

Creating Supportive Connections: A Decade of Research on Support for Families of Children with Disabilities

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Raising a child with disabilities involves balancing a number of challenges, including seeking and gaining support. A synthesis of past research on support for families is needed to map directions for future research. This article reviews the past 10 years of empirical research on formal and informal support for families of children with disabilities. The review includes quantitative and qualitative studies representing several disciplines. Nine focus areas are identified: well-being, resources and socioeconomic factors, culture and minorities, intervention, extended families, siblings, professional support relationships, religion, and policy. Research is synthesized within each of the focus areas and suggestions are provided for future communication research. Dominant theories in existing studies are reviewed with directions for future theory-driven communication research.

Having a child with a disability or disabilities has personal, family, and social implications (e.g., Emerson, 2003; Floyd & Gallagher, 1997; Heiman, 2002; Williams et al., 2002). The past decade represents a sharp increase in the number of children with disabilities as well as a noticeable increase in the number of studies focused on support for their families. In the United States alone, the number of children ages 3 to 21 years old who were served in federally supported disabilities programs increased from approximately 4.8 million in 1991–1992 to 6.4 million in 2001–2002 (National Center for Education Statistics, 2003). Scholars across disciplines have acknowledged the potential impact of childhood disability on family life and have responded with considerable research on families of children with various disabilities to better understand family processes in the context of disability.

One area that has received much attention concerns professional and social support for these children and their families. Support is of particular interest to scholars in the communication discipline due to the communicative nature of seeking and providing emotional, informational, and instrumental support (Burlleson, 2003). Indeed, many

scholars have investigated the importance of support for individuals, relationships, and communities (see, e.g., Burlleson & MacGeorge, 2002). Research clearly indicates that support influences well-being for family members, family functioning, and the utilization of social resources (e.g., Brown, Anand, Isaacs, Buam, & Fung, 2003; Redmond & Richardson, 2003; Sloper & Turner, 1996). The context of disability particularly qualifies for studying support communication because families of children with disabilities often are in situations that involve long-term support from professionals, friends, and family members. With the number of children and families affected by disabilities on the rise, and benefits of support indicated in existing literature, a synthesis of what is known about support for these families is needed to map future directions for research and practice.

Thus, a primary goal of this project is to offer directions for future communication research that will extend current understandings of social and professional support in general and, more specifically, for families of children with disabilities. Toward that end, this project reviews original empirical research of support for families of children with disabilities within nine themes that emerged in the literature: well-being, resources and socioeconomic factors, culture and minorities, intervention programs, extended families, siblings, professional support relationships, religion, and the

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interface of policy. Dominant theories in existing studies are reviewed with directions for future theory-driven communication research.

METHOD

One hundred and three peer-reviewed empirical articles constitute the following review of research from 1996 to 2005. Keyword searches using “child,” “disability,” “family,” and “support” were conducted with four social science research indexes and one health research index: ComAbstracts, PsycINFO, Social Sciences Full Text, Sociological Abstracts, and Cumulative Index to Nursing and Allied Health Literature. Wildcard indicators were used for all terms so any derivatives of terms would be included in the searches. In addition, full texts were searched to identify all relevant articles. Articles included in this review met the following conditions: (a) results of original empirical research are reported; (b) support is provided by people rather than by pharmaceuticals or medical technology; (c) participants include families of minor children with intellectual (e.g., autism, Down’s syndrome), physical (e.g., spina bifida, cerebral palsy), or other disabilities (e.g., chronic illness, attention deficit hyperactivity disorder), although several studies also include families with children over age 18; and (d) support is a focus in qualitative studies or a focal variable in quantitative studies.

First, studies were reviewed to identify major themes in existing research. Second, results were synthesized for major findings within research themes. Finally, methodological details and theoretical approaches were recorded.¹ Ages and disabilities of children varied within and between studies. Therefore, age and disability information is specified only for those studies that focused on particular age groups (e.g., adolescents) or disability types (e.g., Down’s syndrome). The Appendix lists studies included in this review, along with theory(ies), method(s), and participants/sample for each study. Studies that focus on more than one subtopic are identified with superscript numbers.

RESEARCH THEMES

Well-Being

Many studies focused on the link between support and well-being in families of children with disabilities, which coincides with the larger body of research on social support (see Appendix). Well-being includes indicators such as

stress, adaptability, family functioning, marital satisfaction, empowerment, social competence, self-esteem, and child development. Most quantitative studies of well-being and support use the Family Support Scale (FSS; Dunst, Jenkins, & Trivette, 1984), which measures received support and helpfulness of that support.

Informal support. Many studies have found that higher levels of received informal social support (from friends and family), and perceptions of helpfulness of such support, associate with lower parental stress, greater feelings of parental empowerment, and higher levels of marital satisfaction (Duvdevany & Abboud, 2003; Hastings, Allen, McDermott, & Still, 2002; Hauser-Cram, Warfield, Shonkoff, & Krauss, 2001; Keller & Honig, 2004; Pal, Chaudhury, Das, & Sengupta, 2002; Saloviita, Italinna, & Leinonen, 2003; Sharpley, Bitsika, & Efremidis, 1997; White & Hastings, 2004). Overall, studies report that informal support is related to parental well-being across disability types and severity levels (Britner, Morog, & Pianta, 2003; White & Hastings). However, Manuel, Naughton, Balkrishnan, Smith, and Koman (2003), measuring *perceived available* support, rather than *received* support as measured with the FSS, found an interaction effect of functional levels of children with cerebral palsy and perceived levels of social support on levels of maternal distress. That is, mothers of high-functioning children experienced less distress when they perceived high levels of available social support than did mothers of low-functioning children, but perceptions of low levels of available social support were associated with higher levels of distress in mothers of high-functioning children and lower levels of distress in mothers of low-functioning children.

