
RESEARCH

Barriers to Parental Empowerment in the Context of Multidisciplinary Collaboration on Behalf of Preschool Children with Disabilities

David Lansing Cameron

University of Agder, Kristiansand, NO

david.l.cameron@uia.no

The purpose of this study was to explore the role of parents in multidisciplinary collaboration on behalf of their preschool-aged children with disabilities from the theoretical perspective of empowerment. The study employed a multiple-case study design, including twenty-six individual and two focus group interviews with parents and professionals supporting six children and their families. Three interconnected themes emerged from the analysis. First, parents struggled with navigating a system that was perceived as rigid and cumbersome. Second, parents often found themselves in the position of having to ‘police’ the professionals involved in supporting them. Third, parents expressed a desire to ‘just be parents’ and relinquish a degree of control to professionals. Findings highlight central dilemmas associated with the goal and process of empowerment in the provision of social, educational, and health-related support.

Keywords: Collaboration; Disability; Parents; Empowerment; Preschool

Children with disabilities and their families typically interact with a wide range of professionals on a daily basis. For children with extensive support needs, formalized coordination of services often begins soon after birth and involves professionals from the health, education, and social-welfare sectors. In recent years, both researchers and practitioners have placed an increasing emphasis on ensuring that services to children with disabilities are family-centered (Dempsey and Keen 2008). In a family-centered approach, parents are recognized as the most significant and influential people in the child’s life (Rouse 2012). As Lindblad, Rasmussen, and Sandman (2005) argue, parental roles are strengthened when professionals and parents share tasks and goals that are of direct benefit to the child. Yet, the participation and coordination of multiple professionals required by this type of support is not without challenges. Given the likelihood of differences in the perspectives and priorities held by families and the professionals who support them, some level of conflict may be inevitable (O’Connor 2008). Such conflicts can weaken collaboration and lead to negative consequences for both the child and the entire family.

Thus, it is unfortunate that families of children with disabilities often report that the support they receive is inadequate (Wodehouse and McGill 2009; Villeneuve et al. 2013). Frequently encountered barriers include a lack of time for collaboration, high levels of stress, high employee turnover and staff shortages, a lack of available resources, and poorly established routines (Cassidy, McConkey, Truesdale-Kennedy, and Slevin 2008; Sandberg and Vuorinen 2008; Sandberg and Ottosson 2010). In their evaluation of the experiences of parents of children with disabilities, Wodehouse and McGill (2009) describe several additional concerns, including poor coordination among agencies, insufficient communication between parents and professionals, difficulties accessing services, and the perception that families are only able to receive support in the form of emergency assistance. It seems that an overriding theme across much of this research is the perception that professionals are often insufficiently responsive to the input of parents (e.g. Fylling and Sandvin 1999; Lundeby and Tøssebro 2008).

In light of these findings, a great deal of emphasis has been placed on the idea that professionals should seek to ‘empower’ recipients of support and bolster their participation in decision-making. Although parents of children with disabilities are often well aware of the need to advocate for their children, they also recognize that this role will take different forms at different stages of life (Hutchinson et al. 2014). Particularly in the preschool years, when many aspects of formalized collaboration are not yet firmly established (Villeneuve et al. 2013), efforts to increase parental empowerment face professional, ethical, and practical challenges. Moreover, the significance of these challenges vary in relation to the particular role and responsibilities of the stakeholders involved in providing support. Therefore, the purpose of this study is to explore the role of parents in multidisciplinary collaboration on behalf of their preschool-aged children with disabilities from the theoretical perspective of empowerment.

Empowerment and underlying dilemmas

Empowerment is often described as both a process and a goal (e.g. Nachshen and Minnes 2005). As a process, it is seen as an approach to increasing power among individuals, groups, or communities with regard to making decisions and changes to improve their life circumstances (Israel, Checkoway, Schultz, and Zimmerman 1994). As a goal, empowerment refers to the attainment of increased power in order to improve life conditions and address the lack of control that the individual or group experiences (Gruber and Trickett 1987; Itzhaky and Schwartz 2001). Strengthening the role of parents in this manner has long been considered a major component of family-centered planning on behalf of children with disabilities (Dempsey and Dunst 2004; Dunst, Trivette, and Deal 1988).

