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Descriptions of children's needs and parenthood among mothers with intellectual disability

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This study looks at how mothers with an intellectual disability describe their children's needs, their own parenting and parenthood, and their encounters with professionals providing them with help and support. The analysis draws upon a relational perspective on disability, theories of modern parenthood, and the concept of the sense of coherence in examining the strategies used by the interviewed mothers in their everyday lives, such as consulting people they trust. Having a child and being entrusted with the role of parenthood were described by the interviewed mothers as creating meaningfulness in their lives, while the comprehensibility of their everyday lives was often found to be lacking and the information given them by professionals not always understandable. Better information and communication thus seem to be necessary to render these mothers' parenthood and its context more comprehensible.

Keywords: children's needs; intellectual disability; mothers; parenthood; professionals

Background

The last couple of decades have seen a perspectival shift in research on parents with intellectual disability, from a focus on individual impairments to a recognition of the role of attitudes and limitations built into the various support and help systems in place (e.g. National Board of Health and Welfare 2005). In Sweden, however, the debates have remained relatively polarized between positions stressing either children's needs or the parents' ability to parent. In this discussion, questions about the organization of the support and help provision, the consequences of the existing legislation, and the notions of parenthood held by professionals in the field have been left largely unexamined (Ineland, Sauer, and Molin 2009). It is against this context, then, that the present article sets about to consider how mothers having intellectual disability describe their children's needs, their own parenthood, their encounters with professionals out there to help and support them, and the support system itself.

Previous studies have noted that parents with intellectual disability often encounter attitudes, as well as social barriers and restrictions, which affect their ability to parent. They frequently face difficulty in winning acceptance for their parenting plans and preferences when confronted with the attitudes and viewpoints of professional support workers and others in their informal network (Llewellyn

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et al. 1999; Traustadóttir and Sigurjónsdóttir 2008). The perception of being questioned as a parent is not unlike that of other parents. It is reported (Höjer 2007) by other parents with children placed in foster care that they have to subject themselves to special requirements and conditions, and there is frequently a feeling that the experience and knowledge accrued of one's own child is not considered as important. The experience of having one's parenthood questioned and criticized is also described by those who, on account of their children's special needs, remain dependent on professional assistance (Hedov 2002; Starke 2003; Todd and Jones 2003). In sum, parents affected by various kinds of life circumstances have reported perceiving their encounters with professionals as something problematic.

Theoretical perspective

The aim of this study was to capture the experiences and descriptions of mothers living with intellectual disability regarding their children's needs, parental responsibility, and encounters with professional support and help workers and the support system itself. Towards this purpose, different theoretical perspectives were utilized. To provide a general perspective on disability, a relational or environmental definition of disability was adopted (Grönvik 2007). This perspective stresses the ongoing interaction and relation between the individual, the impairment, and the surrounding structures (Pfeiffer 2005). The notion of intellectual disability as used in this article is thus taken to refer to both the individual condition and the societal and social barriers that limit a person's ability to function in major life activities (Lindqvist 2007; Ineland, Sauer, and Molin 2009). Such a relativistic approach is in accordance with the feminist viewpoint presented by Wendell (1996, 2001) and Thomas (1997, 1999), who stress the importance of the subjective understanding of disability. The relativistic perspective, furthermore, closely corresponds to a social model in which disability is understood as a form of social exclusion operating through disadvantages and social barriers that individuals face (Thomas 1997).

The relative perspective is expressed for instance in the Swedish Act on Service and Support to Certain People with Disabilities (SFS 1993:387). According to it, access to service and support provision is restricted to persons having different impairments and some are defined in medical terms such as intellectual disability (Lindqvist 2007).

For those eligible for assistance this means access to support geared primarily to help them overcome the limitations and barriers imposed by the surrounding society. Accordingly, the support offered is to be so designed and organized as to allow the individuals receiving it lead their lives as autonomously and freely as all the other citizens in society. This, then, should also mean the ability to obtain societal support for parenthood and parenting, even if it is not specifically so stated in the current law.

