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‘No no, you cannot say that!’ Perceptions and experiences of parents of preschool children with intellectual disabilities in Sweden

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Using semi-structured interviews this study investigated the personal experiences of parents of pre-school children with intellectual disabilities within the Swedish social support system. Thirteen parents of 10 children participated. Interview transcripts were qualitatively analysed using interpretative phenomenological analysis. Three themes emerged: orchestrating formal support; early intervention; and informal support. Parents described orchestrating different organisations within the formal support system and thinking through how they articulated their needs in order to obtain desired supports. Syndrome specific parental groups provided information which parents used to obtain support from the municipality and/or habilitation. The importance of adapting early intervention to both child and family needs is highlighted. The implications of these findings from a family-centred perspective are discussed.

Keywords: family-centred; intellectual disability; interpretative phenomenological analysis; parents; Sweden

Introduction

The birth of a child with a disability has been described by parents as a life-changing event (see Blacher 1984; Blacher and Baker 2007; Roll-Pettersson 2001), affecting practically all aspects of daily life. Research on parenting a child with an intellectual disability has traversed a long road from the deficit paradigm which dominated psychological research during the 1960s and 1970s. The emphasis has shifted to examining parental needs, perceptions, and cognitions within an interactional framework. In the context of this approach, studies have examined parental well-being in diverse areas, such as resilience (Walsh 2003), the restorative effect of positive emotions (Folkman 2008; Hastings et al. 2002), the bolstering functions of informal social support sources (Hastings et al. 2002), the relationship between parental locus of control and well-being (Lloyd and Hastings 2009), the role of professionals as promoters of coping strategies (Ylvén and Granlund 2009), and the importance of formal support services (cf. Dunst, Trivette, and Hamby 2007).

In regard to formal supports the social welfare support system in Sweden has a long history of emphasising the importance of family well-being (Brem-

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berg 2006). Support to families of children with disability is provided through both the municipality and county council. The municipality is responsible for providing pre-school placement, personal assistance and respite care to families on a demonstrated need basis. Consistent with a family-centred philosophy, habilitation centres provide parents of children with disabilities regular and ongoing support, at no charge (Bjerre et al. 1999) of which medical, psychological, educational and social professional services are available. Requirements are that advice and treatments are 'evidence-based', individualised, and adjusted to parents' preferences and a child's needs. The present paper focuses on the current support outlook for parents of a child with an intellectual disability within the Swedish social welfare system.

The organisation of formal support services influences both parental and child well-being. A recent meta-analytic review of 47 studies revealed that family centred approaches improve parental self-efficacy and child skill development (Dunst and Trivette 2009). Dunst et al. (2007) identify two interacting core help-giving approaches that are central in family centred practices: firstly, help-giving should be relational, predicated on optimal clinical behaviour, i.e., attentive listening skills, expressing compassion, empathy, etc.; secondly, supports should be participatory and individualised, i.e., person centred. According to Bernheimer and Weisner (2007) parental perceptions of supports are influenced by social and cultural conditions: the family's overall life situation, values, and goals. In their longitudinal study of 102 families in which one member had a disability, the authors noted that when parental accommodations to the child's disability (such as implementing early intervention), were inconsistent with the family's overall life situation, the accommodations were perceived as stressful. Bernheimer and Weisner note that family routines, values, and goals can and do change over time and interventions often find a place within family routines, goals and values. The authors warn that exclusive focus on child outcomes without consideration of family context may dilute the efficacy of interventions. The relationship between parental well-being and child characteristics are well-documented; child problem behaviour has been found to be the main detrimental factor increasing maternal stress, depressive symptoms, and social isolation (Blacher and Baker 2007; Hastings et al. 2005). Using surveys distributed to 288 parents of children with an ID, as well as parents of children without an ID, Olsson, Larsman, and Hwang (2008) studied sense of coherence, well-being, and self-reported risk. Though the majority of parents rated high on well-being, parents of children with ID rated lower levels of well-being, which correlated with a higher accumulation of risk factors, including child problem behaviour. Correlations have been found between child skill attainment and decrease in maternal stress, increase in parental efficacy, and improved family functioning (cf. Hedberg et al. 2010). In summary, research underscores the importance of professionals recognising and understanding the potential detrimental effects disabilities have on families, the positive relationship between child skill attainment and parental well-being, and the significance of adjusting supports/interventions to the family's overall life situation. Though substantial research exists on these issues, there is a lack of recent in-depth reports of parents' descriptions of their personal experiences of parenting a child with an intellectual disability within the Swedish support system. For this reason a qualitative study was undertaken to consider parents' perceptions of their experiences.

