be reduced through the help of coordinators. To understand how these coordinators help parents tackle their administrative burden, I use the concept of *negotiated discretion* (Johannessen 2019). The concept is based on Lipsky's concept of street-level bureaucracy (Lipsky 2010). Lipsky (2010) used a bottom-up conceptualisation to understand how public policy is translated into practice and the discretionary decision-making of bureaucrats. Lipsky (2010, 1980, p. 3) defined street-level bureaucrats as those who 'interact directly with citizens in the course of their jobs' and 'have substantial discretion in the execution of their work'. This discretion in how they operate does not imply the absence of rules and regulations, but suggests that there is room for their judgment. Building on Lipsky, Johannessen (2019) argued that the discretion exercised by frontline workers cannot be understood as separate from the people with whom they interact. He used the concept of *negotiated discretion* to show

how decisions between street-level bureaucrats and clients are often negotiated. He argued that we should approach street-level policy as an interactional accomplishment rather than focusing on bureaucrats as the sole agents of policy. Shifting our attention to negotiations enables us to better grasp the power dynamics of street-level encounters by acknowledging the boundaries drawn by coordinators and the role of the client's resources and assertiveness in these negotiations (Johannessen 2019). Johannessen (2019) also used the concept of *negotiation context* (Strauss 1978), which links negotiations to their broader context and the local conditions that shape them. Strauss (1978) highlighted different contextual conditions, but this article mainly focuses on the relative balance of power between negotiators (i.e., between parents and coordinators). The discretion of coordinators—who have no authority in granting services—relates to how involved they should be in coordinating services and helping families. By combining the concept of negotiated discretion with the concept of administrative burden, I wish to explore both the roles of families and the roles of coordinators while investigating families' objective burdens.

RESEARCH PROCESS

This article uses data from a larger research project that investigated the benefits and services received by parents of disabled children in Norway. The study was designed as a multiple-case study (Yin 2018). It followed 12 parents with disabled children and their assigned coordinators for over one year and was supplemented by additional interviews with other coordinators. This article uses interviews with 12 parents and 39 coordinators. The Norwegian Centre for Research Data (reference number 247912) reviewed the project, assessed the interview guides, and approved the consent forms. Informed consent to record, transcribe, analyse, and publish anonymised statements was obtained from all interviewees prior to conducting the interviews. We informed the participants that they could withdraw at any time, stop the audio recorder at any moment, and avoid answering certain questions. Pseudonyms are used throughout this article, and necessary precautions have been taken to ensure that the participants' identities cannot be recognized.

We conducted 27 individual interviews with the parents. All except two of the parents were interviewed several times. The types of impairments in the sample varied, and it was common for the children to have multiple impairments. The analysis emphasizes the connection between coordinators and families rather than the differences in services based on diagnosis and disability type. The families were recruited with help from the coordinators and municipalities. Participation was voluntary, and parents often argued that they wanted to share their stories to help others in similar situations and contribute to research on the topic. Throughout the interviews with parents, we covered topics such as their experiences dealing with health and welfare services, relationships with their coordinators, ideal welfare services, and strategies for acquiring services.

The sample consists of eight working-class parents (five with a primary-school education and three with an upper-secondary education) and four middle-class parents (three with a bachelor's degree and one with a master's degree). Four parents had immigrated to Norway; three of them were fluent in Norwegian, and one interview was conducted with a translator. Five parents were single mothers, while those in the remaining sample lived with partners. At the time of the interviews, six parents were receiving some sort of disability benefit or were unemployed, while the rest were employed. All the parents we interviewed were mothers, except one.

In addition to the 12 coordinators we followed in the parent-coordinator cases, we interviewed additional coordinators through individual and focus group interviews. In total, we interviewed 39 coordinators from six different Norwegian municipalities, which involved conducting individual interviews with 19 coordinators and interviewing 21 coordinators through focus groups (one coordinator participated in both individual and focus group interviews). Among all the coordinators, five spent 100% of their employed time as coordinators, two spent 50% of their time in this capacity, and the remainder carried out their coordinator role in addition to their regular position and spent no designated percentage of time on this activity. All the coordinators acted as such for at least one family, while most were working with three to five families. The coordinators for whom coordination work was a designated aspect of their

position were responsible for more families, with the highest number of families exceeding 50. The coordinators had the following professional backgrounds: physiotherapist (12), school nurse (12), occupational therapist (4), special education teacher (3), learning disability nurse (3), social worker (2), healthcare worker (2), and speech therapist (1). Furthermore, 36 of the coordinators were women, and three were men. In each municipality, we interviewed a central person in the coordination unit to explore how the municipality organised the coordinators. In the individual interviews, we focused on the responsibilities, procedures, and routines related to the coordinator role. In the focus group interviews, we focused on how the regulation of coordinators currently functions and how it could ideally be.