Becoming a parent in Western societies is associated with a number of external expectations that complicate its conduct at the same time as formulation of parenting styles in each case remains primarily a private matter, making the latter relatively flexible and contextually defined (James and James 2008). Autonomy, flexibility and reflexivity have become taken to be granted by the modern parent. Independence gains expression in the relative devaluation of external models provided by previous generations and others around one. Flexibility, again, is necessitated to allow for the optimization of choices and pursuit of personal projects. In addition, parents are also

expected to practice a reflexive approach that includes searching for knowledge and information and an ability to discuss and negotiate different solutions.

All this assumes that parents acquire new knowledge about children that they then process critically (Beck and Beck-Gernsheim 1995; Stacey 1996; Dencik 1999). The reflexive orientation can then give rise to new notions and conceptions regarding children's needs, which, when applied in the everyday life, often leads to a situation where both traditional and contemporary ideas coexist in parallel (Giddens 2006). The choice of one's living arrangements thus remains a private decision simultaneously as one's parenthood is also shaped by external expectations, such as that parents be child-centred and found their relationship on democratic values while demonstrating in their parenting an ability for a reasonable degree of controlling as well (Halldén 1999).

Research has also shown that different family cultures and values are developed on the basis of individuals' differing needs to manage their everyday life and depending on the ideals they hold (Morgan 1999). This relativizes the perspective on what may be considered 'good parenthood', with its meaning constantly changing both over time and across cultures (Gillis 1997). Parenthood will thus always be marked by cultural and social expectations regarding proper mother and father behaviours, and parents must be able to cope with the prevailing expectations about what should be included in the definition of 'good parenthood' (Wetherell 1997).

Parenthood is thus shaped by expectations and demands at the same time as there is also a degree of freedom in determining the content of one's parenting and caring for the child. The fact may contribute to the difficulties social workers working in Social Services have in identifying children at risk of neglect or abuse. Gaining information about parents' care of their children and deciding on whether the children's living conditions are 'good enough' is often enough a formidable task. In the face of the difficulties involved, it may well be asked whether the circumstances might not give rise to a situation where some parents are expected to be less able and proper than others. This, in turn, could lead to some parents' strengths' and abilities' going unrecognized and their parenthood's not being viewed as 'good enough' (Reinders 2008).

In any case, however, parental competence must always be examined in light of the known risk factors for the children and the existing law. An increased risk has been reported that parents having an intellectual disability neglect their child, that the child does not receive adequate stimulation and that the parents fail to provide the child with adequate security in the home environment (Feldman 1998). The challenges and the risks attached to such situations nonetheless vary, and an individual perspective and individual assessment therefore remain necessary (Feldman, Ducharme, and Case 1999).

The fact that certain groups of parents are singled out as especially specially unsuited for parenthood can also be explained by social barriers created by relatively established representations and attitudes in the environment. Unreflected notions about parents with intellectual disability contribute to stigmatizing such parents and reinforce the mechanisms of their exclusion (Reinders 2008). Lack of knowledge among support professionals can be one contributing factor in this sense, even explaining some of the difficulties of pursuing disability policy goals in practice (Espe-Sherwindt and Crable 1993; Clayton et al. 2008). In consequence, while the legislative instruments to break down the existing barriers through appropriate support measures have already been made available, the very cadres responsible for providing such support on the

ground would then, through the attitudes and representations they hold, be only undermining such efforts among those with an intellectual disability who are also parents.

The aim of this study was to chart the experiences of mothers with intellectual disability, in order to clarify their own perspective on what might make up the kind of social barriers referred to above. To facilitate and deepen our understanding of the individual mothers' subjective experiences in their particular contexts (Thomas 1999; Wendell 1996), Antonovsky's (1987) concept of the sense of coherence was used. An individual's sense of coherence arises as the result of the joint effects of resources and processes conducive to health. In the salutogenic orientation, there is a direct relationship between the strength of one's sense of coherence and the person's ability to employ cognitive, emotional and instrumental strategies likely to improve coping and thereby well-being. Three core components have been identified in a person's ability to cope. These include meaningfulness, or the profound emotive experience of life as making sense, which then makes coping desirable; manageability, understood as the recognition of the resources required to meet the demands of the situation and a willingness to search for them out; and comprehensibility, or the conceptual perception of the world being understandable, meaningful, orderly and consistent rather than chaotic, random and unpredictable (Antonovsky 1987).