Moreover, studies explore the complicated nature of the connection between support and stress. Hassall, Rose, and McDonald (2005), using the FSS, found that a strong significant association between received support and parental stress level for mothers of school-age children with intellectual disabilities was moderated by internal locus of parental control. The role of parental characteristics in perceptions of support was also investigated by Lam, Giles, and Lavander (2003) in a study of carer-expressed emotion (EE). The study found that high EE (highly critical, emotionally over-involved, and hostile toward child) and low EE carers of school-age children with learning disabilities and behavior problems reported social supports as significantly less helpful (using the FSS) than did the moderate group, even though reports of actual levels of support received were similar. Macias, Saylor, and Rowe (2003), using the FSS, found no significant associations between maternal stress and support. However, they did find that mothers of elementary school children with spina bifida reported higher levels of disability-related concerns for their children than did mothers of preschoolers with spina bifida. Results of these studies support the conclusion by Burleson and

¹Due to space considerations, general information about study methods and samples is provided in the Appendix. Surveys were used for 52 studies, qualitative methods were used for 33 studies, and 18 studies used both quantitative and qualitative methods. Additional information about study participants is included within the text where appropriate.

MacGeorge (2002) that connections among received support, perceptions of support, and well-being are complex.

Informal support can also affect children with disabilities and other family members (Raina et al., 2005; Rivers & Stoneman, 2003; Sloper & Turner, 1996; Wilgosh, Nota, Scorgie, & Soresi, 2004; Williams et al., 2002). For instance, Sloper and Turner found that perceived available social support for mothers was associated with improvements in self-sufficiency for children with Down's syndrome. Wilgosh et al. found that having contact with other parents of children with disabilities was an important source of support for effective life management within the family. Likewise, Guralnick, Neville, Connor, and Hammond (2003) found that social support availability and parents' satisfaction with that support significantly affected social competence for children with mild learning disabilities. And Rivers and Stoneman found that when marital strains increased, positive qualities of relationships between children with autism and their siblings deteriorated when parental use of social support networks was low, but sibling relationships stayed positive in families with high use of social support networks.

Formal support. Also, formal support by professionals has been investigated as it relates to family well-being. Several studies report that parents express a desire for professional support services and rely on such services (Brown et al., 2003; Heiman, 2002; Nachshen, Garcin, & Minnes, 2005; Poston et al., 2003; Taanila, Syrjala, Kokkonen, & Jarvelin, 2002). However, studies are inconsistent in terms of the association between formal support and well-being. Some studies have found that services that are family-centered (e.g., provide needed information, treat parents with respect, include parental control of decision making) and specific to family needs are related to lower stress, greater well-being, and empowerment among parents (Dempsey, Foreman, Sharma, Khanna, & Arora, 2001; Honig & Winger, 1997; King, King, Rosenbaum, & Goffin, 1999). Other studies indicate that parents do not receive the level and type of formal services that they need, and that parents believe more formal support would benefit them and their families (Maes, Broekman, Dosen, & Nauts, 2003; Wang, Mannan, Poston, Turnbull, & Summers, 2004; Wilgosh et al., 2004). These studies indicate that how formal support is provided is crucial to both family outcomes and its assessment by parents.

In addition, effects and uses of formal support appear to be influenced by disability type and severity. For example, King et al. (1999) found that parents of children with mild neurodevelopmental disorders rated professional caregiving as more family-centered than did parents of children with more severe levels of disorders. In turn, higher ratings of family-centered practices were related to less stress and better emotional well-being in parents. White and Hastings (2004) found that a positive correlation between use of

professional service supports and parental stress became nonsignificant when characteristics of adolescents with intellectual disabilities, such as autism diagnosis, level of adaptability, and behavior problems, were taken into account. Several studies indicate that the presence of behavior problems in children with disabilities influences the amount of professional support services sought by parents, as well as their perceptions of those services (Floyd & Gallagher, 1997; Maes et al., 2003; Nachshen et al., 2005).

Research in this area comports with findings in the larger social support literature about associations between stress and levels of formal support (Burlinson & MacGeorge, 2002; Goldsmith, 2004). For instance, Rivers and Stoneman (2003) found that families with high marital stress and high levels of professional support reported higher levels of negative sibling behavior than did families with lower levels of professional support. Floyd and Gallagher (1997) found a positive correlation between mothers' use of services and higher levels of stress, and that single parents used more professional services than did others. Duvdevany and Abboud (2003) found that marital and parental stress were significantly higher for mothers who received formal help. These studies indicate that families who need support the most—parents who have high levels of stress, parents who do not have partners, and families with negative interaction patterns—are indeed seeking and receiving support through formal channels. However, the cross-sectional design of these studies does not provide strong causal information about the effect of formal support on parental and family well-being.

