

Exploring the Experiences of “Not Being Listened To” from the Perspective of Parents with Disabled Children

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ABSTRACT *Several studies report that parents of children with disabilities complain about professionals ignoring the parents' view and understanding of the child's needs. The aim of this paper is to explore the parents' experience of not being listened to from their own perspective. Findings are based on a longitudinal study including qualitative interviews with parents of 31 children with different types of impairments in pre-school (1999) and early school years (2002). Incidents where parents reported “not being listened to” were distinguished according to different types of conflicts or disagreements: (1) problem-defining; (2) gate-keeping; and (3) jurisdiction. The underlying problem as viewed by the parents was that their knowledge was not valued. Dilemmas and obstacles towards practising user-participation in parent–professional relationships are discussed. The findings suggest a necessity of negotiating partnership, as well as a more humble approach towards parents.*

KEYWORDS: Parents, disabled children, empowerment, user-perspective

Introduction

From the 1960s onwards, there has been important and extensive change in social policy as well as in research regarding the position and conceptualisation of service users. From viewing the users of welfare services as passive recipients, gradually they are understood as active and reflective agents (Sandbæk 2001).

According to Williams (2001), the idea of the active welfare agent (UK) has been driven by three different political trends. First, *the new liberals* were engaged in defending the individual's right to find their (private) solutions to a diversity of needs in a free market, understanding the user as a consumer. Second, *the new labour* was preoccupied with activation focusing on turning

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welfare recipients into wage earners, thereby reducing the number of dependent receivers. Third, *grass-roots movements* (including self-help groups) fought against socially excluding practices and unequal distribution of power, arguing for empowering users through democratisation of welfare services. Correspondingly, social movements run by disabled people both in North America and Europe, especially the United Kingdom, have fought for self-determination (Barnes, Mercer & Shakespeare 1999).

Due to these different forces users of welfare services today are given a more active and *empowered* role. The concept of empowerment is commonly used in public documents treating welfare services and professional/user relationships, often transformed into concepts such as user-perspective, user-rights, or user-participation (Askheim 2003). This is also the case when it comes to parents of disabled children. Today, there is agreement in Norwegian public policy that the family is the preferred place to grow up for children with disabilities. Furthermore, it is an expressed goal that families of children with disabilities should be offered coordinated and flexible services that are accommodated to their needs (ASD 2005, St.meld 40 2002–2003). In day care centres and schools, cooperation between parents and staff is regarded as important in order to provide for the child's best interests. Parents' rights and duties to participate and have genuine influence on their children's education are emphasized in legislation and the national school regulations (KD 1998, 2006). All of this points towards a strong parental influence on services.

Even though concepts like user-participation and empowerment are frequently used in policy, the practical influence does not necessarily follow (Andreassen 2004). First, the concept is given various definitions and meanings, opening for different interpretations. According to Askheim (2003), empowerment deals basically with giving the users of the welfare services some degree of influence and control over the services they receive. Moreover, empowerment is seen both as a goal and as means, as ideology as well as a methodical approach, fighting oppression against individuals as well as social groups (Askheim 2003). Further, in parent–professional relationships, empowerment is often seen as a process where families with disabled children should be offered knowledge, skills, and resources in order to gain a positive control over their own life situations (Dempsey & Dunst 2004). Second, in concrete encounters between professionals and parents, characteristics of the individuals, as well as structural factors such as organisation of services, distribution of power, economic or personal resources and time limits, may act as support or constraints against parents' interests as users.

It is argued in the literature that professionals often do not recognise parents' expertise concerning their children with disabilities (Case 2000, Grant, Nolan & Keady 2003, Lundeby & Tøssebro 2006, Mitchell & Sloper 2001, Read 2000). A common complaint from parents is that their views are not heard, although findings vary with respect to relative frequency of this experience. Knox, Parmenter, Atkinson & Yazbeck (2000) found that the great majority of parents actually felt they had some or considerable influence on decisions affecting their children with intellectual disabilities. However,

although they described their interaction with the service providers as a partnership, the majority considered this partnership to be a result of their own assertiveness, rather than professional encouragement (Knox *et al.* 2000). Focusing on parent–school relationships, Fylling and Sandvin (1999) found that the feeling of not being heard or taken seriously by teachers was among the most common complaints from parents of children receiving special education. In a study of good and bad practises, Mitchell and Sloper (2001) revealed that descriptions of quality staff attitudes were frequently based upon the antithesis of personal experiences. It was exactly this experience of not being listened to that made the parents aware of how important this dimension was, a finding also indicated in Prezant and Marshak's (2006) study on helpful actions. This paper seeks to explore the paradox between strong ideological leads towards user participation and the fact that many parents report a feeling of their views being disregarded.