These concepts – comprehensibility, manageability and meaningfulness – are related to an individual's resources in terms of resistance and absence of resistance. Resources, again, may be identified as factors that can facilitate a more successful way of handling stress and provide better health. Examples of resources include cognitive ability and having access to money and social support. Resistance resources provide individuals with a way of making stressful life situations appear coherent. They assist individuals by promoting life experiences characterized by clarity and participation and help them bring the perceived pressures and stressful moments into balance. According to Antonovsky, consistency between past experience and predictability in life provides the basis for a sense of coherence. This sense of coherence can change, even if it is to be understood more as something that develops into a personality trait. This may come about as a result of external influences, for example when a person's life undergoes radical changes lasting for a long period of time (Surtees et al. 2006) or is impacted by traumatic events (Schnyder et al. 1999, 2000).

With the help of a relational perspective on disability, brought together with theories of modern parenthood and the sense of coherence concept, it will then be possible to gain a new, deeper understanding of the interviewed mothers' descriptions and experiences of their parenthood, their children's needs and their encounters with professionals and the support system.

Methods and data

Study participants

A total seven mothers with intellectual disability were enrolled in the study. They were recruited through a regional adult rehabilitation centre. This is an agency to which those who are supported according to the Swedish Act (1993:387) concerning Support and Service for Persons with Certain Functional Impairments can turn for support.

The mothers all received support, for themselves and their children, through different agencies in accordance with Act (1993:387) and from municipal social services in accordance with the Social Services Act (SFS 2001:453). This meant that they had access to financial and practical support in a number of different areas. In addition, those who lived together with their child/children were also in contact with day care and pre-school services, the school system, and, in some cases, regional children's rehabilitation centres. Accordingly, the mothers maintained contacts with several different service and support providers, sometimes voluntarily and sometimes out of obligation. In Sweden, there is no special national strategy or specific legislation regarding either support for parents with an intellectual disability or their children.

The mothers participating in the study were between 24 and 42 years of age at the time of the interviews. One of the mothers lived with her husband and their two children. The other six mothers lived in one-parent families without the child's father or a new live-in partner. Yet, most of them did not live alone. One of the mothers lived with her child and her own mother (Klara), another with her child and her own grandparents (Berit) and a third had her child taken care of by the foster family in which she herself had grown up (Paula); a fourth mother lived without her children in a sheltered accommodation (Harriet). Two of the mothers lived on their own, either together with their children (Johanna) or alone without them (Kajsa).

The interviewed mothers had a total of 14 children between them. The youngest child was two years old and the oldest one 15. Two of the mothers had their children placed in out-of-home care (Kajsa and Harriet, a total of five children), and one mother (Johanna), who today lives with her three children, had one of her children temporarily placed in a foster family. Six of the children received ongoing support and treatment due to an identified delay in development and/or motor problems. The interviewed mothers identified a total of nine fathers for their children. Five of the fathers had an intellectual disability, accounting for a total of 10 of all the children. Two of the children had fathers with known drug problems.

Participant interviews

The interviewees were invited, both verbally and in writing, to participate in the study by professionals working at the adult rehabilitation centre, all of them well known and familiar to those approached. All of the mothers indicating that they wanted to join the study were included in it. Information about the purpose and nature of the study was then given to them on different occasions to ensure that their informed consent was obtained. A total of eight interviews were conducted between the autumn of 2001 and the spring of 2003 in the interviewees' homes or in other locations familiar to them. The interviews were carried out by a social worker and a psychologist with a long experience of working with the rehabilitation centre; neither of the interviewers, however, knew the interviewed mothers. The interviews were conducted using a checklist of themes, with the issues explained and clarified to the interviewees in the course of the interview. The interviews were recorded and transcribed for a published report (Olson and Springer 2005).