The arguments in favor of empowering families of children with disabilities are multifaceted. Among the most compelling of these is the assumption that when professionals take the opinions and desires of families into consideration, the quality of decision-making and interventions are improved (Dempsey and Dunst 2004; Trivette, Dunst, Hamby, and LaPoint 1996). In addition, improvements are not necessarily limited to the life circumstances of those receiving support. For example, greater family involvement in preschool is seen as beneficial not only to the development of the individual child, but also with respect to various societal goals, such as equality, workforce participation, and economic stability (Sandberg and Vuorinen 2008). From this perspective, empowerment is part of a democratic tradition aimed at strengthening individual rights in a society in which citizens are expected to have influence over the organizations and institutions that exert control over their lives (Cruikshank 1999; Rappaport 1984).

However, a number of dilemmas with respect to empowerment are evident in the literature. Among the most prominent of these involves the question of who gives power to whom and for what purpose. A major challenge for professionals seeking to empower others is that control over important life decisions is not easily given or transferred from one individual or group to another. As Gruber and Trickett (1987) point out, 'there is a fundamental paradox in the idea of people empowering others because the very institutional structure that puts one group in a position to empower also works to undermine the act of empowerment.' In other words, empowerment cannot simply be created by professionals; rather, it must be initiated and upheld through explicit action on the part of those in weakened (i.e. disempowered) positions. Yet, recipients of support may not see the need for such efforts, they may make poor decisions, or they may simply lack the interest or will to make such decisions (Askheim 2003; Linhorst, Hamilton, Young, and Eckert 2002). Alternatively, families or individuals in need of support may have a different understanding of their situation and want other types of assistance. Hence, the process of empowerment can be counterproductive in that it can be perceived as actually restricting those in need of support.

Methods

This exploratory study is part of a larger research project examining the relationships, beliefs, and experiences of professionals and parents involved in supporting children with severe disabilities in preschool. The project incorporates a multiple-case study design (Yin 2003), in which cases are comprised of the multidisciplinary teams surrounding six children and their families. A range of approaches have been employed to expand on the case-study design, including focus group interviews, observations, and researcher participation in consensus building activities. We have previously published findings from the project pertaining to the roles and responsibilities of preschool professionals (Cameron et al. 2014) and the relevance and use of individual plans as a tool for collaboration (Cameron and Tveit 2011).

Participants

The parents of six children with severe disabilities between the ages of three and five years were the principal informants. In four of these cases, both the mother and father of the child participated in interviews, whereas in two cases only the child's mother was interviewed. In addition, 20 professionals involved in the coordination of services for these families were interviewed on an individual basis. These professionals held a range of positions and included six preschool teachers, two childcare assistants, five special educators, four public health nurses, one social worker, one physical therapist, and one educational counselor. We also conducted focus group interviews with the Educational Psychological Services and specialists working in the Department of Pediatrics at the regional hospital. Although these professionals provided important insights regarding the roles and responsibilities of parents, it is the voices of parents themselves that form the core of the current study.

The intensity of support needs for the children fell within the range of 'extensive' to 'pervasive' (Westling and Fox 2000) and included several complex conditions, such as intellectual disabilities, Down syndrome, physical impairments, and multiple disabilities. Each child received full-time support from an assistant when in preschool. The child with the most extensive support needs had limited mobility and no verbal communication. In contrast, other children were more independent, verbal, and considered 'healthy' by parents and professionals. Despite this variability, shared experiences and perspectives across participants were readily identifiable. The six cases also held many commonalities with respect to the manner in which collaborative support was coordinated. In particular, all of the children had an Individual Plan (IP), a legal requirement in Norway for the provision of support to individuals in need of long-term, coordinated services from multiple agencies within the social, health, and education sectors

(NMHCS 1999). Given the intended relevance of the IP for collaboration, we chose to use this as a criterion for the recruitment of participants.