What has been found to be of great importance to families is not just that parents are allowed to express their views, but that professionals ensure that parents may participate in defining the problem as well as choosing the proper solutions (Knox *et al.* 2000, Grant & Ramacharan 2001). Knox *et al.* (2000) argue that parental say depended on the individual professional and his/her attitude. Others point at structural factors, such as power differences between parents and professionals (e.g. Mitchell & Sloper 2001).

One problem in transforming the ideology of user participation into practice is the challenge it present to professionals' working practice (Andreassen 2004). The professional–parents relationship is often categorised according to the different roles and balance of power (e.g. Case 2000, Dale 1996, Ferguson 2001, Turnbull & Turnbull 1990). These vary from the traditional *expert model* where the professional holds the expert power to make judgements and decisions regarding proper actions, to a partnership and *negotiation model* where negotiation and joint decision-making are seen as key elements (Dale 1996). However, in most circumstances, a dilemma even for the most user-friendly professionals is the need to incorporate the *gate-keeper role*, prioritising the use of limited resources (Lipsky 1980).

Focusing on individual relationships, it is important to be aware of some of the dilemmas connected to transforming the ideology of empowerment into practice. Perhaps most obvious is the dilemma between what is considered best for the child and best for the parents. It is not given that the parents always act in accordance with the child's best interests. It is well-known that families are also arenas for child abuse and neglect. Another dilemma is how far professionals should go in trying to fulfil parental wishes. To what extent should they follow their professional convictions when confronted with a different set of ideas from the parents?

Although the literature frequently refers to parents' experience of "not being listened to", few studies have gone thoroughly into exploring what situations parents actually refer to when making such claims. The literature agrees on the importance of good listening skills from the professionals, but in order to improve such skills, it seems important to grasp exactly *what situations* and *what actions* from professionals are experienced as

non-listening *from the parents' point of view*. This may also be important in order to develop a practice closer to the ideal of user-participation and help that is actually regarded as useful. Sometimes frustration among parents is found in the fact that actions that may be considered helpful from the professional's point of view are considered of no use or even counter-productive by the users (Prezant & Marshak 2006).

The present paper goes beyond the question of *if or how often* parents experience not being listened to. Existing knowledge that this is a common complaint is taken as a point of departure. Accordingly, in this paper, only non-listening experiences are focused on, and only from the parents' point of view. The aim of this paper is to describe and explore situations experienced as non-listening from the parents' perspective, to distinguish different types of situations and understandings of these situations, and to point out possible traits of the service system or parent-professional relationship contributing to this experience.

Data and Method

This paper employs data from a longitudinal project following children with disabilities and their families, every three or four years, as the children grow up. This paper covers a four-year period. The study includes children with physical disabilities, intellectual disabilities, and multiple disabilities. The adaptive behaviour of the children varies. All the children included in the study were born in the years 1993, 1994 or 1995. The project consists of quantitative questionnaire studies, as well as qualitative interview studies. In this paper, data from the qualitative interviews of parents of 31 children at two points in time is used. In 1998, parents of pre-school children (aged 3–5 years) were interviewed. In the second round, in 2002, the children were early school age (7–9 years). The families lived in the county of Sør-Trøndelag in Mid-Norway. Participants were recruited from children registered at the Regional Rehabilitation Service, a part of the public health services established in every county across Norway. Children are in contact with these services either for diagnostic purposes, assessment, or for rehabilitation services. A request to participate in the study was sent to the parents of every child satisfying our criteria and registered in this service.

Interviews were carried out with one or both parents according to the parents' wishes. All interviews were conducted by first author, except three interviews in the first data collection that were conducted by the second author. They were all tape-recorded and transcribed. Quotations from the interviews have been translated into English by the first author. The study was conducted according to procedures approved by the relevant research ethic bodies: the Data Inspectorate and the Privacy Issue Unit. Table 1 gives characteristics of the participants.

