

Human dignity at stake – how parents of disabled children experience the welfare system

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Caring for children with special needs and enhancing their potential is an undisputed collective concern; the Norwegian welfare state has established a range of economic benefits and social services to help families with demanding tasks achieve a dignified life. Based on interviews with 11 parents of children with severe physical and learning disabilities, this article explores parents' experiences with the process of obtaining public recognition and compensation for private care work. The analysis shows that the process of applying for such benefits may actually leave parents with a sense of bereavement. Applying means presenting a beloved child as distinctly unequal to other children, and having an application rejected induces an emotionally strong reaction. To provide a setting for the empirical analysis, the article draws on parts of Martha Nussbaum's theory about the conditions for human dignity and her conceptualization of capabilities.

Keywords: parents; disabled children; welfare state; recognition; capabilities; human dignity; self-conception

Introduction

Families with disabled children usually face different and greater challenges than other families and need assistance and economic support if they are to give those children a dignified life. Within the larger framework of the Norwegian welfare state, it is an articulated ideal that all citizens should have adequate possibilities for personal development, participation and self-realization, and, as far as possible, the right to make decisions related to their own life (Ministry of Children, Equality and Social Inclusion 2011). Moreover, it is generally agreed that the preferred place for disabled children to grow up is within the family (St.meld.40 2002–2003). The explicit policy goal is to offer families with disabled children coordinated and flexible services in order to accommodate their needs and enable them to live as normal a family life as possible.

However, recurrent studies find that there is a gap between the welfare state ideals and the reality as experienced by caregivers and people with disabilities (Gustavsson et al. 2005). One of the most distressing aspects for parents caring for a disabled child is their continuous involvement in negotiation, tension and conflict with service providers about public support and assistance (Brett 2002; Read 2000; Lundeby and Tøssebro 2006, 2008; Todd and Jones 2003; Tøssebro and Lundeby 2002; Runswick-Cole 2007). Lack of timely information from social services, providers and other

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professionals about available services and benefits is a recurring challenge (Mitchell and Sloper 2001; Lundeby 2006), and parents who receive services commonly experience a responsibility for coordinating them. These factors add to parents' workload, disrupt family routine, and produce emotional stress (Askheim et al. 2006; Grue 1998). Using this as a point of departure, this article aims to gain further insight into parents' experiences of having legitimate needs for services and benefits that are not met by the welfare state. More specifically, it analyses parents' emotional reactions to having their applications for support accepted or turned down by the relevant authorities. By exploring these parents' experiences with the welfare system and drawing on theories about the relationship between self-concept and recognition, this article contributes to the discussion about the gap between welfare state ideals and everyday reality.

Experience of self and recognition

Recognition is important in human development and for maintenance of a positive conception of self (see, for example Giddens 1994; Honneth 2003; Goffman 1980). Self-concept refers to the continuity, however imperfect, of an individual's experience of self in a variety of situations (Turner 1976). However, one's experience of self is not static; it is an object in relation to other objects, all of which are modified through dynamic relationships (Berger 1966). According to Goffman (1980, 101), a person's self-concept is strongly influenced by the values and attributes society places on his or her role, status or relationships. Because the nature of these values and attributes is generally associated with the character of the person in a particular role, status or relationship, a change in the values or attributes can lead to a change in the person's self-concept.

Parents of disabled children can experience such an alteration in self-concept because although children and the parental role in general are highly valued, disabled children, particularly those with mental impairments, are more often, as Kittay (2002) phrases it, 'difficult to celebrate.' This lesser value is reflected in parents' descriptions of their initial reaction after learning about their child's impairment, in their use of words like shock, loss, grief and anger (see, for example Fisher 2008; McLaughlin 2005). Examples of an altered self-concept are revealed when parents start blaming themselves by questioning their own genetic inheritance or, in the case of mothers, their conduct during pregnancy (Landsman 2009; Gundersen 2011), or when they experience professionals not treating them as 'ordinary' parents (Todd 2003; Fisher 2008).

To maintain a positive sense of self, people are dependent on intersubjective recognition, which, according to Honneth (2003), is institutionalized in society in three domains of life: love in the form of intimate relationships, equality in relation to the law, and achievement in the experience of one's abilities as respected and valued by others. In all three domains, Yar (2001, 59) finds that 'the establishment of one's understanding is inextricably dependent on recognition or affirmation on the part of others, with all three types of recognition leading to human beings enjoying dignity and integrity.' When discussing parents' experiences in relation to the welfare system, I draw on this understanding of the relationship between recognition and self.