The analytical process was an abductive analysis and involved several steps (Tavory & Timmermans 2014). I began by coding the coordinator interviews into broad themes. In the initial analysis, it became evident that the coordinators drew lines regarding their and parents' responsibilities. To explore this further, I coded the interviews with the parents, focusing on their relationships with their coordinators and their interpretations of their coordinator's role. The main codes were *expectations* and *responsibilities*. To further explore how coordinators and parents cooperated, I used the concept of administrative burden and the related costs as a point of departure and went back and forth between the coordinator interviews, parent interviews, and theory.

FINDINGS

In the following section, the role of coordinators in assisting parents is described, and the challenges associated with obtaining welfare services for disabled children are presented. Parents' and coordinators' perspectives are introduced separately before a concluding discussion.

PARENTS' PERSPECTIVES

All the parents in the study wished for someone who would make their lives easier by informing them of their rights and available services and assisting them with writing applications for services:

I wish there was someone who could assist me with all this, because the problem is that my daily life is rather exhausting and rough, so being stuck with these applications during the night is truly burdensome. I wish there was someone who said, 'Okay, you have the right to these services, we will help you apply', and I could just sign the paper. (Isabella)

Although the participants had different administrative burdens, they all argued that these burdens were an exhausting aspect of their everyday lives. Parents spend considerable time searching for information related to the availability of welfare services and their rights to and eligibility for these services (i.e., they face learning costs). Moreover, parents spend time applying for services, specifically writing applications. This involves providing documentation to support their requests and demonstrate their children's level of function. Furthermore, applications are often denied, leading to extra time spent writing appeals. Parents also attend various meetings that require preparation and follow-up work. All of these tasks increase parents' compliance costs. Moreover, most parents find these processes frustrating, particularly regarding their interactions with and applications for municipal services, such as relief services and personal assistance. The participants explained that they are often frustrated with the procedures (which they often considered arbitrary and discriminatory), and not necessarily with the services themselves. Several of them also stated that they had to downplay their children's functional abilities when applying for services, which requires focusing on the negatives rather than the positives, to have a better chance of being granted the services. At least two of the participants avoided pursuing further services because they felt that their fight for additional services had come to a standstill. They argued that the stress and frustration they encountered during the process outweighed the potential gains from engaging in further battles. To different extents, all the parents faced learning costs, compliance costs, and psychological costs related to facilitating their children's services.

The participating parents relied on their coordinators to tackle their administrative burdens. However, the parents varied in their interpretations of the coordinator role. Anita argued:

In the beginning, I had greater expectations of my coordinator. ... She is very good at leading coordination group meetings. But I expected that she would be a little proactive in discussions with parents. (Anita)

Anita understood the role of her coordinator as being somewhat limited. Her expectations shifted after she realised that the coordinator had taken on a restricted role regarding involvement in her child's services. The parents often related their expectations to their experiences and how their coordinator drew lines regarding the coordinator's involvement. For parents, the initial period after being granted a coordinator was usually spent figuring out what to expect from the coordinator and negotiating the coordinator's level of involvement. However, when parents had a coordinator for a longer period, the relationship usually became established after the initial period. Camilla's expectations of her coordinator's involvement also were low. She explained how she had attempted to negotiate their involvement:

I have, for the most part, coordinated things myself... I have never really experienced a coordinator who has taken any initiative. I have tried plenty of times to delegate tasks but have been met with the argument that I should address the service myself since I know the situation best. (Camilla)

Camilla had attempted to get her coordinators more involved several times. For example, she had asked for support in obtaining personal assistance for her son and wished for someone to help her find the best strategy to apply for the service. Finding the best strategy involves a mix of learning costs and compliance costs, because parents must spend time learning how to apply for the service and then applying for it (and, perhaps, appealing the decision). For parents, learning and compliance costs are usually combined and are difficult to separate into different processes, as they must learn the correct way to comply. In the two examples above, the coordinator drew clear lines of involvement, usually limiting their involvement to arranging coordination group meetings. Thus, the mothers' expectations about having more proactive coordinators were discarded. The coordinators drew these boundaries to prevent themselves from becoming involved in longer processes of service acquisition—processes that involve a mix of learning and compliance costs for parents.