We adopted a semi-structured approach for the interviews. An extensive interview guide covered several themes on growing up with impairments and being a family with a disabled child, including the relation to the service system. Parents were invited to speak freely, guided by open-ended grand tour

Table 1. Characteristics of participants ($N = 31$).

Child characteristics	Sex	Boys	14
		Girls	17
	Year of birth	1993	14
		1994	9
		1995	8
	Type of disability	Physical	11
		Intellectual	13
		Multiple	7
	Diagnosis	Cerebral Palsy	14
		Down Syndrome	7
Autism		4	
Others		6	
Parent characteristics	Age range (mean) in 2002	Mother	27–50 (33)
		Father	32–49 (35)
	Marital status, 1999, (2002)	Married/cohabiting	24 (23)
		Single mother	5 (5)
		Single father	1 (1)
		Mother/step-father	1 (2)
	Municipality of residence	Urban	18
		Rural	13
	Respondent in interview, 1999, (2002)	Mother	12 (14)
		Father	3 (3)
		Mother/father	15 (12)
		Mother/step-father	(1)
	Foster mother	1 (1)	

questions, followed by planned and spontaneous prompts. Parents were asked to tell about themselves, the child, the experience of giving birth to a disabled child or gradually discovering the disability, the everyday life and routines in the family, parents' experiences with day care services and school, and transitions between day care services and school. They were also asked to describe social services received by the child and the family, as well as the relationship and communication with public services, day care centres and school. The experiences of not being listened to were not particularly addressed, but were traced as a common topic in most of the parents' narratives on their experiences with the service system. In order to explore this experience, first, the 62 interviews were examined in order to trace all incidents parents report on not being listened to by professionals. In order to grasp the complexity and variety of such experiences, only situations where parents felt they were not listened to have been addressed. However, a parental experience of "listening" professionals is used as contrast. A broader analysis of the diversity of experiences with the service system is reported elsewhere (Lundeby & Tøssebro 2006).

The data were analysed by applying issue-focused procedures (Thagaard 2003) using matrices to categorise the different themes present in the material. Incidents of not being listened to were first categorized with an open procedure,

according to the characteristic theme for each incident. In a second step, the incidents were recoded into three more generalized categories according to underlying types of problems or conflicts common to situations across different themes. The final categories are based on the authors' interpretations and do not necessarily (although sometimes) reflect parents' understanding of the different situations. Rather than being clear empirical distinctions, the categories are ideal types, although most situations will be dominated by one type of problem. The findings are presented by giving examples of situations illustrating the different categories. This means that all possible situations within each category will not be presented; neither will we quantify the findings by counting incidents. We will however sometimes indicate whether a situation is typical or rare.

Findings

Most parents have varied experiences with the service system, reporting good and open dialogues and helpful actions from professionals as well as conflicts. Even so, nearly all of the parents reported "not being listened to" in one or more situations, and these are the experiences explored here. Some of these experiences seem to resemble general communication problems or misunderstandings. Those are not discussed in the paper. The focus is on situations where parents report problems in making their voice heard. These are situations that uncover different types of conflicts or disagreements between parents and professionals. The following three categories have been distinguished: (1) problem-defining; (2) gate-keeping; and (3) jurisdiction.

The Process of Problem Defining

Some parents reported considerable problems of having their view heard in different stages of the process of defining and finding solutions to a problem. We traced four different sorts of such difficulties or disagreements.

Is there a problem? For some parents the initial experience of "not being listened to" occurred when concerned about the possibility that there was something "wrong" with their child. This was quite a usual experience for parents of children with intellectual disabilities or behavioural problems (e.g. autism) not noticeable at birth. The parents presented their concern about their child's development at the child health centre or to a general practitioner. At this stage the child was not yet labelled as disabled. In order to have the child further examined, the parents were dependent upon having the professionals sharing a concern for the child's development. Some parents were met with advice to go home and stop worrying. Several experienced months of worrying, having to return many times, or to turn to several professionals before the child was properly examined. A mother of a severely disabled girl said:

I took her to the health centre when she was one year old. When a child is at that age, she should do quite a lot, but the only thing she did was roll on the floor. Then the doctor

said that she looked fine, and told me to go home and relax. But a doctor cannot say that after having seen her only ONCE...