Combined support. Several studies combined measures of formal and informal support to investigate the importance of overall support (Brown et al., 2003; Fox, Vaughn, Wyatte, & Dunlap, 2002; Hodapp, Fidler, & Smith, 1998; Nachshen & Minnes, 2005; Poston et al., 2003). Nachshen and Minnes concluded that the combination of perceived available social support and family-centered formal support practices led to greater empowerment for parents of children with intellectual disabilities. Also, Hodapp et al. found that larger overall support systems were associated with lower levels of stress in families of children with Smith-Magenis syndrome. Parents in the Fox et al. study indicated that they rely on emotional support and encouragement from professionals, family members, and other parents to meet the challenges of raising children with problem behavior. Two studies of quality of life also indicate that support across formal and informal domains is perceived by parents of children with disabilities as important for family quality of life and well-being (Brown et al., 2003; Poston et al., 2003).

In summary, research of social and professional support for families of children with disabilities is consistent with the larger body of support literature that indicates the many benefits, as well as challenges, of support for individual and

family well-being (Burlison, Albrecht, Goldsmith, & Sarason, 1994; Burlison & MacGeorge, 2002). Yet results indicate that future research should move beyond answering questions about *if* support is associated with positive outcomes in this context to questions of *how* support becomes associated with positive family outcomes.

Resources and Socioeconomic Factors

Studies concerning family resources and socioeconomic factors extend the well-being literature (see Appendix). Several studies involving low-income families have found that these families generally report having low levels of informational support about disability issues, limited access to professional support services, and inconsistent use of available supports (Baxter & Kahn, 1999; Diamond & Kontos, 2004; Duvdevany & Abboud, 2003; Ellis et al., 2002; Kuchler-O'Shea, Kritikos, & Kahn, 1999; Parish, Cloud, Huh, & Henning, 2005; Williams et al., 2002). Large-population studies further demonstrate the needs of those with limited resources. Mulvihill et al. (2005) reported that more children with disabilities that cannot be treated with medication alone live in poverty than do those whose disabilities can be treated with medication. And these same poor children tend to have families who provide their care at home and experience delayed or forgone healthcare. Furthermore, Emerson (2003) found that families supporting a child with an intellectual disability in the United Kingdom were significantly economically disadvantaged compared with families of children without an intellectual disability. In brief, families of children with disabilities are more likely than other families to suffer financial hardships and, by the same token, those with fewer financial resources realize fewer benefits from available supports.

Moreover, situational resources affect the use and outcomes of support (Cigno & Burke, 1997; Gavidia-Payne & Stoneman, 1997; Lewis, Kagan, Heaton, & Cranshaw, 1999; Taylor et al., 2005). Cigno and Burke concluded that single mothers of children with learning disabilities are significantly affected by the lack of partner support, availability of transportation, and overall isolation of their families. Likewise, Parish et al. (2005) found that children with disabilities living with single parents spend significantly more hours in child care than do children without disabilities living with single parents. Furthermore, families of children with disabilities had lower incomes than did families of children without disabilities yet spent more money each month on child care. In a similar vein, Taylor et al.'s research on mothers who serve in the military and have children with disabilities revealed that their military career often caused mothers to be isolated from partner support and from practical support from extended family members, and it also posed unique challenges regarding child care and professional services. Lewis et al. (1999) found that mothers of children with disabilities often use employment

as economic, psychological, and social resources; however, these mothers often lack institutional and organizational supports to allow them to tap important internal and external resources that employment provides.

In addition, internal resources can affect the use of support. For example, Gavidia-Payne and Stoneman (1997) found that parents with higher coping scores were more likely to be involved in early intervention programs than were those with low coping scores. Furthermore, coping mediated the link between program involvement and family functioning. Likewise, Taanila et al. (2002) found that families that demonstrated high coping abilities had extensive formal and informal support networks, whereas families with lower abilities to cope had very limited informal and formal support networks. Locus of control also functions as an internal resource that influences the use and benefits of social support (Hassall et al., 2005). Jones and Passey (2005) found that internal locus of control in combination with integrative and cooperative family coping strategies associated with lower parental stress. These studies coincide with other studies that concluded that several factors serve as potential moderators of the positive effects of social support (see Goldsmith, 2004).

To sum, studies of socioeconomic factors and resources consistently show that socioeconomic status, external resources, and internal resources are significant factors in the use and outcomes of support. With the demonstrated relationship between support and well-being in families, this line of research deserves more attention. Extending this line of research would increase knowledge about how communication practices create supportive systems that foster positive coping strategies and beneficial outcomes in the context of disability.

Culture and Minorities

Studies of specific cultural populations and minorities focus on potential barriers to support as represented by cultural norms, language abilities, or minority status (see Appendix). Several studies indicate that language barriers prevent adequate access to and use of formal support for many ethnic minorities (Bailey et al., 1999; Cook, Cook, Tran, & Tu, 1997; Fazil, Bywaters, Ali, Wallace, & Singh, 2002; Gatford, 2004). Huang, DeLambo, and Kot (2004) found that, although language was not a barrier among participating Asian American parents of children with developmental disabilities, levels of assertiveness and self-advocacy were significantly lower for them than for non-Asian counterparts. In addition, self-advocacy skills were positively correlated with levels of social support received by participants. They further noted that length of stay in the United States was positively associated with levels of self-advocacy skills. Overall, these studies indicate that minorities, regardless of where they reside, can experience added difficulties in asking for and receiving professional and social support.

However, results of one study indicate that immigrant status did not affect the types of difficulties found in other studies of minorities (Duvdevany & Vudinsky, 2005). Duvdevany and Vudinsky did not find any differences in use of social support between immigrant and nonimmigrant families of children with mental retardation in Israel.