Dignity and capability

To provide a setting, or stage, for the empirical analysis, I draw on parts of Martha Nussbaum's (2006, 2002) theory about the conditions for human dignity and her conceptualization of capabilities. The rationale behind this approach is twofold: firstly, the ideal of the Norwegian welfare system can be seen to mirror the normative stance of Nussbaum's claim, that is, the irrefutable importance for a just society to strive for dignity for all its citizens; secondly, Nussbaum offers a way to conceptualize the nature of the work that parents do when taking care of their disabled child.

Nussbaum argues that simply by being human all persons are of equal dignity and worth; hence, the equal citizenship of people with physical and mental impairments should be recognized, and the focus should be on what people are actually able to do and to be. The role of governments should be to provide a framework of core entitlements that facilitates the building of human capabilities (Nussbaum and Sen 1993; Nussbaum 2002). The capability approach begins with the concept of the person as a social being and with a moral claim to support the dignity of all individuals' human needs, regardless of a person's productivity. Dignity, according to Nussbaum (2006, 162), is not defined prior to and independently of human capabilities, but is intertwined with them and their definitions. She lists 10 aspects of living that she holds as important for a dignified existence: life; bodily health; bodily integrity; senses, imagination, and thought; emotions; practical reason; affiliations; other species; play; and control over one's environment (Nussbaum 2006, 76–7). Although one may disagree with the list of capabilities (see for example, Sen 2005), the significant aspect of Nussbaum's approach in this article is her emphasis on the importance of developing all individuals' capabilities. Within this context, a decent society should establish the social conditions that allow for addressing and supporting physically and mentally impaired adults' and children's needs for care, education, self-respect, activity and friendship.

Because not all humans are able to develop their capabilities without help – people with extraordinary challenges due to physical and/or intellectual impairments are good examples – parents or guardians have to play a key role in seeing that their dependants' needs are met and their capabilities realized to the highest possible level (Nussbaum 2006). Such caregiving takes time and energy, and a just society should take into account the burden it places on these caregivers and appropriately support them. Moreover, a just society should arrange for care in a way that does not exploit the caregiver, meaning that it should not take advantage of but should give compensation and recognition for the vast amount of care work done, primarily by mothers (Nussbaum 2006). In principle, the Norwegian welfare state offers different kinds of economic and practical support with the intent of easing parents' caregiving burdens, promoting equal opportunity for all parents to provide their children with optimal development possibilities (ASD 2005), and making it possible for parents to combine work and care (and the Working Environment Act by 1 July 2010; as now specified in the National Insurance Act).

Offers to caregivers from the Norwegian welfare system

The responsibility for organizing and providing various kinds of services and benefits is divided between municipal and state administrations. Entitlements to services and benefits from municipalities are regulated by the Norwegian Social Services Act,

which states that all inhabitants who are unable to care for themselves or are dependent on practical or personal assistance have the right to necessary and appropriate services (§ 4-3). However, it is up to the different municipalities to make decisions about how to organize and provide the services (§ 8-4. [Ot.prp.nr.44 2007–2008]).

The state's National Insurance Scheme (chapter 6) regulates parents' rights to different kinds of economic compensation (attendance benefit, nursing allowance) for documented extraordinary expenses and documented special supervision tasks and caregiving for persons with lasting illnesses, injuries or intellectual impairment. These entitlements are not intended to compensate for income loss, but for the extra costs and burden of care.

To ensure that the welfare system's impartiality is not questionable, rights-based distribution is preferred (Helgøy, Ravneberg, and Solvang 2000; Bleiklie 1997). However, discretion is important when determining the nature, amount, and quality of benefits and sanctions. Hence, decisions regarding welfare services and benefits are based on documentation regarding the severity of the child's challenges and the caregiver's workload. For example, when the Norwegian Labour and Welfare Service (NAV) makes decisions about whether to grant a benefit, documentation is required from both the physician and the caregiver. They have to document: (1) the severity of the physical and/or intellectual impairment; (2) the extent of the care and supervision tasks; (3) the disabled child's need for extraordinary stimulation, education and training; and (4) the extent of the burden placed on those performing these tasks.