Methods

Research design

The qualitative research method used in this study is interpretative phenomenological analysis (IPA). Though several interpretations of the philosophy of IPA exist, its philosophical and epistemological roots are embedded in hermeneutics (Smith, Flowers, and Larkin 2009). IPA seeks to capture the richness and in-depth account of the lived experience of participants by uncovering central themes found by the researcher in the participants' accounts. Thus, the researcher and to some extent the interviewee are engaged in the interpretative process. This interpretative activity is a key component of IPA; it also acknowledges that interpretation is influenced by the researchers' own biographical background (Smith et al. 2009). However, IPA provides validation procedures to help researcher/s keep interpretation within a realistic level (see the section on ethical considerations and validity). Though IPA has primarily been used to conduct psychological research, it has also been used in nursing (cf. Williams et al. 2010). In the present paper we have extended its use to study the experiential perceptions of parents of children with ID from an early childhood special education/developmental perspective.

Recruitment

Recruitment of parents of preschool children with an ID was obtained through the department heads of two central habilitation centres located within a 100-kilometre radius of Stockholm. Department heads were contacted by telephone and, following their approval, they were sent a total of 15 letters to be distributed to the first parents who contacted team members. Each letter provided a description of the study and a consent form requesting parents who were willing to participate to contact the first author. Inclusion criteria for participation were that the child should have an ID and the family should have had contact with a habilitation centre at least one year prior to the study. The basis for the latter criteria was that parents of children newly diagnosed with ID might be experiencing emotional strains but had not yet begun to focus on obtaining support. The first five families from each habilitation centre who volunteered were contacted by phone and a meeting was arranged at a place and time of convenience for the parent. Parents were informed that they would receive a small honorarium for participating.

The participants

The participants consisted of 13 parents of 10 children, five girls and five boys, between three and one-half to seven years of age. Seven were the youngest in the family and all had siblings. At the time of the study all parents were either married or living together. Each child had an ID, often combined with other difficulties (communication and behavioural, though none had a diagnosis of autism), and physical impairments (e.g., visual, auditory, or motor). As can be seen in Table 1, six children had Down's syndrome and four had 'another' syndrome. Ten mothers and three fathers were interviewed. For the purpose of confidentiality, each family is referred to by a number between one and 10, and all girls are named 'G' and all boys 'B'.

Table 1. Characteristics of child and number of siblings.

Family No.	Parent interviewed	Child's sex, age, diagnosis /difficulties according to parent	No. of sibling and ages
1	Mother and father	Girl, 6-years-old, another syndrome, severe communication and motor difficulties	3 siblings; between 8–16
2	Mother	Boy, 6-years-old, another syndrome, communication and motor difficulties and behaviour problems	2 siblings 8 and 10
3	Mother and father	Girl, 3.5 years, another syndrome, intellectual disability functions as a 1-year-old. Lack of functional communication and behaviour problems	3 siblings 8, 10 and 12
4	Mother	Boy 5 years, Down's syndrome	2 siblings 2 and 10
5	Mother	Girl, 3.5 years, another syndrome; severe intellectual disability, blind, severe motor impairment which also effects breathing capacity	1 sibling 10
6	Mother and father	Boy, 6 years, Down's syndrome, difficult behaviour	3 sibling 8, 14 and 20
7	Mother	*Boy, 7 years, Down's syndrome	1 sibling 5
8	Mother	Girl, 6 years, Down's Syndrome	2 siblings 12 and 17
9	Mother	Boy, 5 years, Down's syndrome, and other impairments requiring extensive medical care	2 siblings 4 and 8
10	Mother	Girl, 5 years, Down's syndrome	2 siblings 1 and 14

Notes: In order to ensure anonymity the names/etiology of all syndromes other than Down's will be referred to as 'another syndrome'. *Child just turned 7, attends pre-school class (children in Sweden begin first grade at 7-years-of-age).