Several researchers have noted that an implicit assumption exists that collectivistic attitudes in some cultures lead to strong family support that can substitute for the lack of professional support for minority families (Bailey et al., 1999; Gatford, 2004; Morse, 2002; Sham, 1996). Bailey et al. and Cook et al. (1997) found that Latino and Chinese parents have more support from family members that might function as a substitute for other forms of support, which might mediate family stress. However, other studies have found the opposite process occurring in cultural minorities, with shame, cultural norms that discriminate against disability, and/or lack of knowledge about disabilities preventing family members from providing practical and emotional support to parents (Gatford, 2004; Morse, 2002; Sham, 1996). Darling and Gallagher (2004), using the FSS, compared received support among rural and urban African American and European American caregivers who were enrolled in early intervention programs. African American caregivers in urban areas reported higher levels of support than did African American caregivers in rural areas. However, European Americans in rural areas reported the highest levels of support among study groups. This study indicates that residential location could play a significant role in support for families and represents an area for future research.

To sum, barriers generally prevent minorities from seeking and receiving social and professional support, a finding replicated in the United States, Great Britain, and Australia. Research in this area comports with research of socioeconomic factors in finding that families without resources fare worse in seeking and receiving support than do those who have adequate resources. Given the connection between support and family well-being, it is important to continue to seek ways to improve professional and social support for these families.

Intervention Programs

Many researchers have investigated the efficacy and use of specific intervention or support programs (see Appendix). Such interventions and support programs include intensive family counseling, informational programs for parents and siblings, respite care, parent-to-parent support groups, crisis counseling, early-intervention programs, and multiagency coordinated programs. A variety of positive outcomes have been associated with participation in intervention or support programs, such as increased peer acceptance and social skills of children with disabilities, improved family well-being, improved sibling relationships, increased perceptions

of support received, and increased knowledge of disabilities (Baldry, Bratel, Dunsire, & Durrant, 2005; Boettcher, Koegel, McNeerney, & Koegel, 2003; D'Arcy, Flynn, McCarthy, O'Conner, & Tierney, 2005; Evans, Jones, & Mansell, 2001; Farber & Maharaj, 2005; Honig & Winger, 1997; Hudson et al., 2003; Lobato & Kao, 2002; Pelchat & Lefebvre, 2004; Phillips, 1999; Quah, 1997; Williams et al., 2003).

Overall, research indicates that support and intervention programs are beneficial when family members participate. For instance, Lucyshyn, Albin, and Nixon (1997) reported that professional support aimed at developing routines across family functions improved child behavior and overall family functioning. Likewise, a study of an in-home support service found that receiving just a few hours a week of respite care for children with moderate to severe disabilities reduced stress for parents, enabled "normalcy" in the family, and improved parents' relationships with their other children (Forde, Lane, McCloskey, McManus, & Tierney, 2004). Hudson et al. (2003) compared program delivery across self-directed, telephone support, and group support modes and found that all three delivery modes were beneficial, but that significantly fewer families in the self-directed group finished the program. That is, parents of children with intellectual disabilities who guided themselves through program materials with no group or professional support reported similar benefits in terms of lower stress levels and improved family functioning as those who received group and/or professional support throughout the program. However, the rate of program completion was significantly lower for the self-directed group, indicating that support professionals and group structures are important components to intervention programs. A study of parent-to-parent programs is consistent with this conclusion, as parents of children with mild to severe disabilities reported that participating in such programs was important for receiving emotional, problem-solving, and informational support (Santelli, Turnbull, Sergeant, Lerner, & Marquis, 1996).

Several studies have demonstrated that the role of professionals is critical to the success of intervention programs. For example, Summers and Jenkins (2001) reported that parents of children with intellectual and physical disabilities receiving support through an early-intervention program and those receiving support from community nurses provided similarly high ratings of enabling practices regardless of the type of professional who provided the support. Likewise, Keen and Knox (2004) described the key role that a professional interventionist played in collaboratively developing successful strategies with one family in their case study. Other studies also demonstrate how parents regard professionals as critical components of intervention and support programs in which they participate (Baldry et al., 2005; Pelchat & Lefebvre, 2004; Rahi, Manaras, Tuomainen, & Hundt, 2004). In other words, structure and content are only part of what makes interventions and programs

successful. A key component to success is having professionals who provide supports that family members need and want.

On the other hand, several factors can prevent people from fully realizing benefits of programs or utilizing available support. These factors include cultural norms, lack of information or understanding about available supports, cost, time demands, transportation difficulties, and family member needs (Abbott, Watson, & Townsley, 2005; Boothroyd, Kuppinger, & Evans, 1998; Hieneman & Dunlap, 2001; Quah, 1997; Vardi & Merrick, 2003). For example, Hendriks, DeMoor, Oud, and Franken (2000) found that parents of toddlers with physical and multiple disabilities who participated in a 10-month program still reported unmet informational and support needs. In addition, parent participants in two studies indicated that they sensed a lack of continuity or coordination among professionals, which prevented full realization of program benefits (Abbott et al., 2005; Bennett, DeLuca, & Allen, 1996).

In brief, research indicates that intervention programs are by and large beneficial, but simply putting programs in place does not mean families receive supports they need. Personal contacts with professionals or other families of children with disabilities are critical elements in program effectiveness. Furthermore, this line of research indicates that families respond best to intervention and support programs that include continuity among professionals and collaborative relationships between professionals and parents.