In principle, all who meet the demands are entitled to benefits on a level reflecting the burden of care or services reflecting disabled person's needs. In reality, differences exists between the nature, amount and quality of the benefits and services granted because municipalities have to manage the provision of services and benefits according to their individual economic and organizational circumstances (NOU 2005:06). Although the welfare system in principle represents an impersonal bureaucracy, it is caseworkers who have to balance clients' needs and municipalities' constraints on behalf of the system, and because of this they are often the target of criticism (Lipsky 1980; Terum 2003; Bleiklie 1997). The analysis in this article revolves around parents' experiences of having to document their claims and their reactions to decisions made by the authorities in response to those claims.

The study: method and data

The analysis in this article is based on data from qualitative interviews with eight mothers and three fathers of 12 children¹ with rare genetic conditions, the children range in age from 18 months to 16 years. The interviews are part of a larger study that also comprises a survey; the overall purpose is to investigate parents' reasons for seeking information when they have a child with a rare genetic condition. With the endorsement of one of the Norwegian Regional Committees for Medical Research Ethics and the Norwegian Data Inspectorate for the Social Sciences, the survey and most of the interviews were carried out in 2007.

For the interviews, I aimed at recruiting parents with different backgrounds and with children having different challenges. Three mothers were recruited through professional contacts and two through personal acquaintances, and three mothers and one father volunteered after receiving information about the study at a seminar arranged by a centre of expertise for parents engaged in support work. Recruiting

fathers proved difficult; eventually two were engaged through contact information in the survey.² One reason parents gave for participating in the study was that they had experienced difficulties in obtaining information that they considered important for enabling them to cope with the news of their child's condition. A common feature among the interviewees was a high level of reflection, something that may be a precondition for sharing difficult experiences with a stranger. The parents differed in their views and experiences, and the analysis did not show any differences pointing back to the way they were recruited. I interviewed five mothers in their homes; the husbands of the four who were married were not present. I interviewed two fathers and one mother in my office, one mother in her office, and one mother and one father at a cafe. Before each interview, the parent received information about the purpose of the study, and written consent was obtained. The interviews, each lasting 1.5–3 hours, were recorded and transcribed. Pseudonyms are used here to ensure confidentiality.

The parents range in age from 28 to 42 years. One has less than high school education, three have high school or equivalent, six hold bachelor's degrees, and two have an advanced university degree. Two are divorced and nine are married. According to the parents, two of the children have no learning difficulties, eight have some difficulties, and two have severe physical and learning disabilities. All of the children have one or more physical challenges and are in need of extended help and assistance to aid their development.

In the interviews, I used an open, non-structured approach (Kvale 1996) to explore the parents' reasons for seeking information. I started by asking them to 'tell their story' from when they first learned about their child's condition up to the present. Topics covered in all the interviews included: parents' experiences with and need for health and welfare services, and if and why they searched for information and social support from other parents regarding such services. There was little need to interfere or guide the parents because all had profound experiences to share.

In this study I am inspired by the sociological approach of symbolic interactionism (for example George H. Mead, see Collins 1994). The approach suggests that meaning is made and evolves through interactions embedded in social contexts and that people act on the basis of how they define and redefine a situation through their interactions (Strauss and Corbin 1998). In other words, when exploring human behaviour one needs to focus on social processes rather than on characteristics of individuals. My aim was to establish an in-depth understanding of the parents' experiences, that is, to capture their subjective perceptions and reflections about their information needs as related to specific situations and experiences in their interactions with relatives and friends, professionals and social systems. After transcribing the interviews consecutively, I went through them several times to acquaint myself thoroughly with each one. I coded each interview manually for important themes and then, using these themes, conducted systematic comparisons to find confirming, differing and contradictory narratives among and within the stories (Blanche and Durrheim 2004).

One theme to emerge in the interviews was parents' efforts to help their children in different ways. Another was how experiences of distress and strain seemed related not only to their child's extraordinary care demands, but also to their relationship with the welfare system.

Findings

Understandably, when first learning that their child had a suspected or confirmed rare genetic condition that was likely to entail physical and/or mental impairment, the interviewed parents were most interested in finding information that would enable them to comprehend both the condition and its potential impact on their life situation. Additionally, they needed time to adjust to the news about their child's disorder and to learn about the possible implications and the specific markers for their child. They also had to redefine their understanding of their parental role in terms of the child's needs (Gundersen 2011).

At this point rights and entitlements were matters of lower importance; most said, in fact, that they were initially unaware that they had entitlements. One reason they gave for this lack of awareness was that they had no previous experience in securing services or benefits from the welfare system. Another reason was that they had received little or no information from the welfare system about the entitlements.

