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Perceived needs among parents of children with a mild intellectual disability in Sweden

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ABSTRACT

Parents of children with a mild intellectual disability experience more distress and require more support than other parents. The aim was to investigate the perceived family needs of parents of children with an MID and to investigate the relationship between parents' perceived self-efficacy in their parental role and in collaborating with professionals as well as with their perceived needs for support. Interviews were based on questionnaires to the parents of 38 children. The results revealed that parents perceived need for information, respite, and venues in which to meet other parents in similar situations. The informational needs were related to parental self-efficacy and obtaining support. A lower need for information was related to higher perceived control over services. In conclusion, it appears that professionals need to work to strengthen parents' ability to ask for support and to express the needs. Well-informed parents will develop stronger parental self-efficacy and perceived control over services.

Introduction

The families of children with a mild intellectual disability (MID) utilize social services relatively infrequently (Olsson et al. 2015). Children with an intellectual disability (ID) have significant deficiencies in intellectual and adaptive functioning (American Association on Intellectual and Developmental Disabilities 2013) and exhibit an increased incidence of several other disorders or impairments compared with children without an ID (Allerton, Welch, and Emerson 2011). In addition, families with a child having an MID are more frequently of a lower socioeconomic status (Strømme and Magnus 2000; Emerson, Einfeld, and Stancliffe 2010; Olsson et al. 2015). In addition, some of these parents may have an ID themselves (David et al. 2013). When combined, these difficulties increase the probability that families with a child with an MID must handle daily situations that differ from those of other families with regard to daily routines, social activities, and coping skills, as well as contact with support services (Granlund and Roll-Pettersson 2001; Webster et al. 2008). Common needs of most families with children having disabilities include informational demands, knowledge, and skills regarding how to collaborate with professionals, maintaining parental influence over services, and understanding their children's rights (Bailey et al. 2006).

Specific support needs for children with autism have been described by Hodgetts, Zwaigenbaum, and Nicholas (2015), who found that the most frequently identified need of parents of children with autism was information related to the current and future services available. These parents also indicated a need for help with handling the child's behaviour and for more time for the parents themselves. Another study described the specific support needs of children with an ID, and the parents referred to a strong need for information about available social services, financial needs, teaching strategies, and therapy and day-care services (Sahay et al. 2013).

The specific needs of these families are often related to information and skills regarding how to handle behavioural problems (Bailey et al. 2006) and to adapt the home environment to the child's cognitive needs (Granlund et al. 2008). In a Swedish study, the parents of children with a mild to moderate ID exhibited strong informational needs regardless of the child's educational setting (Roll-Pettersson 2003). In a study from the Netherlands, the parents of children with an ID who exhibited 'somewhat' problematic behavioural or emotional problems often experienced needs related to 'a friendly ear', 'information', and 'child mental health care', followed closely by 'activities for the child' (Douma, Dekker, and Koot 2006).

Parents who report having appropriate knowledge of child development, child impairment(s), and available support resources are more likely to exhibit stronger self-efficacy and to perceive greater control over the services needed or required. Parental self-efficacy refers to how confident the parents feel in their ability to handle child-related problems. Studies have shown that the parents' experienced needs are related to their perceived self-efficacy in helping their child, as well as in their perception the ability to influence the services received (Dempsey and Dunst 2004; Dunst and Trivette 2009). If parents feel that they can handle specific situations related to their child, they are less stressed and feel less in need of additional support. When parents report good self-efficacy, it affects how they feel as parents, how worried they are, and their relationship with their child (Dempsey and Dunst 2004; Wakimizu et al. 2011). Studies have also shown that supporting self-efficacy will have an effect on parental and child well-being and that parents with a high self-rated self-efficacy rate their needs for support lower (Trivette, Dunst, and Hamby 2010). Whether these patterns hold true in Sweden is unknown, but it is likely that parents with higher self-efficacy have lower perceived needs for support and information.

In Sweden, all families are provided with generic support, including financed parental leave and subsidized preschool for their children. Families with children having a disability may require additional support beyond the generic. Formal service systems can help families fulfil needs to optimize child functioning. Such formal service systems for families of children with MID in Sweden include social services and paediatric habilitation services. How the service systems work is partly regulated by law, including how the services are organized, how different types of services are linked, and how professionals interact with the parents.

