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PARENT PERSPECTIVES ON EARLY INTERVENTION: THE PARADOX OF NEEDS AND RIGHTS

Carina Carlhed, Eva Björck-Åkesson and Mats Granlund

Introduction

The main aim of this article is to discuss encounters between parents and professionals and parents' conceptions of perceived support from professionals. The empirical basis is a previous study of parental perspectives of support from a formal support system. The results from this study are discussed in relation to the characteristics and use of methods emanating from models for providing family support. The discussion contributes to an increased understanding of the relationship between family needs and what support families want in order to conceive it as useful support in everyday life.

There is a dialectical relationship in social support models between emphasis on peoples' rights and needs (Rappaport, 1981). The relationship may be viewed as a paradox between different views of people. For example, an intervention design which primarily focuses on peoples

needs tends to treat clients as children, while a model which focuses on peoples rights approaches people as citizens. However, people in need are also citizens, which demands divergent thinking in professionals to assure meeting people's needs and at the same time considering their rights as citizens. If only one side of this combination is maximised, the other tends to disappear. Thus, one has to choose which consideration is in focus for the moment – both sides cannot be emphasised equally. The paradoxical nature of the concepts implies divergent solutions rather than convergent solutions. How professionals in the social support area regard their role in the intervention process and the role of the proximal environment is related to their perspective on intervention. A developmental perspective (focus on the child's development in designing intervention) gives less room for divergent thinking and emphasises professional expertise,

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while a functional perspective (focus on problems in everyday life) gives room for divergent thinking and for parallel solutions to a problem emphasising collaboration between parents and professionals (Björck-Åkesson *et al.*, 2000).

In Sweden, the field of early childhood intervention comprises three systems where the child's well being is attended to. Children with disabilities and their families are offered support and services by well-baby clinics, the pre-school system and habilitation centres. In Swedish legislation, children with disabilities have the right to support and services primarily due to The Health and Medical Act (SFS, 1982) and the Support and Service Act (SFS, 1993). In this article, early intervention for children from birth to school-age (7 years) at habilitation centres is in focus. At habilitation centres professionals assist by providing support to children and families, e.g. special educators, pediatricians/child neurologists, physical therapists, occupational therapists, psychologists, speech pathologists and social workers. A team is created around the child that includes habilitation professionals and support providers from other organisations, the parents and other care providers in the child's proximal environment (Bille and Olow, 1999; Björck-Åkesson and Granlund, 1997). How such a team is constituted depends on the needs of the child and the family and models for collaboration adopted by professionals. Perspectives on how to organise and implement support including the roles of professionals and persons in the child's proximal environment differ. A developmental perspective may be adopted focusing on the child and development in relation to "normal" development, or a functional model focusing on the child's development in interaction with the proximal environment, generating different

meanings of the conception of support (Björck-Åkesson, 1992). Perspectives of the planning and implementation of the intervention process by parents, professionals and administrators do not always concur. The different perspectives may be derived from macro-level factors such as: legislation, educational and cultural beliefs. An example of an explicit factor influencing the intervention process is how the goal of habilitation is described in general (Högberg, 1996). In Sweden, the goal of habilitation is formulated in terms of increasing the individual's functional ability and to develop prerequisites for the child's independent life and participation in society (FUB, RBU, RFA, Tvärsektionsgruppen inom Barn och ungdomshabilitering, 1993). The formulation of the goal may be interpreted in two ways: as intervention practices that are "normalising" the child according to certain developmental criteria, and as re-establishing a well functioning everyday life for the families. In Swedish social policy, it is interpreted in both ways. For this reason, frames of reference and choice of working methods differ between local habilitation services. The normalising intervention approach is comparable to the developmental perspective where the development of the child is the focus in the intervention-design. Attention to everyday life and involvement of the proximal environment in intervention decisions is synonymous to working with a functional perspective (Björck-Åkesson *et al.*, 1997). In the effort to give effective support to families, both perspectives are relevant. However, depending on the problem that has to be solved, one of the perspectives is emphasised.

The expression of a need is often a start of the problem solving process. A need defined by the family is something that is perceived as necessary in order to solve a problem (Björck-Åkesson *et al.*, 1996).