Once they learned about their rights, however, they did a thorough evaluation to determine whether their situation fulfilled the application criteria. For instance, they assessed time spent following up on their child's appointments with doctors, physiotherapists, speech therapist, educational counselling services either at home or at nursery school, the child's care responsibility group, and so forth. Some children had specific issues with their back, arms, legs, feet or hands, and their parents recounted spending up to three hours every day massaging, bending and/or stretching the affected area to reduce the effects of the physical condition. Eight of the children had learning problems and were born with weak muscles, a common finding among children with chromosomal disorders and an indicator that they will need more help and resources than children in general. After comparing their daily care tasks to the criteria set out by the authorities for entitlement to specific services and benefits, 10 of the 11 parents thought they had a justifiable claim for one or more services and/or benefits. They also said that they adjusted the size of their claims in keeping with the child's challenges.

Documentation of care burden

The authorities' requirement for documentation means that parents have to emphasize the burden of care to access their rights on their child's behalf. This imposes a demand on parents to give thorough and detailed descriptions of their daily care tasks, emphasizing the negative aspects of caring for a disabled child. Regardless of the child's functional level, the parents said they fulfilled this requirement with great remorse. Although giving a child with mental and/or physical impairments capabilities that will optimize their capacity involves extra work and worries, most parents indicated that they actively tried to focus on the positive aspects of their situation. Most also said that as their child grew older the experiences of everyday life were somehow normalized, and they did not think much about their child's differences. As one parent, Theresa, put it, 'He is actually my main reference as to what a four-year-old is like.'

All of the parents found that having to write down and thus emphasize their child's shortcomings was painful. One mother, Gry, said:

It is extremely emotionally excruciating to have to do something special to confirm that he is not like others . . . never to be allowed to write how well he is doing, only about the tragic stuff.

One strategy used by some of the parents to reduce these negative feelings was to add a positive comment about their child at the end of the description. Victoria, for example, said she usually wrote ' . . . and he is just wonderful, and we love him very much.' After writing down solely how their child is a burden in their daily lives, adding such a remark can be interpreted as a way for parents to make amends for compromising their child's integrity.

An additional reason some parents gave for finding the requirement to document their situation so difficult was that it made them feel suspected of using their child to swindle the welfare system, 'as if, unwarranted, I had put a straw into the public treasury,' as Ingrid said. Adding to this experience was the fact that the parents regularly had to renew their claims by re-documenting their circumstances, a necessity prompting one parent, Victoria, to comment, 'As if a chromosomal disorder will go away.' The majority of parents therefore thought that the physician's description of the child's medical condition and its consequences should be enough to justify claims for benefits.

Parents' experiences with requests for documentation seemed partly to depend on the response they had received regarding their first application. The four who said they had been granted the applied-for benefit on their first request seemed less disturbed by the demands for documentation. Three of these parents have children with a syndrome for which some information was available at the time, and they described their child's difficulties as not overly severe. It is possible that a greater awareness of a particular syndrome influences the chances of parents receiving a positive response to their initial application for benefits. As Rob said:

We have been granted the lowest rate of attendance benefit, something all children with Prader-Willis syndrome receive. Children with greater challenges are routinely granted an increased rate.

Kathrin, who has two disabled children, rather dryly suggested that her situation has an advantage: 'No one doubts that we are in need of help.' In contrast, the six parents who have children with extremely rare genetic conditions experienced more difficulties in obtaining benefits and services; moreover, five of them had applied for a higher-rate attendance benefit due to the severity of their child's challenges. The impression from this exploratory study is that parents of children with the least known yet often heaviest care burden had the greatest difficulty gaining approval for the requested benefits and services, which added even more stress to their daily lives.

Questioning parents' care burden

The way a caseworker communicates a negative response to an applications for support can influence how parents experience the response. Parents do receive answers that they feel misrepresent their situation and belittle their daily efforts to

increase their child's capabilities. For instance, three mothers said that their application for an attendance benefit had been refused on the grounds that all children under the age of three need their parents. Ann, the mother of a child with severe physical and intellectual disabilities, offered:

The day we received the decision I was at the supermarket with my three-year-old son, who sat in a wheelchair, unable to hold his head up, to talk or to tell me about his needs, and there a child came running and jumping towards us with a crown on her head, stating that she was three years old. That hurt! So, it felt very strange to get a judgment saying that Tom is like every other child who needs his parents. They [the caseworkers] should have borrowed him for a week.