Interview analysis

The interview analysis was conducted by this author, who did not participate in the interviews and had neither met nor worked with the mothers. The task of the textual

analysis of the anonymous interview transcripts was to deepen the understanding of the responses received, by applying a set of theoretical tools as described above. During the analysis, themes and stories were identified in the individual interviews that could help to clarify patterns and distinctive characteristics in the mothers' statements (cf. Miles and Huberman 1994, 269–70). Similar as well as distinct stories and experiences emerged from these statements, which were then brought together for comparison and further analysis in the light of theoretical concepts and previous research.

The interviewed mothers' reflections about their children's needs, parenting and encounters with the support system were sometimes clear and sometimes vague. It was therefore necessary to extend the analysis by asking how the mothers' reflections might be understood within the area of disability more broadly. The mothers' descriptions, specifically, of how they related to their own understanding of what motherhood means, what their children's needs and best interests were and how they applied this understanding in their everyday life practice were thus examined further. To better bring up the complex relations that emerged from the interview statements, the results as presented below are divided into separate thematic sections focusing on the mothers' reflections on their children's needs, their positive and negative experiences of parenting, the strategies they used in their everyday life, and the issues they had about the received support such as being questioned as a parent. Several interview quotes are included to demonstrate the mothers' reasoning and to highlight key events, phenomena and processes. Repetition and digressions from the subject at hand have been removed from the quotes in the interest of clarity. Special care, however, was exercised to preserve the original character and content of the statements in their English-language renditions.

While the qualitative nature of this study does not allow for any general conclusions to be drawn, new perspectives may nonetheless be seen as emerging from its results. The study can, accordingly, be seen as a contribution towards visualizing how mothers with an intellectual disability shape their parenting and adapt their sense of the context in which they function.

Ethical considerations

The ethical principles guiding this research were those of the Swedish Research Council concerning the information obtained, consent, use of data and confidentiality (Vetenskapsrådet 2002). The study participants were provided, both verbally and in writing, with comprehensive information about the purpose, aims, procedure, as well as potential risks and benefits of the study, and the possibility they had of withdrawing from it at any time. This information was given to them by adult rehabilitation centre staff the study participants knew well and by the interviewers. The data obtained on the interviewees was sufficient to not ensure the confidentiality of their identities. De-identifying the information was thus imperative, given the limited number of interviewees involved and the fact that they all came from the same, relatively small region. At the same time, the responsibility to present the results in such a manner that none of the interviewees can see themselves at risk of becoming recognized limits the amount of information that can be presented about each research participant. All interviewee names have subsequently been changed, with all the children presented as boys and all support workers as women. Situations that could be perceived as compromising confidentiality are omitted from the

presentation, as are the names of localities and other such potential identifiers. Ethical issues, however, may also arise from the use of extensive quotations in the presentation. Yet, the quotes serve the important function of allowing the reader to assess the accuracy of the interpretations and confirm the analysis as sound, while also enabling the consideration of alternative interpretations and that way further improving the trustworthiness of the results (cf. Miles and Huberman 1994, 262–3).

Results

In what follows, the results of the analysis are presented thematically, focusing separately on the interviewed mothers' experiences of parenthood and parenting, their reflections on their children's needs, their strategies to find support and their experiences of being questioned as parents.

Children's needs and parental responsibility

In discussing their children's needs and their own perceived parental responsibility in fulfilling these needs, the interviewed mothers sometimes resorted to the perspective of the child and sometimes to the perspective of the parent. Berit, for example, spoke from the parental perspective when reflecting on children's needs in general:

> Children need regular times, clear orientation; they need to be fed, bathed, have their teeth brushed, diapers changed, and you must remember all this because otherwise it will be difficult for the child to grow up, if they don't have regular times, for instance. I keep everything very regular. I brush his teeth . . . I think three times a day now that he's so big. I manage to bathe him every other day, although he sometimes showers more often than bathes. Hygiene is very important for children because otherwise they don't feel good . . . . You have to change the diapers when the thing happens . . . . When they poop you need to take it out at once, otherwise it hurts them. Imagine yourself how it would feel to go all day with poop in your pants.

This can be understood as using a health perspective when discussing the child, with Berit showing a reflexive attitude in making her argument. She uses her knowledge to reflect on how children need to be cared for in general, which then influences her notion of what it all means for her own parenting practices. Another interviewee, Paula, adopted the perspective of child safety, focusing on the importance of a secure environment: 'Children always need this security, peace and quiet; they need to stay in one place and things like that'.