Some parents expressed that they understood the professionals' behaviour, as they expected many worried parents just needed reassuring that there was nothing to worry about. However, for most of the parents in question here, they were already worried, and continued to be worried, and felt they were too easily turned down, resulting in delays in help for their children. Several parents reported that the child's problems had to escalate before they were listened to.

The degree of seriousness of a condition may be disputed. Also later on, some parents reported difficulties having medical professionals seeing or accepting a problem introduced by the parents. One girl with multiple disabilities suffered from reflux, resulting in gastric acid almost destroying her teeth. The parents had tried for a long time to get help for this problem. The mother stated:

We were never listened to, really, until the teeth were almost gone. Then suddenly, WOW, they started looking into it. So you have to be very clear about what you want. It is almost like you have to know what they need to examine her for.

The girl in this example was close to losing her teeth. Some families reported doctors being unfamiliar with their child's condition, refusing to send the child to a hospital as strongly requested by the parents. A few children were even close to losing their lives; and, parents of one child were asked to sign consent to stop lifesaving treatment for conditions later proven easy to cure. This represents classical judgements that medical professionals face every day, making use of their professional knowledge to decide what kind of treatment is appropriate. Nevertheless, although reported only by a minority of the parents, not listening to parents in these situations had very serious consequences. To the parents, such experiences lead to lack of confidence in professional knowledge and judgements.

Defining the child's abilities and needs. Many meetings between parents and professionals begin with establishing an accurate description of the child and his/her situation and needs. Professionals contribute their professional knowledge and interpretations, and parents are (sometimes) expected to contribute their descriptions and views. In such meetings, some parents felt that professionals disregard the parents' ability to offer accurate information, for instance describing what the child is capable of. According to the parents, their descriptions were not taken seriously until a professional made the same observation.

Generally speaking, professionals frequently have to make judgements about a child based on limited information, examinations, or test results. Moreover, professionals may have important contributions based on knowledge not available to parents, but many parents see themselves as the only ones who really know the child as a whole person within its natural setting. One severely disabled girl, for instance, managed to walk some steps at home

when the parents supported her. The parents noticed, however, how this information was disregarded by the professionals until the child managed to walk at the child care centre two months later. Furthermore, if parents found that the professionals' descriptions of the child were biased or outdated, or if parents felt the professionals did not acknowledge the parental understanding, the parents then had difficulties accepting the actions suggested by the professionals. This was the case for a mother refusing the physiotherapist's suggestion for an electric wheelchair for her daughter. At this point in time the mother had seen that she was able to walk. Accordingly, the mother found the suggestion was based on both an outdated and a too narrow set of observations.

Defining feelings and emotions. A few parents reported meeting professionals that questioned the parents' descriptions of their own feelings or needs. One example is a father of a girl with Down syndrome. The social worker at the hospital was eager to get him starting his sorrow work. This father reports how she would not listen when he told her that grieving was not what he felt like, and every effort to get some practical advice on how to take the best care of his daughter was turned down with reference to the important sorrow work.

There are probably many different reasons why parents sometimes feel they are not listened to when expressing their needs and feelings. Lack of time or resources may stop the professional from offering what the parents ask for, or they may simply not grasp what the parents are saying. However, another possible interpretation, more in line with how parents describe the situation, is that some professionals hold the opinion that they are better suited than the parents themselves to judge what the parents need. Although professional knowledge, for example that many parents with a disabled child may go through phases of grief and sorrow, can be useful for some parents; it may as likely be experienced as a straitjacket if forced upon a particular individual feeling differently. It seems important to keep in mind that although parents sometimes need help to see their needs, it cannot be taken for granted that the professional knows what these needs are. Different people have different reactions and want to deal with a situation in different ways.

Defining causes and cures in family external arenas. Some parents reported experiencing not being listened to when children had difficulties in school or day care. The story of a boy with an intellectual disability can serve as an example. During the previous year, the boy had physically resisted going to the day care centre. According to the father, the parents and the staff in the day care centre did agree that there were problems that needed to be resolved. However, when the parents tried to talk to the staff about their concern and how they believed they could go about solving the problem, they were rejected. The father said:

He has been in a child care centre since the age of one, and the reason he does not want to go there, is how they organise, it does not suite him. So he does not want to go. He had the same assistant for three years, but last year she was taken away from him. She is

still at the same day care centre, but with another kid. And he responds negatively to that. She is there, but takes no notice of him, and he will not accept that. This is what we have tried to explain to the staff, but they will not listen.