After receiving the grounds for the decision, all three mothers said their first response was to start questioning their own endeavours, but they soon concluded that the statement was both preposterous and insulting. Their anger towards the system increased. Two of the mothers decided to 'fight back' by writing appeals, which eventually resulted in the granting of their initial claims. The third, however, whose child has physical impairments, said she found the response so condescending that she decided not to have anything further to do with social services. Instead, she would try to get a tax reduction for care-related costs such as her weekly visits to the hospital with her daughter.

The resentment felt by these parents stemmed from the welfare system's response, which they experienced as a devaluation of the enormous amount of care work they performed regardless of the child's age. Their reaction may also be connected to how such a reply signals an underestimation of the emotional and psychological stresses they may be experiencing. For instance, from the time he was a baby, Ann's child occasionally stopped breathing in his sleep, which caused her great distress. Such psychological factors may go unrecognized if the system makes decisions based solely on the evaluation of practical care work

Discounting parents' efforts and sacrifices

Although the parents generally found responding to requests for documentation difficult, some saw the requests as unreasonable. This seemed to be the case for those who felt that the requests signaled doubts about their efforts to increase their child's capabilities, and questioned the sacrifices they were making for their child. The following example is illustrative.

Victoria has a five-year-old son, Knut, who has a rare chromosomal disorder. As an infant, Knut was unable to suck, so to improve his chances of living and getting adequate nourishment, Victoria spent hours each day feeding him with a spoon. To increase his bodily integrity, she worked with him every day so he could learn to crawl and subsequently to walk. To enable Knut to communicate and thereby foster his capability to use his imagination, to think and to reason, the whole family learned how to communicate by using sign language.

This case shows how parents' care and attention fosters a child's capabilities, giving the individual a life that, according to Nussbaum, is worthy of human dignity. The efforts of Victoria and her husband allowed Knut to develop capabilities related to life, bodily health and integrity, and emotions (i.e. attachment to people and things outside himself).

Victoria had decided to quit work when her child was born so that she could provide the care demanded by his particular condition. When Knut was four, his parents participated in a seminar at a centre of expertise for parents of children with rare genetic conditions, and that is when they first received complete information about all of their support-related entitlements. At the seminar Victoria learned not only that she was entitled to an allowance compensating her for her care work, but that she probably was entitled to back payment as well. However, when she applied for the allowance she felt that the social security office made a mockery of her request:

They said, 'There is no doubt that your son is in need of care, but if you want back payment, you have to prove that you and your husband were so emotionally broken that you did not understand that you should have applied for the nursing allowance.' I felt as though they were making a laughing stock out of us. The two first years were traumatic; Knut stopped breathing three times and nearly died. Who thinks about money then! We would have done anything to take care of our child, and at one point we even considered taking out a loan. Well, I never went through with it [applying for back payment].

Victoria thought she was entitled to the nursing allowance, or, in line with Nussbaum, to compensation and recognition for the care she had provided over the previous four years. But, as this case illustrates, instead of giving parents a sense that they are supported for the vast amount of caregiving they provide, the welfare state's administrative arrangements – requirements for documentation, for example – can have the inadvertent consequence of violating parents' dignity. Money can come at a price that parents feel is simply too high: the sacrifice of their self-respect. This case also shows how the system makes it the parents' responsibility to keep themselves updated about entitlements: It is the parents' own fault if they do not make timely applications.

Disregarding the family's needs and experience-based knowledge

According to the Social Service Act, municipalities have considerable freedom in determining how to organize and provide services (Ot.prp.nr.44, 2007–2008). Thus, the legal obligation to provide services tailored to individual needs and, as far as possible, in collaboration with parents, can conflict with a municipality's judgement of what constitutes the best possible support/benefit given the authority's economic and practical constraints. Parents can find it difficult to accept something other than what they applied for, particularly if they make their application on the basis of a thorough consideration of their child's and the family's needs. The following is a case in point.