However, other parents had higher expectations of their coordinators. Ingrid told us that she contacted her coordinator regularly. She was planning to apply for a support contact for her son and explained that she contacts her coordinator whenever she needs more information: 'If I need help with anything, I call my coordinator and ask her. I expect that she will help sort it out' (Ingrid). She expected her coordinator to be involved in the everyday navigation of welfare services and to help her with the learning and compliance costs of acquiring a new service. Ingrid described herself as assertive and explained that she often requested high involvement from professionals. By being more assertive, she negotiated a higher degree of involvement from the coordinator. Another mother, Nora, argued that her coordinator was essential to her:

She [the coordinator] has helped me with multiple applications and appeals, with things at the hospital, with the school and with the municipal service office, which we have had big problems with. And she has done much of the talking... She does much more than is expected of her. (Nora)

Nora explained that her coordinator stands by her side in tackling the loss of autonomy and stresses of attending tough meetings with other professionals. She is grateful and advised that her coordinator does not need to help her so comprehensively but that the coordinator does it out of sympathy and care for her. The practical and emotional support she receives from her coordinator helps her tackle the psychological costs of her administrative burden, as well as the learning and compliance costs. Nora does not describe herself as assertive but is grateful for her coordinator. By being grateful, she reinforces their good relationship.

However, not all parents reported that they had their coordinator on their side in their struggle for services. Those who understood the coordinator's role as limited considered their coordinator a neutral figure rather than their advocate. However, parents were seldom frustrated with their

coordinators per se; rather, they were frustrated with being refused services and with the lack of flexibility in the services they had. One mother reflected on the role of her coordinator in the greater health and welfare system: 'When the municipality is not willing to grant anything, there isn't much that she [the coordinator] can do either. It's not that she hasn't tried' (Benedicte). According to this mother, troubles arise from not being offered appropriate services. She argued that her coordinator has attempted to help her, but the problem is that the municipality does not provide the services she requires. Although the parents were frustrated with 'the system', they usually recognised the role of coordinators in the larger welfare system and understood that the coordinators had limited influence over decisions regarding services. The way parents considered their coordinator in relation to their psychological costs depended on the extent to which they believed the coordinators had their backs when facing the system.

Although parents often experience being at the mercy of their assigned coordinators, they have different lines of flight (Goodley 2007). Lines of flight is a concept used by Deleuze and Guattari and adopted by Dan Goodley to understand the parents of disabled children's ways of escaping narrow framings of their situation. Marianne told us that her child had recently been assigned a new coordinator who was hesitant to take on the task and subsequently went on sick leave. After a couple of months of attempting to get in touch with the municipality to acquire a new coordinator, Marianne wrote a complaint:

I wrote about what I was discontented with and explained that we wanted a new coordinator. And I wrote a little threat [laughter] that if I didn't get a reply before a certain amount of time, I was going to contact the county governor because that's my right... . And then my request went through. (Marianne)

After this, she was appointed an experienced coordinator with whom she had regular contact. In the last interview, we asked her about her current relationship with her coordinator, and she replied, 'I was at a place where the coordinator simply didn't work, but then I wrote a complaint and got the best!' (Marianne).

Parents were free to terminate their coordinator arrangements at any time. During our fieldwork, Camilla and Benedicte terminated their coordination groups and stopped collaborating with their coordinators without applying for new ones. Benedicte argued that the meetings were often used to simply update the coordinator on their current situation. Both argued that they received limited support (which both had attempted to negotiate) from their coordinators and argued that it was less burdensome for them to contact the service providers directly. Their children were also older, implying that they knew the welfare system better than parents with younger children and had already established what services they could receive, hence limiting the need for a coordinator.

COORDINATORS' PERSPECTIVES

Coordinators recognise parents' stories of high administrative burdens. They argue that these families have a lot on their plates and need support from the public. However, one of the issues they discussed most frequently amongst themselves was regarding when to get involved and when to leave tasks to the parents:

Some might want help with absolutely everything, but where do you draw the line between your role and what the parents in fact have to do themselves?
(Physiotherapist, interview)

The coordinators varied in the extent of their involvement and interpretation of their roles. However, a common perception was that being a coordinator means, at the very least, being a person that families can easily contact with their questions concerning health and welfare services. One coordinator argued, 'In general, I think a coordinator should be someone they can call if they have questions or need help with anything' (occupational therapist, interview). Parents are involved with a range of services, and having one person they can contact regarding their questions and concerns is valuable. However, since most coordinators are health professionals, they are seldom familiar with which welfare services are available to families; this implies that they also must learn how to navigate the system. Coordinators agree that

part of their job is to help families with the learning costs of having a disabled child. However, the coordinators vary in their interpretation of whether their professional obligations extend beyond providing families with information:

It's not like we have to do everything and make every call. I think that our role could sometimes be to find out where the parents can call and assign responsibility to the parents by saying, 'We can help you with this, but you have to reach out yourself'.
(Physiotherapist, focus group)

Several coordinators claimed that the best way to help parents was to teach them how to navigate the system. They believed the best way to do this was to let parents do most of the work themselves. The interpretation of what work belongs to coordinators and what tasks are parental obligations shifted towards assigning more responsibilities to the parents. This theme was discussed in a focus group:

Physiotherapist: I have the impression that we sometimes create passive parents. This can lead to increased helplessness, where the parents just argue that we can do everything and repudiate their responsibilities... .

Interviewer: Why is it important that families have the responsibility?

Physiotherapist: It is multifaceted. First, it's not like you have a coordinator for the rest of your life. You actually need to fix the basic things yourself. And we know that for these families, this is much more comprehensive, and we get it. However, if we as coordinators should do everything for the parents, then the role of the coordinator needs to be expanded substantially because we don't have the time and capacity to do it. And I don't know if it is right to do everything for the families, either.
(Physiotherapist, focus group)

Thus, it is evident that with their current resources, it is not possible for them to help families extensively. However, as noted in the excerpt above, this is also a normative question of accountability and self-reliance. The cited coordinator argued that parents need to be accountable for their children, and by doing too much for the parents, the coordinators are doing them a disservice. Being accountable for facilitating services for one's child is regarded as normal parental work. The coordinator believed that by not enabling parents to learn to navigate the system, they may create passive users who are unable to get by without assistance. The administrative burden, particularly compliance costs, was part of what this coordinator deemed ordinary parental responsibilities.

Some coordinators were more hands-on in working with families. These coordinators declared that they often worked extra hours to help their families. They carried out tasks beyond providing information, such as helping families with applications or contacting other professionals. One coordinator claimed:

I think I am more involved with these children than I should be. For instance, I tell the parents, 'Just sign this paper, and I will apply for you'. And I am rather kind to a fault, but I have to be. (School nurse, interview)

This coordinator argued that she often goes beyond the scope of her role to provide support for families, including helping them with applications. Her rationale for doing so was that she was a nurse by profession, and she reported that she is an exceptionally caring person, bordering on "being naïve". She did not argue that tasks such as writing applications are not the responsibility of parents. Her argument was that although these tasks are part of parental responsibilities, these families need extra support because they have too much on their plates.

Furthermore, the coordinators acknowledged the psychological stress these families face when navigating welfare bureaucracies. Several argued that parents are 'overwhelmed' or feel 'let down by the system'. However, the coordinators varied in how they supported families in dealing with the psychological costs of their administrative burdens. The head of a local coordination unit, who is also an experienced coordinator, elaborated on how it is important for coordinators to remain neutral even though they might agree with a family's frustrations. In supervising other coordinators, she often advises them as follows:

To be a coordinator is to be a neutral person. In the first meeting, you sort out expectations. Some will typically go, 'Poor family, they have no services and way too little relief—ugh, it's awful'. Thus, as a coordinator, it is important not to get carried away. Because if you promise something on behalf of the municipality, it can put you in a squeeze. (Disability nurse, interview)

She argued that being too supportive of families by agreeing that they receive too little can put coordinators in a position where the families become even more frustrated and lose trust in the coordinator if the service is not granted. The fact that these coordinators have no resources or power to grant any services but are the frontline representatives of the system puts them in a squeeze. This Janus-faced nature of the coordinators is boosted if parents are dissatisfied with the services provided to them. However, other coordinators argued that the most crucial feature of their role is to support families emotionally and relationally in navigating the concerned systems, even though they may go against the rest of the municipal system:

In my cases, it has been about fixing the relationship with the municipality; they hate us and everything we haven't done... It feels like they are at war, and I am trying to be the negotiator, and they become known as 'that family'. But they are only ordinary people who are experiencing a crisis and maybe say some wrong things, and things get out of hand. (Special education teacher, focus group)

Furthermore, coordinators see their roles as interconnected with the rest of the welfare system. Being more familiar with the available services than most parents, several coordinators argued that a central aspect of their job is to guide parents' expectations regarding what it is possible to achieve. One coordinator described her role in the following manner:

You are an important ally for the family but also a person who can tell them what is not possible to achieve. Because we receive some requests where there is a huge gap between expectations and the here and now. Unfortunately, our role is often that of providing families with realistic expectations about what they can achieve, and that is perhaps the worst part of the job. (Physiotherapist, focus group)

Parents often have expectations regarding the level, flexibility, and processing time of available services that coordinators feel are unrealistic. Hence, they need to guide parents' expectations towards what is possible to achieve in terms of the provision of services. By attempting to create realistic expectations among parents, coordinators hope to limit psychological costs as the gap between expectations and reality is reduced.

Furthermore, some coordinators argued that how they are involved is often related to the characteristics of the families they serve. The coordinators described how they enjoyed working with families that were grateful for the work they put in. The coordinator working with an immigrant family with limited Norwegian language skills, reported that she enjoys working with families who 'do not only see the negative stuff':

Obviously, it is easier when someone is grateful and you are not just getting yelled at. I care, and I have always been told that in my job as a nurse, I care especially for vulnerable families and those who struggle more than others. I am very engaged in helping others and when they also are grateful, I think, 'Okay, this is time-consuming, but it means the world to them'. (Nurse, interview)

This coordinator describes her relationship with the family. They were rather grateful for the help they received. The coordinator argued that helping vulnerable families is particularly important to her. However, other coordinators argued that families differ in their expectations about their coordinator's involvement and that families with fewer resources struggle to get the help they need:

Undoubtedly, those with more resources are better at using me and the available services than those who don't know about the services or are not used to standing up for getting these services to the same degree. They are less visible and disappear a bit. (School nurse, interview)

She argued that those with more resources, such as economic resources or a higher education degree, contact her more often to acquire support in tackling their administrative burden. By contacting her more frequently, they may receive more support during the administration of their services and obtain better services than parents with a lesser sense of entitlement.

CONCLUDING DISCUSSION

This article shows that parents face an administrative burden involving learning about services, complying with rules and regulations, and managing psychological stress related to encounters with professionals. Furthermore, this study has demonstrated that coordinators argue that they assist families by conveying information about services but differ in their understanding of whether their job is to provide further assistance. Consistent with previous research (Runswick-Cole 2007; Nowak et al. 2013; Kittelsaa & Tøssebro 2014; Thomas 2021), the findings show that families with disabled children struggle to access public services.

Similar to Traustadottir (1991), Ryan & Runswick-Cole (2008), and Blum (2015), I find that a central part of mothering a disabled child in a modern welfare state is 'fighting' systems and bureaucracies. This mothering includes what Green (2007) called an *objective burden*. By using the concept of administrative burden (Herd & Moynihan 2019), I show that the objective burden that parents face involves learning, compliance, and psychological costs. These different costs are distinct features involved in navigating welfare services for families. Learning and compliance costs are often mixed for parents, and acquiring a service involves both. Understanding how to best comply with rules and regulations involves much learning. Parents also talk about psychological costs, such as feeling that they have experienced unfair treatment, arbitrariness, and discrimination related to navigating welfare bureaucracies. As Gundersen (2012) argued, these families feel let down by the welfare state. The discrepancy between the state's ideology and the practical reality that parents experience, particularly in interactions with municipalities, is a source of psychological resentment among parents.

The findings show that parents feel more emotionally supported by their coordinators when they are aided in tackling learning and compliance costs. This, in turn, affects the amount of psychological costs they report. According to Thomas (2021) and Skagestad et al. (2023), parents often experience stigma from institutions, contributing to a wider hostility towards disabled people and their families. Green (2007) showed that perceived stigma towards individuals with disabilities can increase the objective burden faced by mothers. Therefore, coordinators' attitudes and values may impact parents' experiences of their administrative burden and subjective burdens, such as embarrassment, guilt, resentment, entrapment, and emotional upset. Additionally, receiving support from coordinators can make parents feel less alone in their struggles.