Extended Families

A growing body of research focuses on support provided to parents by extended family members, particularly grandparents (see Appendix). Some researchers have focused on types of support desired from or provided by grandparents, such as instrumental (e.g., child care, financial support) and emotional support (Green, 2001; Heller, Hsieh, & Rowitz, 2000; Katz & Kessel, 2002; Seligman, Goodwin, Pachal, Applegate, & Lehman, 1997; Trute, 2003). Others have focused on outcomes of family support received or variables influencing support from extended family members (Cronin, 2004; Mirfin-Veitch, Bray, & Watson, 1997; Scherman, Gardner, Brown, & Schutten, 1995; Sharpley et al., 1997).

Several studies focused on outcomes related to different types of support. Trute (2003) found no significant relationship between parental reports of instrumental support provided by grandparents and levels of parental depression, stress, or self-esteem in families of 12-year-olds with developmental disabilities. However, Green (2001) found that parental well-being (operationalized as positive emotional outlook and physical energy) was positively associated with instrumental support from grandparents in families of children of various ages with a variety of disabilities.

Furthermore, Heller et al. (2000), Seligman et al. (1997), and Trute found significant positive correlations between perceived emotional support provided by grandparents and parental well-being. Two of these studies found that maternal grandmothers provide more instrumental and emotional support to mothers than do other grandparents or family members (Seligman et al., 1997; Trute, 2003), but Trute also found that perceived emotional support by paternal grandmothers was significantly related to fathers' well-being.

Grandparents' perceptions of their involvement, support, and relationships with their disabled grandchildren also have been investigated (Gardner, Scherman, & Efthimiadis, 2004; Katz & Kessel, 2002; Mirfin-Veitch et al., 1997; Scherman et al., 1995). These studies indicate that relationship factors predict grandparent involvement much more than disability does. For example, Mirfin-Veitch et al. found that relationship history between parents and grandparents and the belief that the family naturally helped each other were reasons given for providing support for grandchildren with disabilities. Likewise, grandmothers in the Gardner et al. study indicated no dramatic changes in family relationships with the birth or diagnosis of a grandchild with disabilities, and expressed desires to provide more practical support across a variety of family domains.

Of course, grandparents are not the only family members available for support. Cronin (2004) found that mothers of children with cystic fibrosis reported receiving extensive instrumental and emotional support from family members that helped normalize routines in the family. However, in the same study, mothers of children with ADHD indicated that they receive little such support from family members and had difficulty creating normalizing routines within their families. Sharpley et al. (1997) found that simply having access to family members who could provide instrumental support was not significantly related to well-being in parents of children with autism. However, the Sharpley et al. study indicated that lower levels of anxiety and depression among participating parents were significantly associated with parents' perceptions that family members providing assistance had a good understanding of the child's needs.

Overall, studies indicate that relationship qualities and knowledge of disabilities are important for extended family support. Researchers in this area have suggested professional training and support for family members to increase their involvement, but training that focuses on creating quality relationships could be equally productive for these families.

Siblings

Researchers have recently investigated the needs of siblings of children with disabilities (see Appendix). Evaluations of intervention or support programs for siblings have found positive outcomes for siblings and families of children with

disabilities in terms of decreased depression and anxiety, improved self-esteem, decreased sibling-related stress, improved knowledge, and increased perceived available social support (D'Arcy et al., 2005; Evans et al., 2001; Lobato & Kao, 2002; Phillips, 1999; Williams et al., 2003). In addition, three studies found that the availability of social support for families is associated with sibling well-being, coping responses, and sibling relationships (Opperman & Alant, 2003; Rivers & Stoneman, 2003; Williams et al., 2002). This relatively new area of research reflects a holistic approach to family functioning and well-being in families of children with disabilities. Results from existing studies can be used as a springboard for communication researchers to investigate family processes and factors that link to positive relationships and outcomes for all family members.

Professional Support Relationships

Several studies have focused on parents' relationships with professional support providers (see Appendix). Professionals represented in existing research include health care providers, teachers, social workers, and individuals in similar positions. Two studies indicated that school-related professionals feel constrained in providing the emotional support desired by parents due to bureaucratic structures of support agencies, overwhelming caseloads, and confusion about whether they should be providing more than instrumental support (Lord-Nelson, Summers, & Turnbull, 2004; Middleton, 1998).

Several studies reveal that parents want professionals to work outside of narrow job descriptions and deal with families on a personal basis (Ballard, Bray, Shelton, & Clarkson, 1997; Kerr & McIntosh, 2000; Lindblad, Rasmussen, & Sandman, 2005; Lord-Nelson et al., 2004; McKeever & Miller, 2004; Middleton, 1998; Todd & Jones, 2003). Participants across studies indicated that they often experience a struggle with professional support providers to be respected and treated as equals in decision making. Mothers of children with intellectual and physical disabilities reported that they view their relationships with medical professionals and other formal support providers as generally combative and that they often struggle to get services they need for their children or for themselves (McKeever & Miller, 2004; Todd & Jones, 2003). Professionals who had a positive impact were viewed as exceptional.