The interviewed mothers also used the perspective of children's needs, relating it to what they thought would make good parenting and parenthood. Johanna, for instance, expressed that parents and their children should try to be 'comfy and cosy together'; parents should be available to their children and they should 'talk about problems'. According to her, 'a good parent helps and stands up for her children' and 'parents should be there to help their children'.

Helping and supporting was described by many of the interviewed mothers as an important function of parents. Their comments on what good parenting should entail can here be also understood as an expression of the mothers' willingness to place their children's needs at the centre and have the kind flexibility that is necessary to be able to perceive and respond to these needs (Bäck-Wiklund and Bergsten 1997).

Kajsa described the strategies she used in attempting to provide good support for her son, who had special needs. These included reading, painting, training and practicing various skills together, and taking the son to different activities. She stressed the importance of praising the child: 'After he's done with playing, he puts all his toys back in his room . . . I then praise him for having cleaned up his room, and he becomes so happy and feels so big and great'. In describing all this, Kajsa adopted the perspective of a parent as a pedagogue who proceeds guided by empathy. Her description can be interpreted as indicating that the child's needs were had become comprehensible to her, rendering her life more consistent, understandable and predictable.

Paula, for her part, stated that when she became a parent it meant that she 'had grown up and matured in a way different from before'. She also described her parenthood as follows: 'Yes, it's fun in itself to be a mother, but it's also very hard . . . very stressful'. As confirmed Ester: 'Yes, it's both difficult and fun. Both of these, yes, but I wouldn't want to be without them [her children] . . . They are the best there is'.

Paula and Kajsa both had sons with special needs. Both expressed that they had learned much from their children and appeared to think that they had developed their own resources as well in the process. The child's learning processes as described by the two of them would have then also involved a learning process for the mothers.

The way the interviewed mothers described stress in their lives is in line with previous research reporting mothers with intellectual disability to generally experience more stress compared to other mothers (Feldman et al. 1997, 2002). The amount of stress reported by the interviewees in this study can, however, also be explained by the fact that several of them had children with special needs. This, too, is in line with earlier findings: in studies conducted with parents, the parents having children with special needs have reported more stress compared to other parents (Hedov 2002). Yet, the interviewees in this study did not talk about their children's special needs as something particularly stressful. The way they discussed their children differed from descriptions given by previous studies of parents living with children who have special needs. These have often centred on crises, parental grief, and the parents' perception of having lost the child they had expected (e.g. Fyhr 2006). Yet, also other aspects have been brought up in research, such as that the needs of the child have contributed to the parents' own development or to a change in their perspective (Grant et al. 1998; Atkin and Ahmad 2000). Recognizing this possibility may thus be considered as one of the resources of the mothers who took part in the present study.

Overall, the interviews showed that the mothers participating in the study were able to maintain a reflective attitude about their children's needs and about parenting more generally. What they further testified to was the importance that parental flexibility and an ability to interact with their children and have a close relation to them seemed to have for the interviewed mothers. The interviewees also frequently repeated their conviction that the children's needs should remain at the centre of attention. 'A mother should be nice and caring, but also fair, and she needs to set limits', stated Paula. This description might be seen to present the ideal of the 'good mother'. The norms and values that the interviewed mothers associated with parenting can also be interpreted as a way to understand their own parenthood. Just as all the other parents, these mothers, too, were affected by the ideals and notions about what should constitute good parenting. For them, too, such constructs can

function supportively helping to shape one's parenthood, providing knowledge and information to avail options and enable choices. At the same time, they can also be burdening in the sense that ideals are often hard to measure up to.

Ester mentioned that having children had opened up a new life for her and her husband. She explained that before she became a mother she had been 'quite shy', but now she thought she had 'become more open, a little more; but I remain a bit cautious still'. Becoming a parent had allowed her to develop as a person, and she perceived parenthood to have created for her and her husband a new situation and brought new social contacts: 'We were very alone before . . . I think this is good, that we now meet more people'. In Ester's view, what she and her husband had experienced was the same as with all parents: parenthood for them had meant becoming part of new contexts, creating new relations, and in this sense the child had contributed to the renewal of the family's everyday life. Ester's description can be interpreted to mean that before becoming parents she and her husband had remained largely confined to living without many social connections. With the transition to parenthood, some of the social barriers to these had then withdrawn. This conforms to findings from previous studies showing that parents with intellectual disabilities, just like all the other parents, have found high-quality social contacts to function as a resource helping them to develop their parenting ability (Stenfert Kroese et al. 2002).