The father explains how the new assistant had a hard time getting in contact with the boy. She was not taught the sign language that he used for communication. The father's concern was to make sure that the day care was organised in a satisfying manner for his son. Bringing the present state up for discussion, he was particularly frustrated by the reactions from the special education teacher, who rejected his view, referring to her professional pride. He felt he was not allowed to criticise anything that happened in the day care centre, and if he did, he had to think very carefully about which words to use. By referring to her professional pride, it became clear to him that he was neither viewed as competent nor welcome to discuss alternative organisations in the day care centre. Consequently, the parents' understanding of the problem was refused. The only thing the professionals had recognised was the parents' struggle to get the boy to the day care centre every morning. Accordingly, they made a suggestion that someone from the service system should come to his home and pick him up and take him to day care, a proposal rejected by the parents. They only saw this as moving, not solving the problem, as it would be of no help to the child's resistance towards being in the day care centre.

This example is closely linked to the question of who holds the *right* to influence particular situations (see jurisdiction below), as conflicting views on parents' rights to interfere were demonstrated. However, here the underlying conflict was actually on *defining the problem per se*. Parents experiencing such conflicts could often be invited to come forward with their knowledge and ideas. However, once met with a conflicting view on how to define the problem, the parents were turned down.

Another example is the case of a boy with autism entering an ordinary school. In order to prepare for start of school, the parents had many meetings with school officials where they described the child and particularly his need for a sheltered and highly predictable everyday life. Contrary to this, he was placed in a large group with all the other children with no expressed strategy on how to meet his individual needs. The parents saw aggravation in the child's behaviour, a regression in abilities, and growing emotional problems. This led to a long and hard conflict where the parents and the school held different opinions on what methods would be best in order to help the boy fit in. Parents and professionals held different views on what caused the child's problems. While the parents called attention to problems within school as the important issues, the professionals were said to point at factors in the child's personality or conditions or even at the parents themselves. Such situations were particularly difficult for the parents, as they involved arenas where parents were not present themselves, and accordingly, emphasis might not be given to their views. The parents in the last example reported how they finally involved a specialist unit for autism, and by their intervention, the parent's view were heard.

To a varied extent, nearly half of the parents had experienced not being listened to in discussions about organisation of day care or school. Such problems were rarer for the pre-school parents, but increased as the children

entered school. And most often, these conflicts concerned children with some sort of learning difficulties and/or behavioural problems.

Gate-keeping

Sometimes the professional role as gate-keeper seemed to act as a hindrance towards user-participation. Parents could report a feeling of not have been listened to when rejected or turned down on an application for a benefit or service.

Parents of a boy with multiple disabilities were granted different sorts of assistive aids, including a large wheelchair. Parents of children with disabilities may get support for a specially adapted vehicle if necessary to prevent the child or the family from becoming isolated in the home. After having explained their need for a large car to transport all the equipment, the father was told that instead they could apply for a towed vehicle. The father, trying to imagine himself looking for a parking space for a car with a trailer outside the supermarket on a crowded Saturday afternoon, stated: "I was about to explode". The case worker has to make sure the person applying fulfils certain criteria, and make a judgement on whether other and less expensive solutions may exist. However, this father felt as if the case worker had not paid attention to what he said, as the suggested alternative was no answer to their need as expressed by the father.

When a family has applied for care allowance, a cash benefit paid to parents with a particularly heavy burden of care, a caseworker comes for a home visit in order to verify the extra work load. The criteria applied to determine the size of this benefit vary between different municipalities. The following example was given by a mother of a very active 8-year-old girl with intellectual disabilities. The care allowance was reduced after the home visit, and the mother stated:

You have to take into consideration that she is much more demanding than before. The only thing they had calculated on was how long we needed to nurse her, and how long it took to feed her. But then it is no longer an individual evaluation! They had their form to judge by, that was quite strict . . . So I told her it is particularly heavy everything with Nina. Not just when we are feeding her, and not just when we take her to the toilet. It is particularly heavy all the time when she is indoors. I have to be on her heels. And for that they had no calculations.