By also drawing on interviews with coordinators, the article shows that coordinators recognise that parents face a high administrative burden that involves all related costs. However, coordinators hold numerous internal discussions regarding when to get involved and when to leave tasks to parents. Albertini Früh et al. (2023) showed that coordinators are stretched between high demands and limited time, affecting how much they help families. As street-level bureaucrats, coordinators have significant discretion regarding how to carry out their role insofar as they have substantial autonomy and few clear regulations to abide by. Their decision-making is, nevertheless, not found in the granting or denying of services. Rather, it lies in balancing a lack of time and resources with demanding and complex tasks that they often have little experience carrying out. Because of these organisational issues, I argue that municipalities assign decisions regarding how much help these families should receive in navigating services to coordinators. Because they have limited time, coordinators often do not prioritise helping these families with compliance costs and instead stick to providing information. Coordinators are caught in a zero-sum game between carrying out their ordinary jobs (e.g., as physiotherapists) and helping these families. Consequently, they may limit their involvement, often compromising their conscience, or become involved by going beyond their full-time positions.

As Johannessen (2019) pointed out, street-level policy is often an interactional accomplishment between street-level bureaucrats and users. How a policy plays out is the result of professionals

exercising their discretion in interactions with users. I argue that parents and coordinators negotiate their roles insofar as parents try to get coordinators to become more involved than they are, and coordinators try to limit their involvement. However, the negotiation is happening in a specific negotiation context in which coordinators have limited time and resources, and there is an uneven balance of power. The uneven balance of power relates in part to how epistemic power is unevenly distributed between parents and professionals. Mladenov and Dimitrova (2022) showed that parents of disabled children are constantly undermined and deprived as epistemic peers (i.e., they suffer epistemic injustices) in meetings with professionals. I argue that parents face epistemic injustice in not having their cries for help and more support taken seriously by all coordinators. In my research, some coordinators argued that parents seek assistance with everything. This implies a perception that parents do not take their responsibilities as caregivers seriously and want the welfare state to solve all their problems. Parents requests are dismissed due to the claim that these are 'ordinary parental tasks'. This resembles discourses of mother-blame found in previous research on mothers' involvement with bureaucratized professionals (Blum 2007; Malacrida 2003). Blum (2007) argued that although a medicalized framing does relieve mothers of blame for their child's troubles, shifts to higher accountability of relentless actions of mothers' involvement in their children's development still provide mothers of disabled children with experiences of mother-blame. Being turned down by coordinators is a devaluation of their efforts as mothers, as they fail to fulfil what are portrayed as 'ordinary parental tasks'. Furthermore, coordinators prevent many issues from being negotiated by limiting the boundaries of the legitimacy of their negotiations with parents (e.g., by refusing to assist parents at hospital visits or in medical or pedagogical reviews). Moreover, coordinators' involvement and boundaries also relate to normative questions regarding the boundaries of the welfare state. Although coordinators recognise that these families face an extraordinary administrative burden, most appear to argue that tackling the administrative burden is a parental task and not the responsibility of the welfare state.

Furthermore, the negotiation (context) is characterised by a quick segmentation of roles. Both coordinators and parents point out that the initial stage after being assigned a coordinator is crucial for clarifying expectations and negotiating roles. For coordinators, who have the most power in the situation, this usually means lowering parents' expectations. Coordinators are advised to 'not get carried away' and beware of being 'eaten alive'. Parents' expectations often decrease after initial contact. In other words, negotiations are primarily carried out at the start of their relationship, and coordinators seem eager to establish their boundaries as early as possible. After the initial phase, roles are established and the relationship often becomes settled. Despite this, parents attempt to negotiate the role and involvement of coordinators after the initial period. For example, Marianne, a middle-class mother, was successfully appointed a new coordinator who was much more hands-on in helping her with compliance costs. Jacobsen (2023) showed how levels of cultural capital can help parents in enduring the navigation of welfare institutions. Parents willing to question or challenge bureaucrats are more likely to get what they want than those who simply defer to the bureaucratic system. Assertiveness is associated with variables such as class and education (Lareau 2011). However, for parents with disabled children, assertiveness is often pathologised (McKeever & Miller 2004), and even parents with class advantages have little authority to confront specialists in medical and educational systems (Blum 2015). Nevertheless, class advantages may help parents keep communications pleasant when dealing with professionals (Jacobsen 2023). Another aspect of parents' attempts to navigate the welfare system is how families learn to navigate the system and gather experiences in navigating institutions, which may make families with more experience better negotiators (McKeever & Miller 2004).

In conclusion, parents face an extensive administrative burden in navigating their children's welfare services. Coordinators vary in terms of whether they do more than provide parents with information, and there is a significant amount of arbitrariness in how the coordinators' tasks are carried out. This arbitrariness may lead to more significant inequalities, and the welfare state, which is supposed to limit social inequalities, may thus reinforce these inequalities instead.

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The author has no competing interests to declare.

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