Two themes emerge from these studies: first, confusion exists among professionals and parents alike as to relational boundaries and types of support that should be expected or provided; and second, positive, supportive professional relationships contribute to positive child and family outcomes, whereas negative or extremely formal relationships do not provide families with the support or outcomes they would like. Research in this area consistently suggests that parent-professional relationships constitute a critical element in the uses and outcomes of professional support, but what

characterizes positive versus negative relationships remains underinvestigated. Communicative processes that differentiate supportive from nonsupportive formal relationships deserve attention to gain a better understanding of this important aspect of support. Such investigations would also extend existing conceptualizations of the communicative nature of support (Burlison & MacGeorge, 2002; Goldsmith, 1994, 2004; Miller & Ray, 1994) by focusing on ongoing interactions between professionals and parents of children with disabilities.

Religion

Recent studies focus on religion as an internal resource as well as on religious organizations as sources of external support (see Appendix). A consistent finding across studies is that parents gain strength and meaning from faith that help them relate to their child with a disability and deal with the challenges that disability poses (Dollahite, 2003; Marshall et al., 2003; Poston & Turnbull, 2004; Skinner, Correa, Skinner, & Bailey, 2001). In addition, many parents in these studies express that their religious organizations or communities provide emotional and spiritual support for themselves as well as their children with disabilities (Marshall et al., 2003; Poston & Turnbull, 2004; Skinner et al., 2001). Although most parents perceive love and acceptance from their religious communities, sometimes parents experience difficulty in integrating their children into religious activities (Marshall et al., 2003; Poston & Turnbull, 2004). This fairly recent line of research represents new avenues for communication researchers to explore regarding the associations between religion and the communication of social support.

The Interface of Policy

A few researchers have explored the connections between macrostructures and micropractices through investigations of policies (see Appendix). These studies indicate that a dire need exists for policymakers to attend to the disconnect between policy and practice. For example, a study of parents' use of the Disability Living Allowance in England indicated that problems occur in translating well-intentioned policies into practical and useful support for families (Steyn, Schneider, & McArdle, 2002). Heyl's (1998) study of a grassroots parent organization in Germany identified discontent with the policy of special schools for children with disabilities and disagreements between parents and policymakers on how the policy translates into positive outcomes for children and society. Olsson and Hwang's (2003) investigation of structural supports in Sweden indicated that families experience difficulties in receiving satisfactory professional support in spite of substantial public financial assistance. Redmond and Richardson's (2003) study reported that a lack of coordination in service planning and delivery in

Ireland is more burdensome than supportive for many families, and bureaucratic regulations of eligibility often cause resentment and frustration among parents. Moreover, Kagan, Lewis, Heaton, & Cranshaw (1999) found that parents continue to struggle for full inclusion in work, family, and leisure activities due to lack of institutional supports for their unique needs as working parents of children with disabilities. These studies shed some light on the importance of support structures for families of children with disabilities. However, much more research is needed to understand how macroprocesses influence microprocesses of support.

THEORETICAL PERSPECTIVES ON SUPPORT

Very little research reviewed herein is based on theory. Of the 103 studies included in this project, only 31 make explicit use of theory or a theoretical perspective. The two most prominent theories used in these studies are systems theory and the ecological framework, with various stress and coping models also used to frame several studies (see Appendix).

Researchers using systems theory recognize that support outcomes for individual members are influenced by the entire family system. This is a productive approach to support research, especially regarding research that focuses on well-being, intervention programs, siblings, and extended families. Future research would benefit from using a systems approach to understand communicative support processes and outcomes by taking into account multiple family members' interactions. Considerable emphasis has been placed on parents, particularly mothers, in existing research. This is understandable considering that parents (mothers) are usually primary caregivers and contact people for support providers and researchers. However, a systems approach that includes other family members in study designs could lead to more complete understanding of how support processes function for multiple family members across family functions.

The ecological framework moves beyond family systems theory by taking into account other systems with which families interact, including the larger environmental context. Support for families of children with disabilities is a fruitful area for applying the ecological perspective. These families are particularly situated to interact with educational, community, and government microsystems. Practices and policies of these other microsystems often influence family resources and functions, and these families are uniquely vulnerable to cultural contexts that influence how they seek and receive social and professional support. Although existing studies have been based on ecological concepts, many components of the ecological model proposed by Bronfenbrenner (1979) are absent in analyses. Future investigations can take advantage of the richness of this

approach with in-depth analyses of how interactions are interrelated and how support processes are influenced across multiple systems.

One theoretical approach that could be applied to this area of research is structuration theory. Like the ecological framework, structuration theory emphasizes the co-influence of macro- and microprocesses, but it stresses that (inter)action and structure have a recursive relationship; that is, large social and system structures enable and constrain everyday action while such action also serves to produce, reproduce, and transform structure over time (Giddens, 1984). Results reviewed in this project lead to the conclusion that much remains to be understood about the process of providing and receiving social and professional support and about how everyday (inter)actions of support are constrained and enabled by social structure. Furthermore, a structurationist approach would enable researchers to analyze how support interactions are examples of structure and how they produce, reproduce, and have the capacity to transform structure over time. This approach would be particularly useful in analyzing connections between structural features such as policies and interventions, as well as the interactions between professionals and families that put those policies and interventions into practice.