When parents express their needs they tend to describe necessary resources or known intervention methods, rather than the problem these resources or methods are intended to solve. Many times this phenomenon creates a problem since professionals have a tendency to interpret parental needs as problem descriptions (Granlund *et al.*, 2001). Thus, professionals believe that the problem is solved when the resources asked for are provided. If the solution asked for does not match the problem, the perceived problem remains and parents feel that they are not listened to. That is, they do not experience support. This may be discussed in relation to other studies, which have shown a discrepancy between delivered services and the needs of the child according to the parents (McWilliam *et al.*, 1995). For this reason it is interesting to inquire into parents' perspective. How do they perceive and conceptualise good or sufficient support? As an example, a study of parents' conceptions of support will be described.

Method

The analysis was conducted using an overarching interpretive (hermeneutic) approach, which means that the researcher tried to understand the parent's perspectives by interpreting their statements in interviews. Hermeneutic interpretation is carried out by careful text analysis (Bontekoe, 1996) and consisted in this study of interview transcriptions. The phenomenographic method was used – i.e. *describing phenomena as they appear to people; the qualitative different ways in which phenomena are experienced and perceived* (Marton, 1981). In this article the central concept is support and in the analysis, questions addressed *what* is sup-

port, and *how* is support perceived? The participating group consisted of eight parents (two fathers and six mothers), each family were interviewed individually. The children were 2 – 5 years old and had different diagnoses, such as: cerebral palsy, infantile autism, spina bifida and Downs syndrome. One child did not have any medical diagnosis but had disabilities. The parents live in small towns and have contact with the same habilitation centre. They have met at the centre and at meetings with other parents in parents-organisations, thus they personally know each other. The research group was contacted by one of the parents after a lecture at the university. This parent mediated contact with the others. Thus, the sampling procedure has convenience characteristics. Data were collected by in-depth interviews with the parents. The interview approach was non-standardised and three themes were provided for the parents to enter in depth. The three themes were focusing experiences about: (1) the first encounter with professionals in the habilitation centre, (2) the need assessment, (3) "good and bad" support and supportive professionals. Parents were encouraged to talk freely about their experiences, and the researcher had a rather passive role. This was done to enable parents to give their perspective and withhold researchers' control of what is the appropriate opinion. The interviews took place in the families' homes and took about 1½ - 2 hours each; the interviews were then transcribed at their full length. In the analysis, a computer programme, especially designed for sorting and categorising in phenomenographic analysis, was used (Booth, 1990a; Booth, 1990b). The procedure was conducted in a stepwise fashion - (a) Repeatedly reading the transcribed interviews, in order to establish a impression

of the whole phenomenon. (b) Quotes were selected from the transcriptions using a search-question: What is support? They were collected into the first stack – “the pool of meanings”. (c) From this pool the quotes were then categorised into different themes using a content analysis approach, i.e. quotes which addressed the same concept were gathered in the same stack. (d) In the next step of the analysis, the underlying structure among the themes was studied, in other words, the relation among the themes was studied. At this stage of analysis, one might discover that the system of categorisation is not satisfactory and needs to be revised. This means that step *c* and *d* will be continued until a satisfactory structure has been created. Thus, the product of such an analysis is a categorisation system with a clear and understandable structure, which increases the understanding of the phenomena. In this study, it was intended to bring clarity, giving a clear shape to the parents’ conceptions of support from habilitation centres. Positive experiences were interpreted as desirable support and negative experiences as undesirable support. An independent researcher in the area participated in an inter-rater reliability check of the coding of quotes from interviews into themes in the category system (Silverman, 1993). In sum, there were 206 quotes and 196 of them were judged with unquestionable agreement, i.e. 93 %. A respondent validation was also carried out (Silverman, 1993), i.e. the transcribed interviews were sent back to the parents, to give them the opportunity to judge if they were correctly quoted. There were no comments about incorrect quotes or withdrawals made by the parents.

Results

The interviews focused on formal system support. Although informal support was never a focus in the questions, all parents mentioned this kind of support as highly important. The informal support was mainly support from other parents who have children with disabilities. Parents exchange information and build social networks where they can talk to others in a similar situation. Support from formal systems is divided into two categories, which reflect different areas for formal support. They are: within the habilitation centre and outside the habilitation centre (see Figure 1).

