Empowerment and Families: Building Bridges between Parents and Professionals, Theory and Research

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Abstract

Despite the widespread use of the term empowerment in clinical literature to describe both a desirable process and outcome of service delivery (Dempsey and Foreman, 1997), and it's status as a "buzzword" in disability literature, the term remains more of a theoretical rather than practical construct (Salzer, 1997). Although families of children with developmental disabilities are generally considered to be unempowered, few researchers have examined the predictors and outcomes of empowerment within this population. The purpose of this article is to describe the current theoretical and empirical literature on empowerment, and discuss ways by which the concept can be used in research with families of children with developmental disabilities.

Parents are becoming increasingly involved in the education and treatment of their children with developmental disabilities. Financial constraints and changing ideologies have expanded parents' roles to include the jobs of "information seeker, problem solver, committee member, public educator, political activist and, most importantly, spokesperson for the needs of their children" (Minnes, Nachshen, & Woodford, 2003, p.665), who may be unable to communicate his or her own needs to those in power." Encompassing these multiple roles is the term empowerment, reflecting a parent's active agency and sense of control over themselves, their child and their family. The purpose of this paper is to explore the theoretical concept of empowerment and discuss how it can be incorporated into research with parents of children with developmental disabilities.

Defining and Measuring Empowerment in Families

Despite the widespread use of the term empowerment in clinical literature to describe both a desirable process and outcome of service delivery (Dempsey and Foreman, 1997), and it's status as a "buzzword" in disability literature,

the term remains more of a theoretical rather than practical construct (Salzer, 1997). Part of the difficulty in research on this topic is that empowerment is context and population specific, suggesting that a universal measure of empowerment may not be possible (Zimmerman, 2000). However, it is possible to examine empowerment as it relates to specific populations, such as caregivers of individuals with developmental disabilities.

The most commonly cited definition states that empowerment is "…an intentional, ongoing process … through which people lacking an equal share of valued resources gain greater access to and control over those resources" (Cornell Empowerment Group, 1989, p. 2). At the opposite end of the spectrum, unempowerment encompasses the stress, frustration, and hopelessness (Koegel, Brookman, & Koegel, 2003) that can pervade the lives of caregivers for individuals with developmental disabilities.

Discussions of empowerment indicate that it can exist at three main levels (Shultz, Israel, Zimmerman, and Checkoway, 1995). At the broadest level, community empowerment reflects actions taken by a group of people to improve life in a community. Organizational empowerment involves processes and structures designed to enhance goal-directed actions by members of an organization. At the individual level of analysis, psychological empowerment requires an understanding of the sociopolitical environment, which includes knowledge of the laws and an appreciation of one's rights and responsibilities. It also incorporates beliefs regarding competency to act in regard to that understanding. These beliefs encompass concepts of self-efficacy, locus of control, and self-esteem. Finally, empowerment involves an effort to exert control over one's environment, through proactive action or advocacy. Empowerment research with families focuses on perceiving families as active agents interacting with the larger community.

Empowerment theory states that empowerment can be viewed both as a process, incorporating actions, activities, or structures, and as an outcome, suggestive of an achieved level of empowerment (Zimmerman, 1995). At the individual level, empowering processes include both giving and receiving help in a mutual process focusing on gaining control over one's life (Zimmerman & Warschausky, 1998). The process of empowerment, incorporating the ways by which empowerment can occur, is difficult to assess due to its dynamic nature and is most often studied using qualitative methods. Empowerment outcomes, which are more easily measured, include intrapersonal, interactional, and behavioural components (Zimmerman & Warschausky). The intrapersonal component is conceptualized as the individual's set of

beliefs about their control, self-efficacy, and perceived competence. The interactional component incorporates the individual's relationship to their social environment. Finally, the behavioural component focuses on a person's actions taken to exert some control over the environment. Each of these components can be measured in a study of parental empowerment.

In their Family Empowerment Scale (FES), Koren, et al. (1992) present empowerment as consisting of two dimensions. The first dimension, the Level of Empowerment, consists of three levels reflecting empowerment as it is outlined by Shultz, Israel, Zimmerman, and Checkoway (1995). The three levels are (a) Family, reflecting the parent's ability to manage day-to-day situations; (b) Service System, reflecting the degree to which the parent is able to work with the service system, and; (c) Community/Political, reflecting the parent's advocacy for improved services for children with disabilities in general. The second dimension, the Expression of Empowerment, consists of three levels mirroring the understanding of the sociopolitical environment (interactional), beliefs regarding competency (intrapersonal), and effort to exert control (behavioural) outlined by Zimmerman & Warschausky (1998) in their discussion of individual empowerment. These three expressions are: (a) Attitudes, reflecting the parents' beliefs and mirroring the intrapersonal component of empowerment; (b) Knowledge, reflecting parents understanding of their environment and mirroring the interactional component of empowerment, and; (c) Behaviours, or what a parent actually does, reflecting the behavioural component of empowerment.