Several theoretical approaches to support communication could be used to extend existing research. For example, Burleson et al. (1994) proposed a conceptualization of social support *as* communication. A communicative approach to support highlights interaction features rather than simply sources and frequency of support (Burleson & Goldsmith, 1998; Burleson & MacGeorge, 2002). Other communicative approaches to studying support that could be usefully applied to this context include investigations of memorable messages (Miller & Ray, 1994), facework strategies (Goldsmith, 1994), comforting messages (Burleson, 1994), and conversational features (Burleson & Goldsmith, 1998). Likewise, Goldsmith (2004) offers a theory of enacted social support as a communicative phenomenon that could extend current understanding of support in this context. Communicative perspectives provide lenses through which to investigate how formal and informal support link to various outcomes. Indeed, research in all nine themes of this review can be extended with communication-focused research.

FUTURE DIRECTIONS FOR COMMUNICATION RESEARCH

Clearly, time has come to move beyond assessments of needs and sources of support to investigations of which communicative behaviors count as useful support for families of children with disabilities. We can look to existing research of supportive communication for information about supportive communication in acute situations, but

these families often seek and receive support from a variety of sources over an extended period of time. Is the nature of their situation systematically different from those of others who seek and receive support? Furthermore, we know little about the role that relationship dynamics play in the way support functions for these families. Some studies indicate that factors such as family harmony, sibling behavior, and marital quality associate with support. Investigating family communication patterns within these domains would enrich current understandings theoretically and practically. Addressing such issues allows for the recognition of the constitutive nature of communication. In other words, communication within families and between families and support providers *constructs* relationships, whether they are supportive or nonsupportive, beneficial or nonbeneficial.

Moreover, future research could focus on how power dynamics between professionals and parents with few socioeconomic resources are constructed through interaction. Little is known about how the framing of formal and informal support availability influences use of such support. Such communication-centered projects would increase understanding of important features of interactions between professional support providers and families. Also, communicative approaches will contribute to knowledge about differences between family-centered and non-family-centered practices. For example, Burlleson's (2003) concept of person-centered support messages could be applied to investigations of parent-professional interactions.

Also, intervention programs offer opportunities for communication researchers to observe professional-family interactions and family interactions in laboratory or natural settings. Such projects would provide additional information about the constitutive force of communication in family and professional relationships. In addition, communication researchers could examine how communication between professionals and families affects program utilization and benefits.

The past decade of research on support for families of children with disabilities provides useful information about many aspects of support. However, this review also indicates that many issues remain to be explored regarding the construction of supportive connections. Future research that theoretically focuses on interaction processes across formal and informal support-providing contexts will shed more light on factors that influence beneficial outcomes of support for families of children with disabilities.

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APPENDIX

EMPIRICAL STUDIES OF SUPPORT FOR FAMILIES OF CHILDREN WITH DISABILITIES 1996–2005

Category	Author(s) and Date	Theory	Method	Sample
Well-being	Baldry, Bratel, Dunsire, & Durrant (2005) ⁴	None	Survey/interview	6 professionals 63 family members
	Britner, Morog, & Pianta (2003)	Systems	Survey	87 mothers
	Brown, Anand, Isaacs, Baum, & Fung (2003)	None	Survey	34 parents
	Dempsey, Foreman, Sharma, Khanna, & Arora (2001)	None	Survey	205 parents
	Duvdevany & Abboud (2003) ²	None	Survey	100 mothers
	Emerson (2003) ²	None	Survey	9,726 mothers
	Floyd & Gallagher (1997)	Ecological	Survey	360 parents
	Forde, Lane, McCloskey, McManus, & Tierney (2004) ⁴	None	Survey/interview	16 parents
	Fox, Vaughn, Wyatte, & Dunlap (2002)	Positive behavior support	Survey	20 family members
	Guralnick, Neville, Connor, & Hammond (2003)	None	Survey	74 parents
	Hassall, Rose, & McDonald (2005)	Stress and coping	Survey	46 mothers
	Hastings, Allen, McDermott, & Still (2002)	None	Survey	41 mothers
	Hauser-Cram, Warfield, Shonkoff, & Krauss (2001)	Developmental-contextual systems	Survey	183 parent sets
	Heiman (2002)	Ecological	Interview	32 parents

(Continued)

Appendix (Continued)