In the initial stages of the investigation, we invited families to participate via the regional agency responsible for the administration of special education services for this age group. In addition, we contacted preschools that were identified as having special programs for children with disabilities. In this manner, administrative leaders within this agency and preschool administrators functioned as 'door openers' for initiating contact with families and informing parents about the project. Parents who were willing to participate then contacted the research group directly. Once consent from parents was secured, we then contacted the various professionals involved in the IP process and asked them to participate. The children themselves did not participate in interviews or observations. The project is registered at the data protection agency for social science research, the Norwegian Social Science Data Service, in accordance with Norwegian law on ethical standards in research.

Interviews

We conducted a total of 26 individual interviews and two focus group interviews. The interviews ranged from approximately one to two hours in length and were conducted either in families' homes or in the workplace of the professionals who participated. Interviews were semi-structured, following a series of open-ended questions based on the broad goal of exploring the nature of collaborative support provided. Topics included: (a) participants' understanding of the child's challenges, (b) the roles and responsibilities of those involved in providing support, (c) the nature of communication and collaboration within the group, and (d) participants' dreams and expectations for the child's future. Although these topics were chosen beforehand, the interviews can be characterized as flexible in that we attempted to follow the participants' initiatives and pursue lines of inquiry that they deemed meaningful.

Analysis

Interviews were audio-recorded and transcribed. Once transcribed, we used the digital data analysis program, Nvivo 8, to capture participant responses and isolate meaningful sequences of text. We continued working with these sequences, concentrating on those that gave insight into participants' understanding of the different roles and responsibilities of parents with respect to collaboration. This phase of analysis was mostly explorative, for as similar responses were identified, they were grouped together and patterns began to emerge. This process led to the formation of different categories and specific theoretical associations, such as the connection to empowerment theory (see Miles and Huberman 1994). These theories provided a lens through which to interpret the data, with a particular focus on the role of parents with regard to collaboration in light of the social process and policy goals of empowerment.

It is noteworthy that only a small amount of data derived from interviews with professionals was included in the analysis. There are both practical and methodological reasons for this. First, the quantity of data that was collected from the larger project required a systematic approach. Focusing primarily on the contributions, experiences, and challenges of one group of participants at a time provided a manageable means of organizing these data. Second, our starting point for the larger project was connected to theories about the interactions occurring across professional boundaries (e.g. Abbott 1988) and collaborative processes (Mulford and Rogers 1982). These theories delve substantially into the distinct roles of different professions, organizations, and recipients of support, providing a natural foundation for exploring the position of parents as 'users' of professional services.

The research group also held two seminars in which participants from all six cases were invited. During these meetings, we presented our interpretations at different stages of the analytic process. Together with individual correspondence with participants, seminars provided the opportunity for group members to provide feedback regarding the accuracy of our findings, and for the researchers to make adjustments about our interpretations, so as to strengthen the overall trustworthiness of the study (Miles and Huberman 1994). To protect the anonymity of participants, personally identifiable information (e.g. gender and health-related conditions) have been changed or omitted from the discussion that follows.

Findings and discussion

The families in this study shared many experiences related to the challenge of engaging in multidisciplinary collaboration across support agencies and professionals. These experiences highlight important dilemmas with regard to the processes and goals of empowerment. The discussion that follows is organized around three themes: (a) navigating the system, (b) 'policing' the professionals, and (c) the desire to 'just be parents'. With respect to the first of these themes, a central issue concerns the question of who holds power in a system that families are required to navigate to gain access to resources and support. The challenge of 'policing' professionals reflects families' struggle to experience control and the interplay with professionals that is necessary to achieve that control. The third theme addresses the risk that well-intentioned actions rooted in empowerment-perspectives may actually contribute to the burdens placed on parents under certain conditions.