In Sweden, among children who are enrolled in compulsory schools for pupils with an ID, those with an MID are educated in accordance with a reading-based curriculum (Roll-Pettersson 2003). Children with an MID may attend a self-contained class or be integrated into a mainstream class. A study of how parents of Swedish children with an MID utilize social services revealed that families with children enrolled in self-contained classes were 13 times more likely to utilize disability-related social services (Olsson et al. 2015). This indicates that the way in which services are organized and linked affects service utilization. The authors argued that parents who enrol their children in self-contained classes are more likely to be exposed to information about available services through meetings with other parents in the same situation and by knowledgeable teachers compared with parents whose children were integrated into mainstream classes. This result also indicates that professionals working to provide support to these parents must interact with parents in a manner that optimizes the parent's access to information and perceived control over the available services. When professionals apply capacity-building practices to promote the parent's active involvement in problem-solving and decision-making, the parent's perceived self-efficacy in controlling services

and as a parent increases (Dempsey and Dunst 2004). Thus, parents with high parental self-efficacy and high perceived control over services will perceive a lower support need.

The difference between the present and a desired state presents an ongoing problem (Ylvén, Björck-Åkesson, and Granlund 2006). Parents often apply for resources that they believe will solve their problem(s) rather than describing the problem(s) at hand (Carlhed, Björck-Åkesson, and Granlund 2003). Needs represent the resources and tools needed to solve a problem. By using collaborative problem-solving when asking parents about their perceived problems, it is possible to map family concerns (Ylvén, Granlund, and Persson 2012; Ylvén and Granlund 2015). By listening to the expressed needs, professionals can indirectly understand the problem and whether the requested needs (i.e. resources) are linked to the problem they are intended to solve. If professionals use a collaborative problem-solving approach to identify not only needs but also the problems that the needs are related to, support will be more efficient and parents will feel more in control. Strong negative relations between perceived parental control, parental self-efficacy, and parents' perceived needs will provide support for this hypothesis.

This study has two aims: to investigate the perceived family needs of parents of children with an MID and to investigate the relationship between parents' perceived self-efficacy in their parental role and in collaborating with professionals as well as with their perceived needs for support.

Research questions:

- What are the family's perceived support needs in terms of information, psychosocial support, explaining to others, community service, financial needs and support with family functioning?
- Do parents that perceive lower levels of support report high parental self-efficacy and high perceived control over service?
- Is there a difference in perceived support needs between families of children diagnosed with an MID alone and families of children diagnosed with an MID and one or more additional disorders?

Methods

Participants

The sample consisted of the parents of 38 children enrolled in compulsory schools for pupils with an ID, 87% of whom were estimated by their parents to have an MID. All children were between the ages of 7 and 17 years, with a mean age of 13 years. Of the 38 children, 24 were boys, and 14 were girls. All participants lived in Sweden (Table 1).

Procedure and data collection

The families were informed of the study at parental meetings at all compulsory schools for children with an ID in a county in Sweden. Parents were then free to contact the research team if interested in participating in the study. Parents chose the location of the interview. The interviews primarily occurred in the participants' homes.

Material

Structured interviews were conducted with the parents, primarily in the home and in some cases at the university. Sometimes the interviews were conducted with both parents and other times with only the mother or the father.

Two questionnaires were used in the interviews.

Table 1. Sample characteristics, relative frequencies (absolute frequencies in brackets).

The child with an ID		
Age		
7–12		39% (15/38)
13–17		61% (23/38)
Gender		
Male		63% (24/38)
Female		37% (14/38)
Health status: has at least one diagnosis besides the ID		
Yes		68% (25/37)
No		32% (12/37)
Family situation		
Child living together with both his/her parents		68% (26/38)
Child living together with one parent		32% (12/38)
Contact with services, age of the child at the first contact with:		
Social services		Mean 7,9 (33 children)
Pediatric habilitation services		Mean 4,8 (34 children)
Parental education	Mother	Father
Compulsory school for pupils with an ID	3% (1/36)	3% (1/32)
Compulsory school (nine years)	5% (2/36)	12% (4/32)
Upper secondary school	64% (23/36)	66% (21/32)
University	28% (10/36)	16% (5/32)
Other	–	3% (1/32)
Parental work status		
Paid work	81% (30/37) working time mean 72%	91% (29/32) working time mean 89%
Applying for work	3% (1/37)	6% (2/32)
Studying	–	–
Other (the parent have not defined the work status)	16% (6/37)	3% (1/32)

Note: The diagnoses were epilepsy, Autism, Asperger, Cerebral palsy, ADHD/DCD, Speech-/language disorder.