It has also been reported that mothers' experiences of family life during their own childhood seems to affect their ability to develop parenting skills (Kollberg 1989). However, even when the mothers interviewed for this study might themselves have lacked good parenting models, they were clearly able to reflect about the need for them. As stated by Berit:

> A mother is someone you can cry with when you need who doesn't run away saying 'No, go away!' It was the first time I thought of that [when I became a mother]. When I was little, when I cried, I never got to come and sit on my mom's lap and cry . . . It was now the first thing in my mind. When my son cries he can cry in my arms . . . and I know I don't want him to have the experience I had and my sister had, that we were just pushed aside. I don't think my son will ever be having that experience.

In this example Berit reflects on her past experiences in seeking to create something new based on her notions about children's needs and parenthood. Her description can thus be seen to be representative of reflexive motherhood. It also demonstrates Berit's relative autonomy, in showing how she frees herself from the influence of inherited models in shaping her own parenting on the basis of her own reasoning about the needs of her child and the duties of the parent.

Strategies used to obtain support

What kind of support did the interviewed mothers express themselves needing, and how did they obtain that support? Many of them stated that they would have liked, and would continue to like, to have support from professionals so as to help them develop their coping skills to better take care of their children. This was so especially when it came to the mothers' ability to set limits for their children and their feelings of insecurity about their caring skills. The desire for support could thus be interpreted as deriving from a belief that professionals could lessen such anxieties by teaching parental skills to the mothers. Insecurities of this kind were, however,

often handled by consulting someone else that the mothers trusted, such as their mothers. As Kajsa reported:

> You don't always know that you are right, and in those cases I usually ask my mom. She knows more than I do. She has given birth to three children . . . When it gets really difficult, I therefore ask my mom because she's had children of her own and she would know.

Here the interviewed mothers expressed no need to be autonomous; instead, they preferred to take advantage of their own mothers' experience. Very clearly, having trusted persons around them was perceived to be important, to provide help in acting right and making choices and as a source for new knowledge about children. The interviewees also indicated that having such contacts had strengthened them as parents, improving their parenting abilities, which had made them feel better about themselves as well. It, in other words, had resulted in an increase in comprehensibility as well as manageability in their everyday lives. Several of the interviewed mothers stated that when they did not know what to do about their children they asked their mothers or foster mother (Paula) for help. It was precisely their own mothers that the interviewees perceived as best able to provide the kind of advice and support they felt they needed to help them cope with their children and develop their parental skills. For some of the mothers, also other relatives, friends, and social workers were seen as important sources of such support.

The mothers' stories on this point concur with previous research where mothers with intellectual disabilities have been found to receive significant help from their own mothers (Llewellyn 1997; Traustadóttir and Sigurjónsdóttir 2008). Such helpful relations are, to be sure, rather special in that one's own parents are usually more readily available than other sources of support; they, it was felt by the interviewees for this study, too, can also be trusted and more easily contacted when need be. Involving the child's grandmother often also makes it possible to observe another person's way of interacting with the child, which has been found beneficial for the development of one's own parenting skills and resources.

To sum up, all of the interviewed mothers indicated resorting to people they trusted for support and advice. They all perceived and could also articulate a need for support, seeking help when a situation was experienced as difficult. Informal good-quality support networks have been found to be important for the well-being of both children and parents in general, and their special significance for families with parents with intellectual disability has been shown in previous research (Llewellyn 1995; McGaw 2000; Llewellyn and McConnell 2002). In line with these findings, the mothers interviewed for this research reported having received useful advice and support through such networks, including the provision of parenting models helping them to strengthen their own parenting skills and reduce some of their barriers to parenthood.