Navigating the System

Findings suggest that an important part of the parental role in these cases consisted of navigating a support system that was perceived as rigid, bureaucratic, and cumbersome. In order to ensure that their children received adequate support, parents described dealing with repeated applications, appeals, and multiple other administrative tasks. 'It is unbelievable how much paperwork, all kinds of crazy things, you never get it in order,' commented one mother (Case 6). She went on to describe her family's situation in the following manner:

'I don't have anything to complain about in my life. I have two fantastic children, both fantastic in their own ways, and life actually functions fine. If it hadn't been for all the different people I have to deal with and all the paperwork I have to do, and all the hospital visits we have to have... had it not been for all that, then, my life would be just a joy, you know?' (Mother, Case 6)

It has been observed that people with disabilities and their organizations have little power relative to the agencies responsible for assisting them (Askheim 2003; Dempsey and Dunst 2004; Nachshen and Minnes 2005). Frustrations such as those described by this mother, regarding the lack of usability of the support system, have certainly been a key factor in bringing about the emphasis on empowerment among people with disabilities to date. That is, increased empowerment is considered a means of improving the functionality of this system and, consequently, the quality of life for many people with disabilities and their families.

In navigating a complex network of health, welfare, and educational institutions; parents placed significant emphasis on the struggle to secure resources and services for their children. As one mother put it, 'In an ideal world, it would not be concerns about money that are the first thing on the agenda. That's just wrong. If I had to prioritize working overtime, then that would eat up the time that I have together with my child' (Mother, Case 4). This finding is consistent with evidence suggesting that parents of children with disabilities often feel that they have to fight to gain access to resources (e.g. Wodehouse and McGill 2009), a dilemma that is logically tied to the question of who has the authority to grant such access. In their position as 'gatekeepers' to resources and services, professionals may easily be perceived as limiting parental participation and control (Lundeby and Tøssebro 2008).

In addition, challenges connected to navigating the support system appear to be tied to the availability and flow of information to users. An attempt at addressing this concern was proposed by a father in one of the cases, who suggested that information could be better 'packaged' in a way that was more tailored to the family's individual needs:

They should have an automatic system—that information comes out to families and children with special needs, so that they have sort of 'custom-made packages' ... where they analyze what needs they have to fill, and that the municipal system is the first one to take them [families] in. (Father, Case 1)

Central to the success of empowerment is the idea that recipients of support have the opportunity to take control of their own lives and influence their living and working conditions (Rappaport 1984). However, analyses of the concept have described a number of aspects that go well beyond a sense of control or self-efficacy. These include factors such as meeting personal needs, understanding the environment, and having access to resources (Dempsey and Foreman 1997; Dunst, Trivette, and LaPointe 1994). From the perspective of participants in the current study, access to information was critical in determining the extent of parents' feelings of control and influence over their child's education and care.

'Policing' the Professionals

The six families in this study have interacted with professionals in health and social services over a long period. As these families became aware of their rights and legal protections, their relationships with professionals often became more formalized. Within this context, one of the greatest responsibilities held by parents was to ensure that professionals provided the services to which their children were entitled. For a number of participants this responsibility clearly carried with it a degree of frustration and emotional strain. 'You struggle to keep up the whole time,' concluded one mother (Case 2), 'it is exhausting to feel like you have to police whether different professionals are doing their jobs.'

Studies of collaboration on behalf of children with disabilities have often found a lack of communication and coordination among professionals, resulting in parents feeling isolated from decision-making and that they are not being heard or taken seriously (Fylling and Sandvin 1999; Wodehouse and McGill 2009; Lundeby and Tøssebro 2008). An illustration of the day-to-day frustrations of parent-professional collaboration under such conditions is reflected in the following interview excerpt:

'They were supposed to give him a test, and that was decided in February, but it hasn't been done yet. She probably just forgot it. I'm sure she has a good excuse [...] but it's pretty tiring to have to be the person that always speaks up, and then I end up saying it when they least expect it. It probably doesn't come out in the best way either. It just comes when I have finally gathered up enough strength to say something. It's not a good feeling to have to tell people that this is just not good enough.' (Mother, Case 2)

As noted by McIntosh and Runciman (2008), the need to develop and maintain trusting relationships with professionals can be a continuous source of stress for parents. At the same time, research indicates that parents' satisfaction with their relationship to professionals is crucial for the effectiveness of the services they receive (Bidmead and Cowley 2005; McIntosh and Runciman 2008; Farrell, O'Sullivan, and Quinn 2009). Indeed, many of the professionals involved in this study also noted the vital role that parents play with respect to ensuring that children receive appropriate support. When asked about the role of the mother in the case described above, a counselor from the Educational Psychological Services (EPS) had this to say:

She's his mother and I would do the same for my child. That's just what you have to do, I think. She's the one who has to take that responsibility. She's the one who knows where the shoe pinches. I think sometimes these support agencies need someone to kick them from behind, because suddenly one can forget something or that ... 'Oh, no, it's already gone a half year and I see in the journal that I should have called them in June!' [...] Every once in a while, we need someone to push us a bit and get a bit mad. (EPS counselor, Case 2)

Dempsey and Dunst (2004) describe two forms of help-giving practices: participatory and relational. Participatory practices occur when recipients of support are involved in joint decision-making and 'activities that develop their existing competencies'. Relational practices, on the other hand, deal with the professional-family relationship, and are connected to professionals showing empathy, listening, and perceptions of professional competency. Both forms of help-giving practices appear to be associated with higher levels of parent empowerment (Dempsey and Dunst 2004).

As described in the previous section, parents in the current study emphasized the value of participating in the support provided to their children, as well as having the skills to do so. Yet, they also struggled to find a balance between maintaining a positive relationship with professionals (e.g. relational practices) and making sure that the same professionals did the work that was expected of them (e.g. participatory practices). In performing this task, parents endured the discomfort and frustration that is often associated with being at the center of interpersonal conflict. As one might expect, several parents described feeling reluctant to complain about the performance of professionals, yet, felt that they had no choice. Another mother described her thoughts on the issue:

'If you feel like you are not being listened to, you can't give up. You have to let them know what you think is wrong and what you want, and if there are people there that you just can't get along with, then, you have to get rid of them... because that is actually a real option. [...] It's hard enough with a handicapped child in life. If you are also dealing with a bad relationship to the people you have to work with, that makes things completely impossible.' (Mother, Case 6)

A central component of virtually every analysis of empowerment in the context of professional support is the idea that the experiences of individuals and groups should engender a sense of control over important aspects of their lives (e.g. Dunst et al. 1994; Israel et al. 1994; Itzhaky and Schwartz 2001). Consistent with this perspective, parents in this study did, indeed, experience a level of control. However, increasing empowerment in this sense appears to have been as much a result of parents' own actions and resourcefulness, as it was professionals' encouragement or openness to developing it. This dilemma was particularly evident when families were asked about what advice they might give to other parents in similar situations:

'One of the bits of advice I'd give to others is to take control, because if you lose control, you can quickly lose much of yourself. So, I think that is very important ... that the parents are allowed to keep control (...) all the professionals and agencies that are around can contribute to it... It's just, like, when I talk to a physical therapist, occupational therapist, or anyone else, that they try to work things out so that it's going to be alright with us, and then I feel like I have control. They don't just barrel through with this is the way it's going to be, but I feel that there is a dialogue. As long as I feel that there is a dialogue, then I feel like I have control.' (Mother, Case 3)

Thus, with respect to the role of professionals, empowering parents does not necessarily mean giving them total control; rather it involves listening to their needs, involving them in dialogue and reaching decisions jointly. In an examination of various aspects of empowerment among 68 families, Knox, Parmenter, Atkinson and Yazbeck (2000) found that parents typically felt that they had significant influence over the decisions affecting their children. However, as in the current study, this belief was largely seen as stemming from their own efforts or assertiveness (Knox et al. 2000). Taking these findings into consideration, it is reasonable to conclude that professional efforts towards empowering families also involve recognizing that part of the process is in the hands of the parents themselves.

'Just Parents'

Although parents expressed the need for control over the support provided to their children, they also reported struggling to find the time for more traditional roles and activities. This dilemma is closely linked to research suggesting that parents are often required to administer interventions and healthcare directly to their children with special

needs (McCann, Bull, and Winzenberg 2012). Leiter (2004) refers to this phenomenon as the ‘therapeutic imperative,’ underlining the idea that while transferring knowledge and skills to families, professionals place strong demands on parents to implement and follow up on therapeutic efforts. Similarly, Fylling and Sandvin (1999) found that parents of children with disabilities were seen by teachers as ‘implementers’ of special education programs and, as such, their role was in large part perceived as an extension of the goals and measures underway at school.