Questionnaire 1

The questionnaire included socio-demographic variables and questions related to community services and healthcare services: for example, how often and what type of services the family utilized? In addition, the questionnaire contained questions about the parents' experiences with support. The questions were answered on a five-point Likert scale – 1: We know almost nothing about available support; 2: We know a little about available support; 3: We know somewhat about available support; 4: We know almost all about available support; and 5: We know all about available support. The questionnaire was based on one developed by Bailey et al. (2006). A Swedish version of this questionnaire has been tested for validity and reliability (Ylvén, Granlund, and Persson 2012). Based on research published by Bailey et al. (2006) and Dunst and Trivette (2009), the questions relating to parental self-efficacy and parental control were used to create indexes.

Parental self-efficacy is an index based on four questions regarding parents' perceptions of their parental role: How much the family knows about child development?; How much the family knows about how ID affects their child?; How much the family knows about how to help their child to develop and learn?; and How much the family knows about how to help their child work well with others? (Ylvén, Granlund, and Persson 2012). It is based on Bailey et al. (2006).

Parental control over services is an index based on three questions about parents' perception of their control over collaborating with professionals: How much the family knows about available support?; How much the family knows about the services they are entitled to (to help the child and themselves)?; and How comfortable and involved the family feels in meetings with service providers? (Granlund et al. 2008).

How parents perceive the general support is an index based on five questions from Bailey et al. (2006): How often the family has someone who listens and talks to them when they need it?; How often the family has someone they can rely on for help when they need it?; How often the family has the opportunity to do things they enjoy?; How well healthcare services meet their child's special needs; and How well childcare services meet their needs for child care?

How parents perceive the specific support is an index based on six questions from Bailey et al. (2006): How much the family thinks that support from paediatric habilitation services has informed and helped the family to understand their rights?; How much the family thinks that support from habilitation services has informed and helped the family to understand their child's needs?; and How much the family thinks that support from habilitation services has helped the family to assist their child to develop and learn? The same questions were asked regarding support from the local authority (i.e. municipality).

Questionnaire 2

The second questionnaire contains 36 questions about family needs (Bailey and Simeonsson 1988). The questions were answered using a three-point scale with the options yes, unsure, or no. The questionnaire has been tested previously for reliability and validity in Sweden (Granlund and Roll-Pettersson 2001). Perceived needs are divided into indexes.

Needs for information was assessed based on seven questions; if the parents need information about the child's impairment: How to meet the needs of the child?; How to teach the child different skills?; How to play and communicate with the child?; What services for the child are available at present and will be in the future?; and finally, information about the child's development.

Needs for support (i.e. psychosocial support) was assessed based on eight questions concerning the following needs: for the family to talk to about problems; whether they need more friends to talk to; whether they need to meet other parents who have a child with impairments; whether they need more time to talk to the child's doctor; whether they regularly meet to talk to and receive support and advice from; whether they need to talk to a priest or the equivalent; whether they need written information about parents who have a child with the same impairment; and whether they need more time for themselves.

Explaining to others was assessed based on five questions: whether they need assistance with explaining their child's impairment to the child's siblings, other members of the family, or to other children; whether the husband/wife needs support to understand the child's impairment; and whether they need assistance regarding how to respond to friends neighbours and strangers who ask about the child's disability.

Community services were assessed based on six questions: whether they required support to contact a physician or dentist that understands the child's needs; child care; respite care or short-term care for the child; support in obtaining appropriate recreational activities for the child or to affect the child's schooling; and child care when participating in different activities.

Financial needs were assessed based on six questions: whether they require financial aid to cover expenses such as food, rent, medicine, clothes, or transport; the ability to buy assistive devices for the child; the ability to cover expenses for treatment or other services that they and the child require; the ability to cover expenses for a babysitter/respite care and to be able to buy toys for the child; and whether the parents require child supervision and support to find employment.

Family functioning was assessed based on four questions: whether the family required support to discuss and solve problems, to learn how to support each other in difficult situations, to decide who is responsible for child care and other tasks in the home, and to find recreational activities that the family can participate in together.

Analysis

Descriptive statistics. For Questionnaire 2: Cronbach's alpha was calculated (Table 2). The mean value of the variables included in the index was calculated and correlations were computed. Despite the low number of participants, the internal consistency estimates were relatively good except for informational needs. The relatively low alpha value for informational needs likely depended on the rather broad set of informational needs assessed for clinical reasons.

Table 2. Index and Cronbach's alpha for Questionnaire 2.