Data collection

A semi-structured interview guide was used; interviewers also followed participants' leads and concerns (Smith et al. 2009). Congruent with GT key concepts, themes that were raised in one interview were alluded to when relevant in subsequent interviews (Corbin and Strauss 2008). The interview questions dealt primarily with descriptions/experiences: child disability/diagnosis and parental experience with both the formal and informal support systems. Interviews took place within a three-month period. Seven mothers were interviewed individually; in two families, parents were interviewed as couples; and in one family, the mother and father were interviewed separately. Each author interviewed the parents of five children. The interviews lasted from one hour to ninety minutes; all were audio-taped and transcribed verbatim. Field notes were taken directly following each interview, summarising main impressions and concepts or themes to be pursued in upcoming interviews.

Data analysis

Data were analysed in accordance with IPA procedures (Smith, et al. 2009). This entailed reading and rereading the transcripts, followed by interpretative notes written in the left margin of the transcript. These consisted of memos, perceptions, and summaries of each interview. Following this procedure, we returned to the data and identified emerging themes which were then noted in the right margin. A list of themes was produced and citations consistent with each theme were identified. This process resulted in some themes being re-conceptualised omitted or merged with others parallel with this procedure, a search for similarities and differences within themes was conducted. The following transcript notations are used: '...' in citations to indicate that material was omitted to shorten quote, and text enclosed in a bracket consists of material that explains the context.

Ethical considerations and validity

In order to assure confidentiality, information that might reveal the identity of families was changed. The mothers in Families 5 and 6 who had both been cited regarding sensitive issues were contacted by telephone and sent via email a copy of the draft with highlighted sections of citations taken from their interviews. A follow-up telephone meeting was arranged with each of the mothers. At the follow-up call, both mothers verbally approved the citations for publication and commented that the findings very much reflected how they interpreted their situation. Member-checking for the remaining parents was done by sending the parents a copy of the draft with highlights, requesting them to contact one of the authors if they felt they had been misinterpreted or if they had additional interpretations which they thought should be incorporated in the text (cf. Colaizzi 1973). With the exception of two parents who commented that the draft accurately reflected their situation, none of the parents contacted the authors. In order to improve validity of interpretations, the authors engaged in ongoing 'checking procedures' concerning transcripts, choice of emerging themes, extracts chosen to illustrate participants' experiences, as well as correctness of citation translation from Swedish to English.

Results

Three themes were derived through interpretative analysis of the interviews. Themes are: (1) orchestrating formal support; (2) early intervention; and (3) importance of informal support. Descriptions of each theme are presented together with verbatim quotes from interviews.

Theme 1: orchestrating formal support

The parents described how they actively mediated contact between different formal organisations. All parents were in contact with numerous sectors of the welfare system: a regional and local habilitation centre; the social security insurance office; and service providers within the municipality, including preschool or preschool class. These organisations provided different supports and according to the parents, it was often their responsibility to arrange collaboration between the organisations congruent with what they perceived as beneficial for their child and family. The mother in Family 2 was satisfied with the individual assistance her family received, but was critical of the lack of collaboration between the support organisations:

We wish they could see our situation from a broader perspective, a holistic perspective of the supports that B needs. It is extremely tiring to be thrown between organisations. I would like to have some kind of contact person who assembles those involved. . . . For those of us who are determined parents and aware of LSS [Law of supports and services] and our rights, things function well; we don't accept 'no' or 'later' as an answer.