In their article introducing the FES, Koren, DeChillo, and Friesen (1992) provide evidence of the scale's reliability and validity. The psychometric properties of the questionnaire were examined in a study of 440 parents of children with emotional and behavioural disorders. The scale was found to have adequate internal consistency for each of the three subscales (Family: a = .88; Service System: a = .87; and Community/Political: a = .88). The test-retest reliability (N = 107) was also found to be adequate for each of the three subscales (Family: r = .83; Service System: r = .77; and Community/Political: r = .85). Validity of the scale was assessed through a factor analysis, which supported the correspondence of the Level dimension of the conceptual framework. As well, the questionnaire was found to significantly discriminate parents who were involved in a variety of advocacy-related activities from those who were not. The FES has been successfully used in studies involving families of children with emotional and behavioural disorders (Curtis & Singh, 1996), Juvenile Diabetes (Florian & Elad, 1998), and developmental disabilities (Thompson et al., 1997; Dempsey & Dunst, 2004).

Research Questions

The existence of an adequate definition, as well as an empirically validated measure of empowerment, recommend it as a focus of research with families of children with special needs. Empowerment can be examined as both an outcome and a predictor of relevant family variables. To date, most family empowerment research has been theoretical in nature, and very little research has focused specifically on the experiences of families of children with developmental disabilities.

Empowerment as an outcome

One way to incorporate the concept of empowerment into research is by examining the factors that predict or cause it. Using empowerment as an outcome variable fits with the recent trend of looking at the experiences of families of children with developmental disabilities in a manner that is more positive (Hastings & Taunt, 2002). While many studies have focused on characteristics of the child and family that lead to a sense of empowerment in parents (Thompson et. al., 1997; Scheel and Rieckmann, 1998; Dempsey & Dunst, 2004). Scheel and Rieckmann (1998) used the Family Empowerment Scale (Koren et al., 1992) in their examination of 75 parents of children classified as psychologically disordered. A multiple regression analysis indicated that family functioning was most predictive of parental empowerment, followed by parental stress, employment, and education level, with the four predictor variables accounting for 46% of the variance in empowerment. Other studies examining demographic variables such as income and education level have not been consistent in their findings (Curtis & Singh, 1996; Trivette, Dunst, Boyd, & Hamby, 1996) suggesting the need for additional research.

Recently, researchers have begun to focus on the effect of service-provision on parents' sense of empowerment. As services attempt to become more family-centered in their approach, their role in family empowerment becomes increasingly relevant. Dunst and Trivette (1987) argue that the empowering nature of helping relationships is dependent on the helping model to which the help-giver subscribes. As well, more empowering professional-parent relationships predict more effective service delivery (Van Ryn & Heaney, 1997). Therefore, research examining the service delivery-related factors that influence family empowerment is particularly necessary.

Using Structural Equation Modeling Thompson et al. (1997) tested two pathways through which the implementation of "Early On," an early

intervention program for children with various disabilities and/or chronic illness, was hypothesized to influence empowerment. In the first pathway, "Early On" affects empowerment through the degree to which the parents perceived the service to be family-centered. The second pathway begins with "Early On" and runs through social support and stress. The model was found to be a strong fit to the data, leading to two main conclusions. First, family-centered services lead to a greater sense of parental empowerment. The second path indicates that family-centredness is also related to a greater sense of both formal and informal support. Support, in turn, relates to family stress, which is negatively related to parent empowerment.

One way to look at parent empowerment as an outcome variable is to examine the effects of parent training programs. Bickman, Heflinger, Northrup, Sonnichsen, and Schilling (1998) evaluated the effects of a training program designed to enhance the empowerment of caregivers of children receiving mental health services. The training program was designed to enhance: (a) knowledge of the service system, (b) skills needed to interact with the mental health system, and (c) the caregiver's sense of self-efficacy in participating in a collaborative relationship with service providers. In this study, 250 parents were randomly assigned to a treatment group, which received the training curriculum, or to a comparison group. The participants were assessed using self-report questionnaires at a follow-up period of 12 months. The results of this study indicated that empowerment training was effective in increasing parent's sense of self-efficacy in working with mental health services.

A recent small-scale (N = 8) study by Koegel, Brookman, and Koegel (2003) demonstrated the relationship between child improvement and parent empowerment through an examination of collaborative partnerships between parents and professionals using Pivotal Response Training (PRT). PRT involves the parents in the treatment of their child with Autism by giving them an empirically supported set of procedures to increase their child's motivation to participate in social-communicative and play interactions. The researchers used an observational measure of parent confidence relating to the family level of empowerment described by Koren et al. in 1992. Parents whose children made significant gains tended to demonstrate an increase in their level of empowerment. Although the directionality of this relationship is unclear, and the generalizability of the findings is limited by the small sample size, this study suggests that involving parents in treatment may be necessary, but not sufficient to create a sense of empowerment. The reinforcing nature of the child's response to treatment, as well as other variables that might support or prevent parents from becoming empowered, demand research into their relevance for parent empowerment.