The category “Experiences from outside the habilitation centre” contains statements about parents’ dissatisfaction with waiting for assistive technology (i.e. wheel chairs) or responses from community organisations. Examples of positive statements are that (1) someone working in medical departments (i.e. maternity clinics) saw their needs and helped parents to express a need and support it and (2) to be treated as a competent parent. Statements about support from parent organisations were also reported in this category. As a consequence of the focus of the interviews most quotes are found in the category “within the habilitation centre”. In two sub-categories are quotes regarding experiences of: (a) organisational factors such as the hospital-like environment of the habilitation centre and dissatisfaction with the turnover rate among professionals, and (b) the team around the child. Most of the experiences concern the team working with the child and its family. Parents think it is important that professionals are interested in people and are flexible in the manner they work with families. In sum, this category of statements points to it that professionals need to support the parents

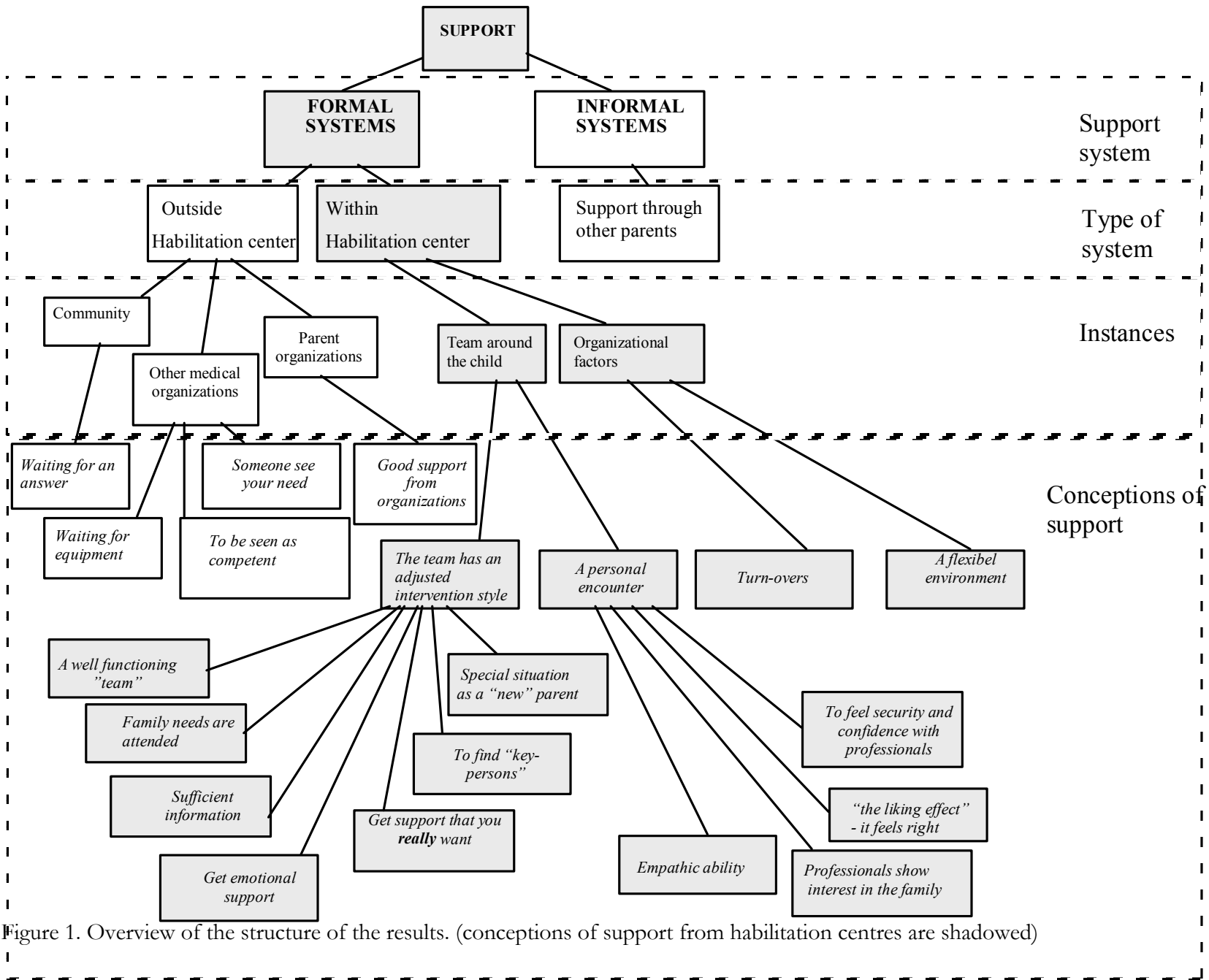


Figure 1. Overview of the structure of the results. (conceptions of support from habilitation centres are shadowed)

TABLE I
Interpretation of interviews according to themes: the desired, ideal and perceived situation in the encounters with professionals at habilitation centres.

Support Levels	Desired/Ideal Situation	Perceived Situation
INTER PERSONAL LEVEL	<ul style="list-style-type: none"> • Professionals show ability to empathise • Professionals inspire security and confidence • "Liking effect" - it feels right • Professionals show their interest in people 	<ul style="list-style-type: none"> • Insufficient ability to empathise • Parents do not feel confident with the professionals • "Liking effect" - it does not feel right • Professionals do not show interest in the families
INTERVENTION LEVEL	<ul style="list-style-type: none"> • The needs of the whole family are addressed • Adequate information is given at the right time • The team is working together and is well organised and synchronised • The team as a whole gives emotional support • Support is designed for the real needs, and the expressed needs • Professionals are able to "read" the family's process and adjust to that • To get hold of a "key-person", that is able to deal with problems and shows different ways to get help 	<ul style="list-style-type: none"> • Child focused interventions • Insufficient information • The interventionists have different opinions about how to give support • Insufficient emotional support • Few kinds of support and services are offered • Sometimes only verbal information • Professionals do not ask parents what they want • Parents have to wait a long time for the first encounter with professionals • If there is an intermediary function - it often does not work • Problems perceived by parents are not attended to • Sometimes a professional from other service systems attends to the problems - but it should be professionals from the habilitation centre