Being questioned as a parent

The interviewed mothers also reported other kind of perceptions of not being able to adequately take care of their children and having had their parenthood called into question. All of them had experienced themselves being questioned by others in their parenting ability. They also expressed their own fears about not being good enough

as parents. For them, this included doubts about the adequacy or sufficiency of their parenting skills in caring for their children.

Some of the interviewed mothers described experiences of not being able to cope with their children and of feeling inadequate in carrying out their parental duties. This led Paula and Klara to turn to social services to ask for help and support with their parenting: 'It was I myself [Klara] who decided to do so because of the circumstances at the time . . . It was so that the children would not be put at risk'. Klara's children had been placed at different 'family homes', and she described herself as not ready yet to become a full-time mother. Paula lived together with her child in the same foster family in which she herself grew up, feeling that she received the support she needed for her parenthood. Johanna and Harriet had experiences of having their children temporarily placed in foster care against their own will. None of them, however, were able to give the reasons for why their children had been taken away from them. Many of insecurities in their case might then be interpreted as an effect of unclear information about what good parenthood might consist in. As reported by Harriet:

> They said that we didn't take good care of our sons . . . They said that we put the boys to bed too late at night, and that we give them cola, that they drink cola with their meal in the evenings and so on. That's the only thing they told me. They also said that I didn't go out with them during the day. But I did. I don't know.

Based on Harriet's and Klara's accounts, it seems that no one had explained what was required of them as mothers so that their children could move back home again; they were only told that time was needed for that to become possible. Neither one of them appeared to have any information about what was expected of them in terms of their parenting so that the children could return home. This seems to indicate lack of clear communication from the Social Services or insufficient or inadequate information. The same was implied by Johanna's account of how one of her sons ended up moving back home after a stay in a foster family:

> This [the son's moving back home] I of course was not prepared for . . . And then all of a sudden he was going to the clinic . . . Well, what was all that about? . . . And he would also be staying there for them to see first if they could find another family to take him, but there was nobody who wanted him. Only then they [Social Services] understood that he should be with his own mother. Because that's what he needs.

The stories of Harriet and Johanna in particular illustrate the uncertainty about what happens and why. Such lack of clarity about the circumstances could probably be attributed to the vagueness of the professionals handling the case. It may have been the case that information was lacking or that the information given about children's needs and the parents' responsibility had not been given in a manner that made it understandable. This, then, can be interpreted as a case of professionals creating disability. For these particular mothers, it remained unclear what professionals expected of them as parents, with the result that they were unable to recognize what they should do to develop their parental skills. Such shortcomings in communication could thus explain the lack of comprehensibility marring the interviewed mothers' everyday lives, and serve as an example of how social-service professionals may be creating barriers to equal parenthood by failing to provide their clients with adequate knowledge or information.

Discussion

In this interview study, the purpose was to capture the perspective of mothers with intellectual disability concerning their children's needs, their own responsibilities as parents and their encounters with social workers and the support system. The analysis showed the interviewed mothers to perceive their parenthood as something meaningful to them. Their relationship with their children gave them a new, important role that in turn brought them into contact with new acquaintances and actors in their environment. In this way, parenthood can contribute to a person's sense of coherence, thus strengthening one's resources. For some of the interviewed mothers, parenthood can even be seen to have removed some of the social barriers preventing access to new social contexts. The mothers frequently stressed the parental responsibility to care for one's children and the need to focus on their interest and needs, which could be interpreted as a reflexivity attitude towards parenthood giving rise to ideals about motherhood and childcare.

The interviewed mothers identified a need for support and shared similar perspectives on their parenthood. Parenthood was perceived as something positive while also bringing new challenges, demonstrating a reflexive approach to one's situation and role. The difficulties that some of the mothers experienced led Klara to choose to live without her children, Paula to live together with her son in a foster family and Klara and Berit to live together with their own mothers or grandparents.