However, orchestrating collaboration between organisations was also described as time consuming even when successful. For example, in Family 5, when at five months of age, the daughter rarely slept, screamed continuously, and required constant care, the mother said she felt isolated and depressed because she could not attend to her older child. She contacted the social worker at the local habilitation centre who advised her to contact the municipality in order to obtain respite services. The municipality administrator informed her that the infant was too young to receive respite. The mother said she re-contacted the social worker who in turn re-contacted the municipality and explained the situation. Eventually, she received support and described feeling very satisfied with the respite services. The same mother described a similar situation in which she attempted to orchestrate supports in order to obtain 'therapeutic' support for herself. She described waking up one morning when her daughter was nine months, feeling she could no longer cope. She was taken by friends to a physician, diagnosed as suffering from exhaustion, hospitalised, placed on sick leave, and instructed not to attend G for two weeks: 'I tried to be with Lotta [the older daughter] as much as possible; I couldn't do that before. I was always aware that G was not well. . . . Never getting a smile or any response at all was terrifying'.

During this period, she felt the need for cognitive behaviour therapy (CBT) and discussed this with a specialist at the habilitation centre. After a period of time the specialist contacted the mother and informed her that a CBT therapist had just been employed by the local psychiatric clinic and encouraged her to contact the clinic. The mother said she phoned the clinic to arrange a meeting with the CBT therapist; the nurse she spoke with informed her that she needed a letter of referral from a physician. Accordingly, she contacted the child's paediatrician who wrote the referral. Approximately six months elapsed and the mother still did not receive word

from either the doctor or the clinic. Finally she phoned the clinic and a nurse informed her that they had decided that she did not require therapy. The mother said that initially she felt devastated, then realised that if she was going to survive she would have to take charge of her own life.

A couple of parents reported that in order to obtain support, they needed to be able to read through legal documents. One contacted a lawyer prior to meeting with the social insurance officer in order to ensure that he answered questions correctly. The father claimed that this was a decisive factor in the family obtaining support:

[The father describes what he told the lawyer, explaining why the child and family needed assistance and respite support] The lawyer said, 'No, no you cannot say that; it may be that way, but they are not going make allowance for that. You will have to put it this way', etc. He described how I should present things; for that reason the hours we applied for were approved. If we had not had his help and simply resigned ourselves to accepting 'our life situation is falling apart...', we never would have received all the hours we applied for.

Another method of accessing support was to pretend to be 'slightly ignorant'. In Family 9, the mother of a boy with Down's syndrome and other impairments that required extensive medical care, reported that the way in which she asked questions affected the type and degree of help-giving supports she was offered. She also observed that the extent of authority she was given exceeded her qualifications:

I realised that what I say carries great weight... for better or worse. If I don't say anything, then nothing happens. If I say too much, then they completely rely on me. One needs to put oneself on just the right level, asking the doctors questions all the time, asking them what they think so they can be responsible.

Several parents observed that having a child with an ID and successfully navigating the formal support systems had a positive effect on them, leading to personal changes and new perspectives. The mother in Family 2 reported:

I think that parents of children with disabilities learn to be tough and strong. ... I think it is a merit to be the mother of a handicapped child. Now, when I introduce myself I always mention that in some way. I have taken responsibility for my life and career. B has given me so very much.

Theme 2: early intervention

During the interviews it became apparent that children with a diagnosis of Down's syndrome followed to varying degrees an early intervention language-communication program. Though degree of collaboration between habilitation, pre-school and parents varied most of the parents noticed skill attainment and underscored the importance of collaboration. When asked about communication training the mother in Family 3 described her experience:

Yes, we think we have received very good support... we meet habilitation resources; special educator, speech and language therapist and physiotherapist and together with the pre-school we all get first-hand information on what we should train... we put together an individual action plan with the preschool... so that we have the same goals – it is more effective that way... habilitation is very observant and very important. I think it is

good that we have the team. . . As I mentioned before, I think the program for children with Down's syndrome is excellent, everything is there. It is just a matter of taking it.