In most social benefits offered to families of children with disabilities, the case worker has some freedom to make judgements. These judgements are often based on a combination of other professionals' statements (e.g. a medical diagnosis), the case worker's own observations, and the parents' descriptions of the situation. On some occasions, judgements of the family's needs were taken without even examining the concrete family situation, causing great anger among parents. However, the chance of feeling disregarded was even larger on occasions where the parents were turned down after first being invited to describe the situations themselves. Then parents were left with a feeling that the case worker had ignored their information.

Many parents were well aware that their views were sometimes disregarded on the grounds of limited resources, stating, “It’s all about money”. Yet parents did not necessarily feel as if they were not listened to every time an application was rejected. However, as illustrated in the cases above, when applying for large investments like a car, or for social services where professional decisions are highly discretionary (e.g. respite care and especially care allowances), these kinds of rejections are quite common, as were parental feelings of not being listened to.

Jurisdiction

Sometimes jurisdiction, i.e. the question of role-definitions and who holds the formal rights, acts as a constraint to parents having an active say. The jurisdiction is often unclear or unarticulated, and there may be disagreement between parents and professionals with regard to interpretations of parents’ privileges in particular situations, and what formal rights parents have in decisions regarding their children.

The father of a girl with Down syndrome reported on the first meeting when they established a family support team. The parents and 7–8 professionals from different services were brought together. The parents were asked to describe the child and their situation, as the father explains:

So I told them a little bit of how we had experienced the situation so far, and what we would find helpful. But then we got a shock, really, it was the leader of the local help service unit, that made a little speech that we should not think it was like this or that, oh no, for money does not grow on trees.

This may be interpreted as an attempt by the professionals to set the formal as well as practical limit towards parents, formal by indicating that it is not up to the parents to make decisions on the use of public recourses and practical by pointing at the shortage of public recourses. In that sense, the example has an element of gate-keeping. The main problem within this situation from the parents’ point of view was that they were not allowed the right to express their views. Entering such a meeting, parents will most likely have an opinion on the child and the family’s needs, and many will have reflected on how their situation could possibly improve. When invited to describe the child and their situation, they will express their opinions. Whether or not their ideas are put forward as claims or suggestions should be irrelevant. By focusing on restrictions either in money or parents’ rights to make specific claims at this point, the chance of an open dialogue is likely to be closed. What was experienced by the parents was that their view of the situation was regarded irrelevant as a basis for a constructive discussion of possible services. This was hard for parents to understand. Firstly, most parents regard themselves as holding firsthand knowledge on the situation. Secondly, they believe themselves to have full rights to come forward with their views.

The question of jurisdiction was also found in discussions with day care centres and schools. In principle, within directions given in law and other guidelines, parents may influence decisions regarding the social and educa-

tional learning of their own child in school and day care. However, there are different understandings of parents' rights to influence here, as well as disagreement about topics on which the parents should have a say (Nordahl 2007). In everyday practice, several parents have reported being rejected. Typically in these conflicts parents report that they felt that the teachers, head teachers or other staff disregarded parents' opinions when it came to the organisation of the child's day within these institutions. This was similar to the conflicts over causes and cures; however, here parents were more likely to find themselves being viewed as someone interfering in something that is none of their business and thereby rejected at an earlier stage, not getting into a dialogue at all. The parents in the following example had a long conflict over what they described as shortcomings in what was offered to their daughter in school. They stated:

Father: I think that today we have solved most of the problems.

Mother: Only that all the way we had to seek support from the Rehabilitations Service or someone from the Educational-Psychological Service. For you are in a way not listened to as a parent.

Father: Oh no, you must not turn up at school and think you know something. They are the ones who know. It's really a lot like that.

Several parents reported that the school refuses to listen to the parents' wishes and advice. Methods proposed by the parents were turned down by arguments such as "this is the way we do it here", or "school and kindergarten are different things", or "we know how to handle this". Parents reported how professionals emphasized holding the right as well as being the natural authority as experts, while parents felt their own knowledge was ignored. Accordingly, in the parent's opinion the child's best interests were neglected. Not unexpectedly, disagreement over jurisdiction comes to the surface mostly in situations where the child has considerable problems and does not thrive at school. As long as parents are satisfied with what goes on at school, and have the impression that their children are properly taken care of, they do not question the professional's traditional authority.