ORGANISATION LEVEL	<ul style="list-style-type: none"> • All professional categories/therapies available • Continuity among the professionals • Habilitation centres offer a welcoming home-like environment 	<ul style="list-style-type: none"> • Vacancies for professionals • High level of turnover • Hospital like environment

emotionally and need to have flexible capability. The results can also be seen as in TABLE I, which shows the results from interviews referring to ideal/desired situation and perceived situation in encounters with professionals in habilitation centres. Positive experiences described by parents

were interpreted by the researcher as desirable support and negative experiences were interpreted as undesirable support (TABLE I).

Parents perceptions are here interpreted and described in relation to different support levels, *interpersonal*-, *intervention*-

and organisation level. An example of an ideal situation at the interpersonal level where an experience with a professional was considered a good experience, is told here by a mother:

" she [*the professional*] was not afraid to meet the sorrow we felt and she knew what she was doing, a professional security... and she was not afraid to meet in conflicts..." (translation and italics added by the authors).

An example of an ideal situation at the intervention level is, according to the parents, the importance of professionals to really work together and the synchronising of interventions. For example, a mother tells that her daughter needs a special chair in order to sit at the dinner table with the other family members. The physical therapist and the occupational therapist disagree about which chair is to be used and what is best for the child. The mother thinks this is very uncomfortable. She wants them to solve this issue together and then come up with a suggestion for her to consider. Another example at this level is a wish from parents that the habilitation team show that they care about the family and how they feel, give them a telephone call etc. At the organisation level, one example given by parents was the high level of turnover among certain professional groups and the habilitation centre's inability to fill the vacancies. Although the parents understood the reason and circumstances for this situation, they expressed dissatisfaction with the discontinuity as its consequence. It was also experienced positively when the habilitation centre was home-like.