Index	Alpha value
Needs for information	0.49
Needs for support (psychosocial support)	0.68
Explaining to others	0.75
Community services	0.61
Financial needs	0.65
Family functioning	0.77
Parents control over services	0.65
Parental self-efficacy	0.73
How parents perceive general support	0.60
How parents perceive specific support	0.87

Ethical considerations

This study was approved by the Regional Ethical Review Board in Linköping, Sweden (Dnr 2011/275-31). Parents gave written consent (Morrow and Richards 1996). The questionnaires were anonymized and stored securely.

Results

Most parents reported informational needs, both concerning currently available support (79%) and future support (92%). Other common needs involved how to manage their child's behaviour (63%) and how to teach their child different skills (47%).

The most common reported support needs related to the parents need for relief (time for themselves, 63%), to read about experiences of other parents of children with an ID (58%) and to meet other parents of children with impairments (55%).

Some of the parents needed support with explaining their child's condition to others (27% to siblings and 24% to other children). Community services appeared to be available, but almost half of the parents identified difficulties in finding a suitable recreational activity for their child (42%). Approximately a quarter of the parents identified a need for financial support for basic needs (24%), and about a quarter of the parents identified needs related to how to support one another within the family (24%).

An analysis of the relationship between the parents' perceived needs in relation to parental self-efficacy and perceived control over services indicated that informational needs are related to both self-efficacy and parental control over services (see Table 3). Parents' control over services was related both to how helpful they perceived the general and specific support to be, indicating that the perception of control is related to parents' positive perception of received support. Perceived parental self-efficacy was not related to the perception of the support.

Mothers with paid employment were found to have a reduced need for support ($r = 0.364$, $p < .05$) and financial needs ($r = 0.476$, $p < .005$). The mother's educational level was also related to the need

Table 3. Correlation between family needs and parental self-efficacy and parental control over services.

Family's needs for:	Parental self-efficacy			Parental control over services		
	p-values*	Pearson correlation	n	p-values*	Pearson correlation	n
Needs for information	**0.02**	−0.386	38	**0.03**	−0.345	38
Need for support	0.11	−0.272	35	0.16	−0.242	35
Explaining to others	0.32	−0.175	34	0.32	−0.176	34
Community services	0.56	−0.099	38	0.94	−0.012	38
Financial needs	0.51	−0.110	38	0.23	0.200	38
Family functioning	0.91	0.018	38	0.21	0.207	38
How parents perceive general support	0.22	0.236	29	**0.03**	0.410	29
How parents perceive specific support	0.07	0.324	33	**<0.01**	0.561	33
Parental control over services	**<0.01**	0.640	38	–	–	–

*The bold values are the value that were below <.05 and were considered statistically significant.

for support, indicating that mothers with a higher education expressed fewer needs ($r = -0.429$, $p < .05$).

These results identified a difference between the group with a child diagnosed only with an MID ($n = 12$), and the group of children diagnosed with an MID and one or more additional diagnoses ($n = 25$), such as epilepsy, Autism, Asperger, Cerebral palsy, ADHD/DCD, and a speech or language disorder. Families of children with several diagnoses rated more needs for support ($p = .01$ CI 0.14–0.81) and for community services ($p = .05$ CI 0.01–0.67)

Discussion

This study explored the needs of families with children having an MID. The needs that the parents most strongly expressed concerned information, especially regarding what support the child or family may expect as the child gets older but also regarding current support opportunities. The level of perceived informational need was related to perceived parental self-efficacy and to their perceived control over services. Perceived control over services was related to the perceived level of helpfulness of the received support regarding both general and special support. The index of needs for support and community services were the only indexes that were related to whether the child with an MID had additional diagnoses.

The need for information regarding present and future support expressed by the respondents in this study is an indicator that life planning is a common concern among families with children having an MID. With regard to information about future support, a study by Hewitt et al. (2010) revealed that almost all families questioned identified an individual who could support the family member with an ID when the parents were no longer were able to; all families requested a life assistance programme. Douma, Dekker, and Koot (2006) found that parents asked for information regarding where and how they could receive information about services. Our study, like other studies (Roll-Pettersson 2003; Douma, Dekker, and Koot 2006; Hewitt et al. 2010), indicates that the control of information is a key issue. Information is a main component of perceiving control over services and the situation (Dunst and Trivette 2009). Douma, Dekker, and Koot (2006) suggest that a central information source is preferable and that assigning a case manager could achieve this goal. A recent Swedish study (Olsson et al. 2015) reported that only 37% of all families of children with an MID in two Swedish municipalities received support from social services because of the child's impairment in one calendar year. This underscores the importance of obtaining information, not only about available services but also about how to utilize them. In this study, the perceived informational needs were unrelated to the child's number of impairments or diagnoses. This may indicate that informational need is related to a universal need of parents of children with impairments to perceive control over their life situation in stressful circumstances rather than to the specific impact of having a child with an MID.