Ann's seven-year-old son Tom has severe physical and mental impairments. He is dependent on his parents and others to assist him in moving around, eating and communicating, and Ann says that only those who know Tom are able to interpret his needs, preferences and dislikes. Ann wants Tom to live at home. A major challenge for the family is that they live in a two-storey flat with the bedrooms on the first floor. Tom weighs 20 kilos, and his mother is barely able to carry him up and down the stairs. To make it possible for Tom to live at home, Ann applied to the municipality for a personal assistant for Tom and for an accessible house or economic help to make their current house accessible. Her application was rejected, but the municipality offered Tom a place in a children's home. The rejection of her

application and the offer of an undesirable alternative propelled Ann into a lengthy fight with the municipality. For Ann, the offer to institutionalize Tom despite the family's wish to take care of him at home is an expression of the municipality's willingness to simply disregard the bond between them and their severely disabled child – as if the relationship were of an inferior kind. Consequently, Ann seems to regard the municipality, through its offer, as depriving Tom of his capability to experience the emotions associated with loving and being loved (Nussbaum 2006, 76) and, thus, of his status as a human being. She says:

We are so far apart on how we approach and value life with Tom. We, our family and our friends, we see Tom as Tom. He is our son, our first-born and the one we love the most together with his sister, and unfortunately he demands a lot of extra work and assistance. They [social services], on the other hand, see Tom primarily as a burden, as a lot of problems and extra work, and they forget that he is a beloved child.

When parents are denied what they see as legally due assistance to meet documented needs, they may interpret this as a violation not only of their child's dignity but also of their own. Such denials violate their capabilities of experiencing emotions and affiliations in the form of their right to love and nurture their own child, as well as their right not to be subjected to non-beneficial pain (e.g. a long-term illness such as the one suffered by Ann as a result of her physical and emotional care burden). Thus, not respecting a parent's wish to take care of her own child at home or offering less assistance than parents honestly believe they need to provide appropriate and adequate care may be interpreted as a request by the authorities for parents to sever their loving and supportive affiliation with their disabled child. The parents interviewed here were unwilling to make such a sacrifice. Instead, they opted to take on the extra burden of finding solutions, which included fighting the system and, for five of the mothers, quitting or reducing their out-of-home work activity.

Five parents said that they were not granted all of the benefits and services for which they had applied and which, by their judgement, were necessary for giving their children adequate care, for example, assistance in nursery school, care allowance, and practical assistance. Gunhild, for example, has a two-year-old daughter, Trine, with a condition entailing both severe physical and learning disabilities. Trine has full placement at a nursery school but assistance only three days a week, even though she needs help to regulate her food and drink intake and someone to watch over her constantly to ensure she does not fall. Trine has already suffered a severe concussion from being pushed off a low stool. On the days when there is no assistance for Trine, Gunhild continuously worries about her well-being. She has therefore applied for a care allowance that will allow her to afford to stay home and give Trine the capability to experience bodily health and integrity.

Gunhild's anger towards the municipality stems not only from her concern about her child's day-to-day well-being, but also, as expressed by other parents, from a feeling that her judgement regarding Trine's needs is not taken seriously. Bad arrangements can cause parental anxiety related to a child's wellbeing; they can also prevent parents from making preferred choices regarding their own lives. In Gunhild's case, inadequate social assistance forced her to conclude that combining paid work and family responsibilities was too difficult.

Underrating parents' efforts and children's needs

Parents are by law obligated to take responsibility for their children's well-being (Child Welfare Act 1981). However, they share some of this responsibility with the state. This study shows how parents go to great lengths to give their children the capabilities to develop their capacities according to their particular challenges and thereby enable them to have a dignified life. Thus, they may react strongly if they perceive that the state or the municipality does not keep its 'part of the agreement.'

One service disabled people are entitled to is a 'practical assistant,' an individual paid by the municipality to assist another person to have a social life and meaningful spare time (Social Services Act). This is a kind of service permits disabled children to enjoy a life outside the family, and, as such, it facilitates the child's capability to experience affiliation – by engaging in various forms of social interaction – and develops the senses – by being able to have pleasurable experiences (Nussbaum 2006).

Gry's son Nils is 16-years-old and has a rare syndrome that presents challenges related primarily to learning. The combination of a demanding job, extra care for Nils, and ongoing efforts to obtain and sustain needed services and benefits for her son was so taxing that Gry decided to abandon her career as an engineer and work instead as a secretary in an 80% position. She says that she takes great pride in Nils and his achievements, which she links partly to her own efforts. 'I want Nils to get the maximum out of his life from where he stands.' For Gry it is very important for Nils to develop skills, and her dream is that he will be able to move into his own apartment when he is 18 and continue school or find work.