Their interaction and relationships with their children emerged as something to have made a major contribution to the interviewed mothers' lives, giving rise to a sense of meaningfulness and leading to new resources in their everyday lives. The mothers reflected on their children's need for limits, and were concerned about not being able to set such limits. It might be asked whether this preoccupation with limits came about as a result of their interactions with professionals. It is generally understood that children of parents with intellectual disability are at particular risk of lacking proper boundaries. If this is so, the interviewed mothers' reflections then also demonstrate their capability to reflectively process the information given to them. This in turn stresses to the importance of proper knowledge and relevant information as a means to provide parents with new recourses and increase the comprehensibility of their everyday lives.

Also the strategies the interviewed mothers used in their everyday lives can be interpreted as ways to increase comprehensibility. These strategies availed the mothers with resources that helped them remove some of their barriers to good parenthood and the development of parenting skills. However, based on the interviews it is not possible to conclude whether the intentions motivating their actions were also realized or not. One of the strategies described by the interviewees was to seek support from trusted others. This shows the mothers' willingness to use their networks to increase the comprehensibility and manageability of their everyday lives. Yet, even if the mothers consulted others when in need of help, it is not possible to draw any conclusions about whether this, as such, amounted to doing enough from the perspective of meeting their children's needs. It is also not possible to assess to what extent the mothers might have followed the advice they received, or what happened when the advice was not good. What the results do show, however, is that the interviewed mothers were capable and willing to seek help on their own, and that they also were able to articulate their need for help.

Comprehensibility thus seems to depend, at least in part, on information from and communication with one's support network. Inadequate and unclear communication seems to only increase the incomprehensibility of situations and events, undermining one's sense of coherence and contributing to the creation of new barriers. It might consequently be asked whether professionals in the field, when giving out information to their clients, might then be doing so in a manner not helpful to the latter.

The interviews also brought up some interesting perspectives that the mothers had regarding children with special needs. Their descriptions on this point differed somewhat from the picture presented by previous research of parents with children with special needs. Primarily, such children were described by these mothers as just children; and only then, though not at all always, did the interviewees perhaps also note that their children had special needs. Their work with their children appeared to be a source of self-development for these mothers. One interpretation of this finding could be that the interviewed mothers lacked interest in describing their children by their perceived shortcomings. Another way of looking at it would be to highlight the mothers' willingness to learn to how to cope better and make progress with their child-caring. Previous studies on parents with children with special needs have often concentrated on the child's disability, looking at it from a crisis perspective. At the same time, however, there is also research suggesting that care giving might in itself be something rewarding (Grant et al. 1998; Atkin and Ahmad 2000). Capturing the affected mothers' perspectives could thus raise important new knowledge and perspectives about living with and raising children with special needs, inspiring further study.

In line with previous research, the findings of this study support the understanding that there are many circumstances making it more difficult for individuals with an intellectual disability to enter into, develop and frame their parenthood under the same conditions as other parents. One of these, as indicated by the interviews, is lack of comprehensibility, which negatively affects the everyday life of parents such as those participating in this study, creating new barriers. Withholding of information and knowledge, especially when combined with mistrust and negative expectations by professionals, appears to play a major role here. Indeed, one might go so far as to ask whether at least some of the barriers creating difficulties for these parents might have arisen as a direct result of the attitudes of the professionals they dealt with in their everyday lives, as suggested by the interviewed mothers' descriptions of their experiences. It seems very likely that lack of information creates stress and disability and that professionals therefore create social barriers through the operation of the support system.

In this study, the sense of coherence concept, much thanks to its contextual nature, proved useful in deepening our understanding of parenthood and the relational perspective on disability. The theoretical effort above has focused on clarifying the interplay between the interviewed mothers, their resources and the professionals they deal with, looking at the possible role of the latter in defining the terms of these mothers' parenthood. The findings lend themselves to promoting discussion of the existing support system and how it may need to be developed in order to create better conditions for persons with an intellectual disability to enter into and shape their parenthood.

The results underscore the importance of capturing the individuals' own subjective understanding of their disability. The mothers interviewed for this study

frequently stressed the importance of trusted others, role models, access and availability for their efforts to develop their parenthood. More theoretically, the analysis revealed creation of comprehensibility to be a key task for the existing support system, as a way to reduce obstacles to parenthood. To allow persons with intellectual disability to better utilize resources from today's support systems for the good of their parenthood and parenting, it may well be necessary to improve these systems by adapting them to better suit the people who use them.

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