Parents of children with an MID and one or more additional diagnoses perceived stronger needs for support and community services than parents of children with only an MID, while other types of needs were not related to whether the child had one or more diagnoses. The needs for support and community services are more directly related to the impact that the child's characteristics have on family life, for example, the parent's time on their own, the child's leisure opportunities, and needs concerning family economy or perceptions of family relations.

A relatively high percentage of parents perceived informational needs, support in having time of their own (respite), and also meeting with other parents in the same situation. It may indicate that the welfare system in Sweden does not currently has the universal social policy programmes originally intended. The level of informational needs was significantly related to both parental self-efficacy and the parents control over service(s); the better perceived self- efficacy and control over service (s), the lesser was the need for information. If the parent has low levels of self-efficacy, it can result in poor persistence to maintain the level of care needed for their child, depression and diminished satisfaction in their parenting role (Johnston and Mash 1989). Thus, the relationships between

the level of needs, parental self-efficacy, and perceived control over services indicate that services need to be provided in a manner that strengthens parental self-efficacy and control over services. This interpretation of the results is supported by meta-analytic structural equation model studies that show that when professionals work in a capacity-building manner, parents self-efficacy is strengthened, and parental and child well-being increases (Dunst and Trivette 2009; Trivette, Dunst, and Hamby 2010). Further support for this interpretation is provided by the strong statistical relationship in this study between parent's perceived control over services and their satisfaction with the specific support provided to their child.

The parents in this study expressed a need for more leisure activities for their children. In addition, the need for community services, including child leisure activities, was linked to additional diagnoses. Both of these results stress the need to support families in facilitating the child's participation in leisure activities. Participation in activities outside school is important for children's health and positively influences their self-esteem, psychological well-being, social competence, physical fitness and gross motor skills (Murphy and Carbone 2008). Children become motivated when they participate in activities they prefer and enjoy (Watkinson, Dwyer, and Nielsen 2005). The major differences observed in participation patterns between children with disabilities and children without disabilities are in social and recreational activities where children with disabilities participate less. In addition, many of the activities for children with disabilities are performed with parents; children with an MID require more social activities with same aged peers and other children with disabilities without the need for parental facilitation (Shields et al. 2013). The expressed parental need to support the participation children with an MID in appropriate recreational activities is reflected in the results of a study by Olsson et al. (2015). They found that one of the most utilized services provided to these families was a companion service, including short periods of supervision for school-children over the age of 12 years outside their home and short stays away from home. The provision of such services may also reflect the parent's own needs for respite.

The effectiveness of the family's support network of relatives, friends, and professional services may influence how the family copes with having a child with a disability (Whiting 2014a, 2014b). Families with a strong support network have fewer needs. Parents in the present study expressed that they need time on their own and that they need to meet with other parents of children with impairments. This was especially pronounced among parents of children with additional diagnoses. To have a child with a disability is time consuming due to the extra care needed, which is often required beyond childhood. Thus, participation in activities outside the family context may hold a low priority.

Limitations of the study

The sample consisted of the parents of only 38 children. All families lived in the same county in Sweden but were from 11 different municipalities. This group of parents was difficult to reach for many different reasons. We informed families about the study at parents' meetings at school, but some parents do not attend to these meetings, which possibly led to a biased sample.

Another limitation is that in the cohort of children with only an MID consisted of 12 children, whereas the group of children diagnosed with an MID and one or more additional diagnoses was comprised of 25 children. Furthermore, the Cronbach's alpha value for informational need is 0.49. However, if we consider the questions asked of the parents regarding *Needs for information,* the index was comparable to that of other studies with similar results (Bailey, Blasco, and Simeonsson 1992; Bailey and Simeonsson 1988; Bailey et al. 1999).

Conclusion

Parents' perceived control over services and their self-efficacy are related to their informational needs. It is recommended that professionals work to strengthen parents' skills in asking for and

interpreting information about available services and to express the needs of the child and family. Well-informed parents will develop stronger parental self-efficacy and perceived control over services.

Disclosure statement

No potential conflict of interest was reported by the authors.

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