Nils goes to a school for children with special needs. There he learns skills that Gry believes are valuable for building his capability to move away from home. The school is located 15 kilometres from where they live. Originally, Nils took a taxi to school; however, wanting to increase Nils' independence as he grew older, Gry taught him how to take the train alone. She also taught him how to use a cell phone so he could call home to let her know that he was all right and had arrived at school. Gry's parenting style displays the essence of what, according to Nussbaum (2006, 169–70), characterizes good individualized care for a person with mental impairments: She supports her son's capabilities according to his particular challenges and capacities.

To fulfil Nils' need for active and independent leisure time, the municipality approved Gry's application for a practical assistant to accompany Nils one afternoon a week to a leisure activity. Initially the assistant used one hour of this time accompanying Nils on the train. So when Nils learned to take the train by himself, he 'saved' one hour each week, time Gry thought of as 'his' to use for other activities. However, the municipality's response was to reduce Nils' assistance time by four hours a month. This angered Gry, who felt that she and Nils were being punished for increasing his independence, and it motivated her to challenge the decision. After several complaints, Nils retrieved the four hours, which gave him the opportunity to participate at a monthly assembly for youth with learning difficulties one Saturday a month. As Gry sees it, this opportunity led to an important improvement in Nils' life: 'It's super. He is so proud. Now he has friends to visit on the weekends, too. Before this the weekends were long and lonesome.'

It is evident from Gry's story that being granted a personal assistant for a few hours a week can add quality to leisure time for children with special needs. Not only does it increase their opportunities to play and enjoy recreational activities, it also

provides them with the freedom to do things away from their parents. Fostering these capabilities contributes to making a dignified life.

Gry's story of her efforts to increase the quality of her child's life was typical of the interviewees. Parents expected the municipality to recognize and support these efforts. When it did not, the parents ultimately concluded that the welfare system, as represented by individual caseworkers, was trying to escape its responsibilities. This interpretation of the authority's motivation may explain not only the parents' frustrations but also their eagerness to fight the system.

Discussion

From a system perspective, service providers are in a position where they have to reconcile clients' needs, wants and rights with limited resources. The interviewed parents are all 'children of the welfare state,' implying that they were born in Norway and thus grew up with an awareness of the state's financial limitations and professionals' need to balance available resources and clients' needs (Kjølørød 2005). So why do parents react so emotionally to the requirements and decisions imposed by the welfare state? In the following discussion, I point to two explanations, one concerning parents' self-concept and the other concerning the role of the state as an authority influencing how citizens perceive themselves in their various roles.

After learning about their child's disability and finding their previously envisioned future turned upside down, most parents go into a process whereby they adapt to the loss of their 'dream child' and cognitively adjust their expectations (Fisher 2008; Fisher and Goodley 2007; McLaughlin 2005). As they adapt to their new reality, they commit themselves to the concept of self that their new role as parent of a disabled child requires and allows them to have. Investing energy and resources in helping their child develop his or her capabilities, often at the expense of their own health and/or careers, seems to help these parents, especially the mothers in this study, restore a positive experience of self; and by doing so, they are simultaneously able to demonstrate good, even fantastic, parenting.

However, if such parents are to maintain a positive sense of self, recognition in the form of positive feedback is of utmost importance (Honneth 2003; Yar 2001). It is hardly surprising, then, from this perspective, that one of the most demeaning impacts on these parents' well-being stems from the requirement that they document the 'burden' of caring for their disabled child. Asking parents to point out and emphasize the negative aspects of their caregiving role and the sacrifices they are making for their child forces them to objectify their relationship with the child by defining themselves primarily as care providers and not as parents caring for their child out of love. Additionally, it demands that parents strip their child of positive qualities in the eyes of the state.

Further, this analysis shows how parents' caring relationship with their child can make them see the child's human dignity as independent of the impairment and its severity, a dignity that parents believe others should recognize as well. According to Olsen (2001), one way parents of disabled children communicate their child's dignity to other people is by telling positive stories. By passing on their image of their child in this way, they elevate the child's individuality and the pleasure they get from taking care of the child. Viewed from this perspective, the state's insistence that parents detail their child's inferiority in writing and the stress that this obligation imposes

sends the message that these parents have to compromise or devalue their relationship with their child and, as Olsen (2006) puts it, present themselves as victims of their disabled children. It also implies that instead of being given an opportunity to express pride in their children and in their own efforts and achievements, which is important for maintaining a positive experience of self, they are forced to deprive not only their child but also themselves of worth.