A number of parents described their positions as being both coordinators of their child’s support and at least partially responsible for its implementation. Being the parent of a child with a disability comprises multiple roles, including acting as secretary, coordinator, therapist, teacher, and healthcare provider. In the face of these pressures, many participants expressed the desire to ‘just be parents’ and separate themselves from the duties of the professionals responsible for supporting their children:

‘You can’t be a therapist and... or at least I am not built that way... that I can be both a therapist and a mother. [...] You have to get others involved who are interested and at least have some expertise. To read up on all these fields, to be a special educator, physiotherapist, pediatrician, geneticist... You just can’t pull that off.’ (Mother, Case 5)

A potential danger in basing professional support on an empowerment model is that the concept may be reduced to a ‘therapeutic tool’ (Askheim 2003). Such an approach can result in professionals over-emphasizing their role as experts in empowering the ‘consumer.’ This approach may also shroud other professional interests and actually serve to diminish, rather than enhance the role of those receiving support (Grace 1991). A fundamental condition for empowerment is the belief that support recipients have a range of competencies that can be utilized to produce positive change (Rappaport 1981, 1984). However, an over-reliance on parents’ participation also has the potential to undercut a sense of normalcy in families’ lives and emphasize the child’s disability (Leiter 2004).

The burdens faced by parents under these circumstances may also have adverse effects on other family members. In particular, siblings of children with disabilities may experience added stress and loss of time together with parents (e.g. Benson and Karlof 2008). In one of the six cases, the parents of three children described their reaction to the emotional strain experienced by an older sibling of their child with a disability:

‘So, then we asked if it was possible to get some help at home ... so we could get a little bit more time alone with the oldest one. The fact is that siblings of children with special needs do not have parents in the same way, they are just more preoccupied and we had to do something about that.’ (Father, Case 1)

Whereas prompt access to professional support appeared to reduce stress on these parents, professionals also relied heavily on the efforts and commitment of parents in their collaborations. ‘The parents’ voice should be very strong,’ stated a public health nurse (PHN) when asked about the parents’ role (Case 4). Moreover, when parents were clear about their child’s needs, professionals felt that it was easier to reach agreement regarding the services provided:

‘The parents were very involved in planning, like, the agenda for the day. And that is clearly easier. In a lot of ways it’s easier to come in with these kinds of practical things that you need help with than maybe the big, emotional things.’ (PHN, Case 6)

A major contribution of parent participation in multidisciplinary support is their intimate knowledge of their child and his or her needs (Bidmead and Cowley 2005; Villeneuve et al. 2013). Thus, it is positive that the professionals in this study believed that parents should have significant influence over the decisions made on their children’s behalf. Nonetheless, the transfer of responsibility to families under the auspices of empowerment carries with it a degree of risk, not least of which is the creation of conditions that, in fact, limit rather than encourage the capacity of parents to ‘just be parents’.

Limitations

Although the struggles of families of children with disabilities are well-documented, it is nonetheless important to continually explore these challenges under diverse contexts, life stages, and theoretical perspectives. For this reason, the current study focused on the roles of parents of children with severe disabilities in the preschool years within the context of multidisciplinary collaboration, as seen through the lens of empowerment. Despite the potential contribution of these findings to the knowledgebase, a number of limitations are worthy of note. As is the case for all forms of naturalistic inquiry, case studies are viewed as generalizable only with respect to their theoretical propositions for conceptually related phenomena (Yin 2003). Nonetheless, the small number of cases at the center of this investigation presents a potential risk of failing to achieve informational or theoretical saturation (Miles and Huberman 1994). On a similar note, the study’s primary focus on the perspectives of parents may have limited divergent or alternative understandings of their roles and responsibilities in multidisciplinary collaboration. For example, the complexity of

these children's lives and developmental conditions is certainly over-simplified when they are collapsed under broad descriptions, such as 'children with severe disabilities.' At the same time, while the findings of this study may carry over to similar settings in which families are involved in collaboration on behalf of children with extensive support needs, they may not be equally pertinent in other circumstances, such as in the case of behavior disorders or specific learning disabilities that are often not identified until school-age. Finally, given the importance of parental resources with regard to the empowerment of families (Dempsey and Dunst 2004; Nachsen and Minnes 2005), there is a need to recognize that there might be differences with respect to factors that were not investigated in the current study (e.g. material, psychological, or social resources). Thus, it is recommended that future research on the role of parents in family-centered support also consider aspects such as social network and family resources within this picture.