Valuation of Different Knowledge

In meetings between parents and professionals, disagreements and different opinions were frequently experienced. Yet differences in opinion did not necessarily lead to strong conflicts. What characterized a good relationship from the parents' point of view was not that parents and professionals always agreed or that parents necessarily always had their will; rather, parents ask for professional judgement, ideas, and perspectives. They often expressed a humble approach towards professionals and their expertise, and willingness to follow professional advice, but not unconditionally. Parents and professionals could also reach a joint understanding through an open dialogue, where both

parties participated in defining the problem and discussing solutions, as expressed by this father:

The one person in school that has worked with her since kindergarten, she understands this (the importance of open dialogue). She brings forward her own ideas, and even more, takes ours seriously. And then we reach a compromise. . .

Nevertheless, a commonly reported experience for parents facing the described difficulties was the feeling that their knowledge was not recognised as important or was treated as subordinate to professional knowledge, thereby increasing the risk of a conflict. However, even without the strong conflicts, parents found it difficult to reach a full understanding of their competence and viewpoint, as expressed by this couple:

Mother: Cooperation, yes we feel that they have been supportive towards us. . . But sometimes we feel it is a huge difference between living with a disabled child and working with a disabled child. It can be hard to get through with our feelings and thoughts because the experts have worked with all those children, saying that they did this or that with another child, and this should work for you too, while our wishes and our feelings are put aside. And sometimes kindergarten becomes very professional and a bit directing. Very directing, sometimes, and this we find difficult.

Father: I would say we have an OK dialogue, we can talk about whatever we want to talk about, that is ok. However, we notice that it is difficult to reach a full understanding of our opinions. Now I should be careful not to say that I am always right, but as parents you know your child quite well after a while, and as parents you have the ability to think about the totality. In day care, they only think about Nina. But we might have to make other priorities, we can see the whole picture, and sometimes maybe we have to think more about ourselves.

The above quotation calls attention to how parents find themselves holding a different type of knowledge from the professional, both as regards knowing the particular child and knowing the totality of the situation for children and family. Even if many professionals may recognise parental first hand knowledge in these areas, the question still remains on how parental knowledge is valued if conflicting with the professional views.

Discussion

In this paper, the parental experiences of not being listened to were categorised as representing different types of conflicts or disagreement in meetings between parents and professionals. To various extents, parents were faced with disagreements in problem-interpretations, with the gate-keeper rationing public resources, and on jurisdiction. For the parents themselves, most situations were felt as disparagement of their knowledge and of being deprived power to define their needs or what they consider important in their own and their children's everyday life.

A prerequisite to listening to parents is that parental knowledge is judged as valuable by the professional. Murray (2000) has suggested that the professional identity is at stake when parents challenge the view of what is in

the child's best interest. It may be an inherent scepticism towards parental knowledge, difficult to change. Nevertheless, reconsidering the valuation of parental knowledge does not solve one important dilemma of user-participation: the question of who should have the final word faced with conflicting understandings of a situation. Backe-Hansen (2001) calls attention to how the professional must strive to respect users' own definitions of their problems, without rejecting their own research-based professional knowledge, as the professional is also obliged to make use of knowledge not present within the professional-user perspective. However, Backe-Hansen also calls attention to the importance of discussing *what* professional knowledge may be useful in different circumstances, as well as recognising that professional knowledge is not the only possible understanding in order to help parents and children. Further, as pointed out by Sandbæk (2001), it cannot be taken for granted that the professionals can ensure the child's best interests any better than the parents. Thus, professionals need to reflect on the limitations of their own perspectives. Our findings are a reminder of the importance of a humble approach towards parents, and point at a need for upgrading the value of parental knowledge in many situations. Accordingly, a true negotiating partnership among parents and professionals (Dale 1996, Keen 2007) seems to be an important ideal to strive for.

Parental knowledge of their own and the child's situation may be visualized on a line, from closest to the parent, to what is out of parents' immediate reach. We may question where on this line professionals set the limits of parental knowledge and interference. Although questioned by some, many professionals will see the parents as the closest to know how they feel and how to cope in their everyday life. Furthermore, many professionals may see parents as having valuable knowledge of their children, at least within a family setting, (although parents have experienced not being listened to there as well). However, parental knowledge is more likely to be regarded irrelevant, dealing with family external arenas like day care and school. This is problematic, given that parents are supposed to play an active part in cooperation with day care and school. The findings here suggest severe conflicts, unsolved problems, and children suffering when parents and day care centre or school do not reach a common understanding.