Though the overall perception was that early intervention was important, a couple of the mothers thought the communication training was incompatible with their routines and/or goals. The mother in Family 6 described her early encounters with a speech language therapist from the local habilitation centre and the communication program:

I should make different sounds and there were many other demands as well. It was very complicated. . . I felt as if my son's whole development depended entirely on me. I continually had a bad conscience. B was a full-time project. It would have been good if someone had at least come to my home and helped me, even helped me make the material we were suppose to work with dolls, patterns, pictures one was to laminate. I went home with the pictures and just put them away. I didn't have the energy to do more and it sickened me to think about it. I couldn't be a regular mother. It stifled my natural and spontaneous engagement with my child. . . I was so ashamed when I went to the speech language therapist. It was like handing in an incomplete home-work assignment. Nor does it give a good signal to B, he is my bad conscience and the irritation projects out to him.

Lack of information regarding evaluations of interventions was also noted. The mother in Family 8, observed:

What advances develop from the habilitation work with language? Does the fact that it is high-intensive during the first years affect the outcome? One must always evaluate. Actually, international research is being conducted in many different areas. One should utilise the research that has been conducted.

Parents of a couple of the children with 'another' diagnosis questioned whether their child received appropriate support in the area of communication and were troubled by the development of behaviour problems. The parents in Family 3 thought the local habilitation centre provided ample physiotherapeutic support but that communication and behaviour resources were not on par with either their child's or the family's needs:

[Our social life] is totally cut-off. We have sacrificed a lot regarding both our social network and our own recreational activities, including exercise. We have cut down substantially because of G. . . It is a bit difficult to invite people over. We have to base our plans on her. (Father)

It is difficult to take excursions. It is not very relaxing; just having her in the car is a project. . . She screams and pulls the others' [siblings'] hair. . . One sacrifices a lot. . . But to return to our discussion concerning habilitation, it seems as if a lot of things are difficult with G and have been for a long time. . . We brought up communication at the last few meetings, but they mostly suggest that we take out that shoe when it is time to go out and use a sign to strengthen it. I don't know what alternatives there are. I know that in Stockholm they start training communication at an early stage. It seems as if they [habilitation] don't have much to offer. (Mother)

Theme 3: importance of informal support

Engaging with other parents of a child with an ID was experienced as being important. For example parents of children with Down's syndrome were provided courses, lectures, and workshops tailored to their needs by the Swedish Down's

Syndrome organisation. One mother (Family 7) said that the number of options from both habilitation and the parental organisation was ‘almost overwhelming’.

Syndrome specific internet support groups were a prime medium of support and information for parents of children with ‘another’ diagnosis from which they obtained advice which they sub-sequentially used to influence formal support systems. These groups also provided emotional support.

In Family 2, the mother reported:

Perhaps the greatest source of support has been discussions at the [name of syndrome parent group] and exchanges at the [name] syndrome website. We have made friends we will keep all our lives. . . We have been following children who are older than B and see how they have developed and the kinds of supports they received. We told the municipality and habilitation centre that they should provide B with the same treatments. They are often unaware of what B needs. So, we have to take the responsibility to learn what B needs, and then obtain the support.

The mother in Family 5 related:

The families of children with [the syndrome] could join the site’s mailing list. I wrote a long email describing how I felt and our situation. Email replies started appearing from people who had been in the same situation. I received so much support that I felt that my problems were solved. For example, if I needed help with an assistance application, I could get it from the website. Now we are a group of seven mothers from all over Sweden and we and our families interact on a virtual forum. The forum is our life-support.

Discussion

In the present study we investigated how having a preschool child with an intellectual disability can be experienced among a small cohort of parents in the context of the Swedish support system. Three themes, reflective of divergent experiences, were derived from the interviews; orchestrating formal support, early intervention, and the importance of informal support. Orchestrating formal support entailed being strategic, for example when in meetings with professionals, expressing oneself in specific ways, and taking on the role of coordinator, actively arranging collaboration between different organisations. All parents received support and services from the municipality and a habilitation centre. These interactions could be time consuming and entail substantial orchestrating between organisations in order to ensure their child and family with appropriate supports. For example, some parents noted the importance of knowing their legal rights as well as ‘how’ to articulate needs. According to these parents, ‘how’ influenced not only whether they obtained support but also who would be responsible for providing it. Of interest, several parents mentioned that though they had encountered obstacles in their search for support yet had persisted in pursuing it they had ultimately been successful. It is likely that these successful interactions with the support system bolstered their confidence, self-efficacy, and problem-solving skills, traits which serve to ameliorate the effects of potential stressors (cf. Dunlap and Fox 1999). Hastings et al. (2002) postulated that when parents rise to challenges and succeed in dealing with them feelings of personal growth and efficacy are enhanced. Though parents in this study were often successful the issue of inequality is pertinent especially regarding parents who for some reason might lack the resources to articulate their needs.