This can be a distressing, if not humiliating, exercise, so recognition of parents' efforts in the form of a positive response to their application for benefits is important in helping them retain a self-image that allows them to carry on with their lives. In this study, parents' anger can be seen as a response to being denied this kind of recognition. However, instead of falling into passivity, the parents continue to fight for what they perceive as their rights. Thus, their anger has become a source of energy, allowing them to act and to preserve a positive experience of self.

One way to interpret the official ideology of the Norwegian state is as recognition of the danger of the decimation of the value of people with disabilities. Policy documents (see for instance St.meld.40 2002–2003) emphasize that all humans are of the same worth regardless of their level of functioning and that the community has a particular social responsibility for disabled children and their families. In principle, the official ideology and the established rights of persons with disabilities signalize acknowledgment of the extra care work and sacrifices required of parents of disabled children. The analysis in this study, however, shows a discrepancy between the state's ideology and the practical reality experienced by these parents, particularly in interactions with the municipality. Not receiving what they deem necessary to provide good care for their child has caused them considerable distress. It has also provoked resentment seemingly connected to their unrealized expectations.

A consequence of municipal discretion is that it is extremely difficult for parents, as well as for the state, to 'force' a municipality to fulfil the governmental ideal (Kjønstad et al. 2000). Thus, given this structure of service delivery, it is easy to see parents' anger as an expression of the frustration they experience when municipal authorities make judgments that contradict their own experience-based assessment of what their child needs. They are left feeling not only that their knowledge is disparaged but also that they have no power or means to articulate their legitimate needs and what they value in their lives (Lundeby 2008).

Consistent with the reasoning of Honneth (2003) and Yar (2001), the resentment expressed by parents in this study can be seen as a consequence of experiencing the municipality's rejection of their requests as a signal from the welfare state that their abilities and efforts are neither respected nor valued. The effect is a lack of recognition of parents' work and sacrifices in caring for their disabled child and fostering the development of capabilities that make the child's life worthy of human dignity. Parents interpret the denial of adequate services as an expression of how their impaired children are viewed by the welfare system, namely, as having less human value than other children. As one of the mothers said, 'My municipality does not follow the law, saying it's because there is no money; but I think the reason is that the multi-handicapped have no value in society, so they reckon it's okay to break it.'

Conclusion

By using Martha Nussbaum's notion of capabilities, it is possible to conceptualize the vast amount of care work parents do to support their disabled children and make

it possible for them to live a life that is worthy of human dignity. The capability approach sheds light on how and why parents' resentment towards the welfare system in Norway can be linked to a failure of the state to recognize and respect them, as reflected by decisions to reject their applications for services or benefits to support or compensate them for the care work they provide. The consequence is that the Norwegian state, whose ideal is a society that shows respect for the human dignity of all its citizens, instead signals a devaluation of the work, sacrifices and love that parents of disabled children put into fostering those children's capabilities – partly on behalf of society.

The contradiction between parents' expectations of the welfare state and the everyday reality they experience increases their resentment and leaves them feeling that the state is working against instead of with them. This perhaps explains their 'fighting' spirit in a battle that is aided by easily available information and support from other parents, particularly through the Internet. Moreover, parents' negative experiences with municipal authorities appear to influence their more general view of social services and provoke feelings of greater resentment and stress with each new interaction on behalf of their child.

The analysis in this study suggests that what Nussbaum describes from a normative stance – that society should support caregivers, recognize their efforts, and compensate them for the enormous amount of work they do – is also seen by Norwegian parents as an important principle. One could assert that these parents' negative experiences with parts of the welfare state and its representatives are due to unrealistically high expectations. However, if we accept Nussbaum's argument about the importance of capabilities for human dignity, it is obvious that parents need practical support from the state if they are to appropriately and adequately nurture the capabilities of their children. Moreover, these parents' emotional association with their disabled children has to be recognized and supported by the state to ensure that the dignity of all parties is preserved.

One important consideration that has not been taken into account in this article is the strain put on the caseworkers and service providers who have to strike a balance between their loyalty as civil servants exercising a control function on behalf of the welfare state and their loyalty to citizens in need of help (Lipsky 1980; Terum 2003). How do they feel and react when they encounter people in need and have to reconcile the government's ideals and the municipality's limited resources?

Notes

1. One mother has two children with the same rare chromosome disorder.
2. 10 fathers provided contact information; four did not respond, and four others were ruled out because they lived too far away, making their participation practically and economically difficult.

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