Disputes between parents and professionals sometimes reflect strong general disagreements on what is considered best for children, and for children with disabilities in particular. This field is highly ideological, and the solutions may in the end be judged by deeper moral or ideological questions. The understanding of what is best for children is neither static nor absolute, as dominant views are changing over time. Moreover, conflicting views are sometimes due to different understandings of what causes a problem. On one hand, there is a long tradition in understanding children's problems as originating in the parents' behaviour (see Berg-Nielsen 1998). Furthermore, in the case of a defined disability, the child's problems may easily be given a medical interpretation, linked to the diagnosis and rejecting the environmental impact. Some professionals (teachers or others) may then be likely to explain the child's problems as a direct consequence of the impairment or as originating in the

child's home, while parents, having observed the child in different contexts with different behavioural outcomes, may be more likely to place the origin of the problem within what they find to be the relevant context, like school or day care. The different views may of course be interpreted as a tendency from both sides of blaming the other. An alternative interpretation is that parental understanding is more in line with a relational understanding of disability, seeing the child's problem as originating in an environment not accommodating to her individual needs. Similarly, recent psychological methods regarding children with social difficulties, like children with Asberger syndrome, points to the importance of adapting the school environment to the children's needs (Martinsen, Nærland, Steindal & Tetzcher 2006). Determining the "cause" of a problem is seldom straightforward, and most likely causes will be complex. However, it may be of great importance in order to improve parent-professional relationships, that the professionals are open to the possibility that the parental perspective provides valuable insights.

Vehkakoski (2007) has examined the representations of parents constructed by different groups of professionals. Even though the representations were many-sided, they also reinforced certain stereotypes of parents. Cooperation with parents was seen as a professional ideal; however, if the parents were not able to co-operate with professionals and in compliance with expectations set by professionals, they were labelled as problems (Vehkakoski 2007). Larson (1998) found that parents meet the professionals expecting to be viewed as equal parties. Instead, some parents were pathologised or treated as part of the problem, and they frequently felt misinterpreted and categorised based on very limited information. Ironically, the idea of empowerment may come in conflict with listening to parents: If professionals hold the view that most parents are passive receivers in need to be empowered in the sense that professionals should educate parents, there is a great risk of overlooking the parents' views. Although parents seek information from professionals, most parents see themselves as competent, and may therefore demand a different sort of power than the one offered by professionals.

Some comments on our interpretations of the parents' experiences are needed. According to Andreassen (2004), many professionals have a tendency to interpret parents' critical views, not as a reflection of how things really are, but of how it may be experienced from a user point of view. Inherent in such an interpretation from the professional may also be an understanding of their own perspective as representing more objectively correct descriptions, while they doubt that parents can hold accurate information. This cannot be taken for granted. A problem with such a doubt is that professionals do not have to change the situation (e.g. increase their valuation of parental knowledge or change their own methods or actions), only try to change the user's experience (e.g. by explaining to parents how things really are and should be understood). Furthermore, the user's statements are often interpreted symptomatically (c.f. Kvale 1989), as an expression of something other than what is actually said. This is also a typical interpretation of parents expressing anger and frustration towards the service system. They are very likely to be seen as expressing frustration and sorrow because of the child's condition, in

line with the common understanding of grief and sorrow. Accordingly, professionals do not need to take what parents say literally. The fact that parents are particularly angry and frustrated in situations where the child is suffering (as in the conflicts with the family and external institutions) may even be seen as support for the symptomatic interpretation.

We cannot claim that our findings represent the answer to what is happening in situations where parents report not being listened to, or that there are not occasionally good reasons to reject parents' understanding of a situation. Neither will we reject that the parents' emotional state influences how they view and react in different situations. However, without taking the parents' knowledge and experiences seriously, considering the parental understanding of a problem as worth looking into, it will be difficult to establish the open dialogue that is necessary to give help that is instrumental from the parents' point of view.

Acknowledging parents' competence should be essential given the ideals and politics regarding the public–family division of work and responsibility for children with disabilities in present day Norway. Not acknowledging parents' own interpretation of themselves and their children may be experienced by the parents as if their competence as parents is not recognized. If the family is really regarded as the best place for children with disabilities to grow up, and if the welfare state is to offer services that are accommodated to the family's needs, parents' views need to be listened to.

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