In sum, the results call for an emphasis on building good relationships between parents and professionals, both at the interpersonal level (actions as individuals) and at the intervention level, (actions as an organisational team). There seem to be

some communication obstacles between information given to parents about the role of habilitation and information about services available. The results concerning the organisational level point out prerequisites for building these relationships, i.e. there are difficulties in building good relationships when there is a high level of turnover among professionals.

Discussion and Practical Applications

How do these parents want "good" support to be designed? On the one hand the parents tend to emphasise the "need-perspective" of the paradox in community life, as described by Rappaport (1981). Their statements are about the importance of relationships; security, continuity, confidence and a more active and synchronised intervention approach confirm this interpretation. On the other hand, the parents wish for more flexible solutions (the "rights perspective") and think it is difficult and negative when professionals disagree with parents on a solution (have different opinions). Thus, the perceptions of the support that is given these families focus on rights vs. needs to different degrees (Rappaport, 1981), i.e. the paradox of needs and rights. This may indicate that some families are more satisfied with support designed to meet the needs for security and confidence, while others want more flexible solutions for their family and opportunities to decide which support *they* want. It is an example of a complicated balancing act of assumptions in the social support models. For example, when and how do professionals make parents too dependent, and when and how does flexibility of the organisation make the

collaboration too insecure? There is probably not one answer to these questions. Several factors may have an impact, such as the age of the child, the informal support experienced by the families, and organisational features of the services given. The parents in the study knew each other; they have young children and somewhat similar needs. They express mainly the need for a secure relationship with professionals, although this also differs, depending on their specific situation and the child's disability. There are also statements about more flexible solutions. Parents expressing a desire for flexibility are probably more in control than others, they are experiencing empowerment. They know what they want and they are eager to ensure that the services given fit in with the everyday life of the family and their own life-style. It is important to acknowledge that services to families with young children with disabilities are focused on divergent problems. Intervention discussions with parents must cover several divergent problems and solutions. A decision must be made in collaboration with the family about which side of the paradox should be in the foreground for this particular family at this particular point of time. Each family has certain kinds of needs, and the needs change over time depending on perceived problems. Studies have shown that having a child with disabilities implies a life-long adjustment and recurring crises and needs that are individual for each family (Roll-Pettersson, 1996).

The needs - rights paradox might be the consequence of a tendency of parents and professionals to perceive parental statements of needs differently. That is, parents ask for desired solutions without stating the problem. Professionals interpret need statements as problem descrip-

tions and thus believe that the problem is solved when the solution is provided without actually evaluating the outcome of a solution provision to the problem. This phenomenon might be avoided with a better outlined collaborative problem solving process in the intervention cycle. In such a problem solving collaboration the role of parents and professionals regarding problem description, problem explanation, goal formulation, design and implementation of methods and evaluation need to be clearly stated. The parents "own" the intervention process and are experts on describing problems and goals related to the problems. They also have explanations for problems related to their everyday-life. Professionals have expertise in helping parents to make informed decisions by defining problems and goals. They also have expertise in problem-explanations related to the disability and in designing methods. Parents, however, have knowledge of how, when and by whom interventions should be implemented. Using the cumulative expertise of parents and professionals places divergent problem solving in focus, and the intervention process can be individualised and adapted to the needs of the child and the family (Björck-Åkesson *et al.*, 2000).

The results from the study show that the information the families have been given was not enough and/or not perceived as such by the families. According to Swedish legislation (SFS, 1982; SFS, 1993) interventions should be asked for by parents. However, if the information is insufficient or given without regard to current problems and needs, parents do not know what they could ask for or which services are available. A follow-up of the implementation of the LSS-act, (SFS, 1993) has been carried out that confirms the scarcity of sufficient informa-