Dempsey and Dunst (2004) found a strong relationship between help-giving styles and empowerment between Australian and American parents of preschool children with disabilities participating in early intervention programs. Despite a significantly higher level of enabling practices and empowerment in the U.S. sample, the relationship between enabling practices and empowerment was the same. In both samples, enabling practices accounted for the largest percentage of variance in empowerment and was the only significant predictor variable. Demographic variables (parent age, employment/education status, and child age), locus of control, and the frequency of parental contact with the child's school did not significantly predict empowerment. Furthermore, enabling practices accounted for significant variance of empowerment once the other variables were taken into account. The authors assert that both relational and participatory components of help-giving are crucial in the facilitation of empowerment, regardless of cultural and demographic differences. It will be important to determine whether this relationship will continue to hold true for parents whose children do not have a developmental disability.

Empowerment as a predictor

Although previous studies have demonstrated that empowering interventions are effective in improving knowledge and self-efficacy (Bickman et al., 1988), their impact on service use and child mental-health status has yet to be demonstrated. Cunningham, Henggeler, Brondino and Pickerel (1999) argue that the effects of empowerment on child and family functioning must be empirically demonstrated before it becomes a focus of intervention. In this study, families of 118 juvenile offenders participated in either multi-systemic therapy (designed to be empowering) or usual services. Measures of child and family functioning were administered before and after treatment, as well as at a 6-month post-treatment follow-up. The results indicated that increased service system level empowerment was associated with parent outcomes, including decreased caregiver symptomatology, improved dyadic relationships, increased family cohesion, and increased caregiver supervision of their child. However, parental empowerment was not found to be related to child outcomes. The authors suggest that the family is only one of many influences on child functioning, particularly in adolescence.

An important component of empowerment is advocacy. Koren et al. (1992) found that parents' level of empowerment discriminated between parents involved in advocacy-related activities, such as advisory and political activities, and those who were not involved. These findings suggest that

empowerment is linked with community activism, a necessary component to improving the lives of people with disabilities. However, qualitative research by Nachshen and Jamieson (2000) suggests that advocacy and empowerment may not always be connected. The authors interviewed twenty-six parents of children with developmental disabilities in an effort to explore the relationship between advocacy, stress, and quality of life. A qualitative analysis of parents' responses indicated that whether parents' advocacy activities were related to positive or negative outcomes depended on the context in which the advocacy actions occurred. Parents reported that advocacy decreased feelings of stress and improved quality of life when; (a) advocacy was perceived to be a coping mechanism, (b) advocacy efforts achieved positive outcomes, (c) professionals responded to advocacy in a positive and productive manner, (d) advocacy efforts were focused toward planning for the future, (e) parents were able to maintain a personal life, and/or (f) parents were not dealing with their own negative emotions, such as guilt and fear, regarding their child's disability. However increases in stress were connected to; (a) parents' perception of advocacy as a challenge, (b) failure to achieve positive outcomes, (c) negative reactions from professionals, (d) a focus on past events, and/or (e) deleterious effects on personal functioning. These findings suggest that advocacy, often perceived to be synonymous with empowerment, may consist of two types: empowered advocacy and unempowered advocacy. Empowered advocacy may be most relevant to improving the lives of children with developmental disabilities and their families. These findings suggest the need to focus on empowerment itself as a component of advocacy training with parents of disabilities, to prevent the alienating effects of unempowered advocacy.

Conclusion

Empowerment is widely used as a buzzword in the delivery of services to families of children with developmental disabilities. The combination of tightened fiscal policies, increased participation by parents in the care of their child, and the coincident decreased availability and increased demand for services have increased demands on parents to accrue the knowledge, beliefs, and behaviours of empowerment. However, research on empowerment has remained largely theoretical. More recently, empowerment has been defined with an eye toward operationalizing and measuring the concept. Measures such as the Family Empowerment Scale (Koren et al., 1992) are being increasingly used with families of children with behavioural and emotional disorders, and have recently been incorporated into research with families of children with developmental disabilities. Empowerment can be examined on a community,

organizational, and individual basis, through processes or outcomes, measuring attitudes, knowledge and behaviours. Areas for future study include empowerment as a predictor of relevant family variables, or empowerment as an outcome of experimental manipulations.

When one considers the widespread use of the term "empowerment," and the myriad of research possibilities, there remains no excuse for the paucity of research in this area, particularly with families of children with developmental disabilities.

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