Conclusion

Although research has increasingly addressed the challenges of families of children with disabilities, studies of parental empowerment have been more theoretical than practical (Nachshen and Minnes 2005). The current study has sought to bring into focus practical considerations about the role of parents in accessing support, and frame these findings in the language of empowerment. Parents in this study struggled to balance the need to 'just be parents' with the tasks of coordinating the work of professionals and ensuring that these professionals were 'doing their jobs'. This situation was complicated by a cumbersome and bureaucratic social support system, reflecting the limits of empowerment in the contexts of scarce resources and unavoidable inequities in family and professional power. This lack of functionality has led some to question empowerment in terms of rhetoric versus practice (e.g. Cruikshank 1999; Wilson and Beresford 2000). Across the three themes discussed above, a central dilemma must be highlighted. In brief, increased parental empowerment is as much derived from parents' own efforts and resourcefulness as it is from professionals' encouragement and willingness to develop it.

It is assumed that when the families of people with disabilities are empowered, decision-making and interventions on their behalf are improved (Dempsey and Dunst 2004; Trivette et al. 1996). Thus, it is not surprising that a common feature across the six cases in this study was a perception that the quality of support that children received was in large part dependent on parents' level of control and participation in the collaborative process. However, perceptions of the impact and relevance of services also appear to be tied to parents' willingness and capacity to take action. Although professionals are clearly in a position of power (e.g. holding access to resources), they do not have the exclusive means to empower others. Those in weaker positions must also take action on their own behalf (Gruber and Trickett 1987). For parents to gain or 'take' control involves both having to articulate their demands and endure a degree of stress. Whereas some parents may perceive this responsibility as liberating, others may find it burdensome. Nevertheless, findings from the current study indicate that when parents are clear about their needs and expectations, it is easier to reach agreement regarding appropriate interventions and accommodations.

In addition, the literature on empowerment suggests that the concept embodies much more than user autonomy or control. Factors such as meeting personal or individual needs, awareness of the context in which support is provided, and having access to information and resources are also considered vital (Dempsey and Foreman 1997; Dunst, Trivette, and LaPointe 1994; Villeneuve et al. 2013). For professionals working with the families of preschool children, the implication is that there are multiple factors that should be taken into consideration beyond simply allowing parents access to the decision-making process. Parents of children with disabilities are likely to require time, resources, and assistance in becoming familiar with the support system in order to develop the ability to actively engage in collaboration with professionals. In contrast, a top-down approach wherein professionals follow their own agenda is likely to be destructive for the parent-professional relationship (Bidmead and Cowley 2005). While professionals do not necessarily hold an unlimited capacity to empower parents, they can certainly encourage this process. The current study did not look directly at how professional practices and service provision might be better adapted to encourage parental empowerment. However, a number of broad approaches are evident, these include: (a) encouraging parents' views to be heard, (b) engaging in dialogue when decisions are being made, and (c) contributing to efforts to bolster the emotional and social resources that families have at their disposal.

There are strong educational and social arguments for engaging families in multidisciplinary collaboration on behalf of their children with disabilities from a very early age. Not least of these is the need to avoid gaps and pitfalls in the systems of support that can lead to negative consequences for the well-being of children and their families. Empowerment, seen as both a social process and a goal (Itzhaky and Schwartz 2001; Nachshen and Minnes 2005), provides a means of attaining greater family control and involvement in decision-making about the support that they receive. Findings from the current study suggest that, despite political ambitions towards this objective, professionals still struggle to support the empowerment of families of children with disabilities. Thus, continued research is necessary to stimulate effective and comprehensive change across support systems and professional practice in order to ensure that children with disabilities and their families receive the quality of care and assistance they need.

Competing Interests

The author has no competing interests to declare.

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