The parents talked about early interventions in forms of structured training programmes with a focus on language and communication. The findings from the present study reveal both divergent attitudes toward, as well as, access to early intervention. In regard to divergent attitudes, the mother in Family 3 thought the 'comprehensive' person-centred supports her child received was 'excellent' while Mother 6 felt that the demands of early intervention were incongruent with her perception of motherhood, a mismatch which she said led her to continually have a bad conscience for not training her son. The latter example underscores the importance of professionals being attentive to the effects of intellectual disability on the family, as well as taking the family's whole situation into account when planning interventions (Bernheimer and Weisner 2007; Olsson et al. 2008). Clearly, the issues of 'how', 'why', and 'when' of intervention are imperative factors for professionals to consider in order to avoid inflicting guilt on parents as well as securing the implementation of early intervention.

In regard to access to early intervention, it is noteworthy that in this study most of the parents of children with 'another diagnosis' expressed the need for more structured communication training, for example the parents in Family 3 noted a connection between their daughter's problem behaviour and her lack of communication skills. One important question to explore in more depth is the extent to which young children with intellectual disabilities in Sweden obtain communication based early intervention. To be able to communicate rudimentary needs and wants is a basic prerequisite for a decent quality of life. Individuals with severe disabilities are often more dependent than other persons on the environment in order to develop expressive/interactive communicative skills (Snell et al. 2010). Snell et al. conducted a systematic literature review over research conducted between 1987–2007 regarding communication interventions tailored to individuals with severe disabilities and their findings underscored the importance of structured interventions. As previously mentioned, in this study several parents of children with 'another diagnosis' expressed the need for more structured communication training, these results are of concern also as these parents commented their child's problem behaviour restricted their social life, implying that family well-being might be at stake (cf. Blacher and Baker 2007; Olsson et al. 2008). Indeed, current research recognises the interaction between early intervention, functional communication training and reduction of problem behaviour (cf. Dunlap, Ester, and Langhans 2006).

Contemporary definitions of family centred practice (Carpenter 2007; Dunst et al. 2007; Lotze, Bellin, and Oswald 2010) entail that professionals engage in both relational and person-centred help-giving practices. The interpretations from interviews indicate shortcomings in both types of help-giving. As Carpenter (2007) points out the ameliorating effects of early intervention will put new demands on preschool education and habilitation. Several studies conducted in Sweden have noted an apparent lack of knowledge among preschool teachers (Luttrupp and Karlsson, submitted) as well as disability specialists (Roll-Pettersson and Alaí-Rosales 2009) concerning goal setting and intervention implementation. The importance of examining the education and knowledge base of professionals providing help-giving supports needs to be examined in larger scale studies. As Odom (2009) points out, the improvement of early intervention practices is dependent on the promotion of professional development. Consistent with existing research parents in the present study derived emotional strength from informal parent-support sources (Hasting et al. 2002; Kerr and McIntosh 1999). Several parents mentioned

they had developed friendships through syndrome- specific internet platforms. These groups also facilitated parents' acquisition of an in-depth view of their child's specific needs which they used, in turn, to access appropriate support from the habilitation centre and/or municipality. This finding is of interest because it suggests that informal supports mediate the formal support system, it is also of relevance from a higher education perspective as it implies that parents may seek and acquire factual information professionals should possess but lack. Given the small sample size, derived from only one source (parents), findings from this study should be interpreted with caution. Nevertheless, the results are in accord with previous literature and raise concerns about the quality of Swedish family-centred habilitation. Future research could use the findings from this study to contribute to a more in depth study of availability and quality of prevailing relational and person-centred help-giving practices.

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