tion to families about their rights (Socialstyrelsen, 1997). In the legislation, there are key words like: influence, accessibility, participation, continuity and comprehensive view of the individual (FUB *et al.*, 1993). In the light of the families' statements the key words in legislation do not agree with their experiences. There is a clear discrepancy between policy and the families' reality. To what degree can these families claim their rights to support? The Swedish legislation is formulated in terms of the State's *obligations* towards people, not peoples' individual rights towards the State (Trägårdh, 1999). As a consequence, it is not possible for people to appeal for their denied rights. The State has obligations to provide health care and support, but only as long as resources are available also to the number of other people, who need help as well. This is a troublesome dilemma, because the same organisations who provide the services also decide the amount of support or health care that a family is entitled to. This implies difficulties for families to claim their rights to support as shown in this study. Their *collective rights* ensure them support if there are resources available. Living in a small town may complicate availability because of high levels of professional turnover, vacancies for specific professional competence and so forth. The families are experiencing consequences of policies at the macro-level, and there is a gap in relation to the intentions of the legislation. (Trägårdh, 2000). The mediating levels, which comprise systems such as habilitation centres and pre-schools, play a crucial role in interpreting legislation and translating intentions into programme policies. Studies have shown that the main goal in Swedish habilitation is unclear (Högberg, 1996). It is unclear whether the interventions should nor-

malise the child as much as possible or to help families to a functioning everyday life. In the interviews, there were several examples where the parents had expressed a need for the child/family but the professionals had focused on interventions that were not directed toward the expressed need. For example, the parents of a four-year old girl were worried because their communicative interaction with their daughter seemed to decline. She did not interact with the parents or anyone else and was screaming a lot. Contacting a medical doctor the parents asked for a speech and language therapist, but they were told that there was no one available at the time, but it was possible to work on the child's walking skills. Two phenomena are worth noting. First, the doctor did not follow up the request for a speech and language therapist, i.e. what problem did the parents think is to be solved by the requested solution. Second, the parents stated their problem in terms of a desired solution rather than in terms of a problem description. The result was that the the problem remained - they did not have a satisfactory communication with their child. Another parent described an interaction with professionals concerning their son who has autism. They were offered swimming groups and singing groups but no other support. Again, the question remains, what was the problem? What kind of help did the mother need, were there solutions other than the 'ready made' methods available? These are examples of conflicts between parents' and professionals' perspectives regarding functional versus developmental perspective and perceptions of support in terms of stated problems or services available to solve problems.

The results indicate that the first period after the parents are given a diagnosis of their child, they need several opportuni-

ties to ask questions about their child's disability and its consequences. The information given must match the needs currently experienced by the parents. For example, the parents in the study were mainly given verbal information. From their point of view they should also have been given written information. At the same time they thought that they were given too much information, i.e. information that did not match the needs currently perceived by the parents. The parents argue that this first period demands a more active professional approach e.g. it is better to ask the parents if they need this or that. The "good" experiences of support are characterised by professionals showing genuine interest in the family. According to previous research formal social support is most effective if it is asked for (Bailey and Simeonsson, 1988; Dunst *et al.*, 1997). This implies that professionals should not give advice unless parents ask for it. However, parents may need help to formulate questions. In the interviews, informal social support was never focused, but all parents mentioned this kind of support as highly important, particularly support from other parents who have children with disabilities. This is in line with the conclusion of the significance of informal social support by Dunst *et al.*, (1997), after reviewing studies concerning support as a form of early intervention. Some of the questions to ask professionals are first thought of as a result of meeting other parents.

To conclude, although the participating parent group in this study was small in number, it has raised some interesting points in discussing family perceptions of support from habilitation and other supporting organisations. The review of the literature has revealed that parental perceptions of support in early intervention are a complex phenomenon with many interacting factors. These factors do some-

times enhance each other and sometimes create paradoxical effects when interacting. The empirical part of this study indicates that future research must focus on the paradoxical effects of need fulfilment and empowerment that arise in parent-professional interaction, and on how collaboration in the intervention process can be enhanced by using the expertise of both parents and professionals.

Summary

The aim of this article was to discuss conceptions of support in relation to needs and rights based models in early intervention in Sweden, as perceived by parents of young children with disabilities. The discussion is illustrated with data collected by in-depth interviewing of eight parents and analysing the results using a qualitative approach. The theoretical frame is based on empowerment and the data are discussed in relation to this theory. The paradoxical effects of need fulfilment and empowerment that arise in parent-professional interaction are highlighted. This indicates a need for future research about the sometimes conflicting tasks of fulfilling needs and providing proactive support which professionals find in their encounters with parents of children with disabilities. Collaboration in the intervention process based on expertise of both parents and professionals is discussed in relation to these conflicts.

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