Category	Author(s) and Date	Theory	Method	Sample
Resources/SES	Heller, Hsieh, & Rawitz (2000) ⁵	None	Survey/interview	120 mothers
	Hodapp, Fidler, & Smith (1998)	None	Survey	36 parents
	Honig & Winger (1997) ⁴	None	Survey	65 mothers
	Jones & Passey (2005)	Double ABCX	Survey	48 primary carers
	Keller & Honig (2004) ²	Ecological	Survey	92 parents
	Kerr & McIntosh (2000) ⁷	Hermeneutic phenomenology	Interview	63 parents
	King, King, Rosenbaum, & Goffin (1999)	Risk and Resilience	Survey	164 parents
	Lam, Giles, & Lavander (2003)	None	Survey/interview	47 carers
	Macias, Saylor, & Rowe (2003)	None	Survey	64 parents
	Maes, Broekman, Dosen, & Nauts (2003)	None	Survey	98 parents
	Manuel, Naughton, Balkrishnan, Smith, & Koman (2003)	None	Survey	270 mothers
	Nachshen, Garcia, & Minnes (2005)	None	Survey	100 parents
	Nachshen & Minnes (2005)	ACBX	Survey	200 parents
	Olsson & Hwang (2003) ⁹	Ecological	Survey/interview	460 parents
	Pal, Chaudhury, Das, & Sengupta (2002)	None	Survey	46 mothers
	Pelchat & Lefebvre (2004) ⁴	Stress and coping, ecological	Survey	74 families
	Poston et al. (2003)	None	Focus groups, interview	137 family members, 50 professionals
	Raina et al. (2005)	Path model	Survey	468 parents
	Rivers & Stoneman (2003) ⁶	Systems	Survey	50 parent/sibling triads
	Saloviita, Italinna, & Leinonen (2003)	Double ABCX	Survey	236 parents
	Sharpley, Bitsika, & Efremidias (1997) ⁵	None	Survey	219 parents
	Sloper & Turner (1996)	None	Survey	97 children
	Taanila, Syrjala, Kokkonen, & Jarvelin (2002)	None	Interview	8 couples
	Trute (2003) ⁵	None	Survey	97 parents
	Wang, Mannan, Poston, Turnbull, & Summers (2004)	None	Focus groups, interviews	104 family members
	White & Hastings (2004)	None	Survey	33 parents
	Wilgosh, Nota, Scorgie, & Soresi (2004)	None	Survey	107 parents
	Baxter & Kahn (1999) ⁴	None	Survey	37 families
	Cigno & Burke (1997)	None	Survey/interview	15 mothers
	Diamond & Kontos (2004)	None	Survey/interview	207 families
	Ellis et al. (2002)	None	Survey	91 families
	Gavidia-Payne & Stoneman (1997)	None	Survey	80 families
Kuchler-O'Shea, Kritikos, & Kahn (1999)	None	Interview	27 caregivers	
Lewis, Kagan, Heaton, & Cranshaw (1999)	Role	Interview	40 mothers	
Mulvihill et al. (2005) ⁷	None	Survey	417 parents	
Parish, Cloud, Huh, & Henning (2005)	None	Survey	5,065 families	
Taylor et al. (2005)	Systems, role	Interview	6 mothers	
Bailey et al. (1999)	None	Interview	20 parents	
Cook, Cook, Tran, & Tu (1997)	None	Focus groups/interview/survey	32 family members, 62 community members	
Intervention	Darling & Gallagher (2004)	None	Survey	120 female caregivers
	Duvdevany & Vudinsky (2005)	Double ABCX	Survey	100 parents
	Fazil, Bywaters, Ali, Wallace, & Singh (2002)	None	Survey/interview	20 families
	Gatford (2004)	None	Case study	1 family
	Huang, DeLambo, & Kot (2004)	None	Survey	57 parents
	Morse (2002)	None	Survey	300 families
	Sham (1996)	None	Interview/observation	6 families
	Abbott, Watson, & Townsley (2005)	None	Interview	25 parents
	Bennett, DeLuca, & Allen (1996) ^{5,7,8}	Stress and coping	Interview	12 parents
	Boettcher, Koegel, McNerney, & Koegel (2003)	Positive behavior support	Case study	1 family
	Boothroyd, Kuppinger, & Evans (1998)	None	Survey/focus groups	145 families
	Farber & Maharaj (2005)	Stress and life cycle	Survey	39 parents

(Continued)

Appendix (Continued)

<i>Category</i>	<i>Author(s) and Date</i>	<i>Theory</i>	<i>Method</i>	<i>Sample</i>
	Hendriks, DeMoor, Oud, & Franken (2000)	None	Survey	161 parents
	Hieneman & Dunlap (2001)	Positive behavior support	Survey	56 parents and professionals
	Hudson et al. (2003)	None	Survey	65 mothers
	Keen & Knox (2004)	Systems	Case study	1 family
	Lucyshyn, Albin, & Nixon (1997)	Ecological	Case study	1 family
	Quah (1997)	None	Survey	Parents and professionals of 40 children
	Rahi, Manaras, Tuomainen, & Hundt (2004)	None	Survey/interview	147 parents
	Santelli, Turnbull, Sergeant, Lerner, & Marguis (1996)	None	Survey	240 parents
	Summers & Jenkins (2001)	None	Survey	47 parents
	Vardi & Merrick (2003)	None	Case study	1 family
Extended families	Cronin (2004)	None	Interview	44 mothers
	Gardner, Scherman, & Efthimiadis (2004)	None	Interview	30 grandmothers
	Green (2001)	Serial model of caregiving	Survey/interview	91 parents
	Katz & Kessel (2002)	None	Interview	16 grandparents
	Mirfin-Veitch, Bray, & Watson (1997)	None	Interview	12 parent/grandparent pairs
	Seligman, Goodwin, Paschal, Applegate, & Lehman (1997)	Systems	Survey	42 mothers
Siblings	D'Arcy, Flynn, McCarthy, O'Conner, & Tierney (2005) ⁴	Systems	Survey/interview	16 siblings
	Evans, Jones, & Mansell (2001) ⁴	None	Survey	28 siblings
	Lobato & Kao (2002) ⁴	None	Survey/interview	54 siblings
	Opperman & Alant (2003)	None	Interview	19 siblings
	Phillips (1999) ⁴	Ecological	Survey	180 siblings
	Williams et al. (2003) ⁴	Learning, systems, role	Survey	252 siblings
Professional relationships	Ballard, Bray, Shelton, & Clarkson (1997)	None	Interview	15 fathers
	Lindblad, Rasmussen, & Sandman (2005)	None	Interview	16 parents
	Lord-Nelson, Summers, & Turnbull (2004)	None	Focus groups/interview	137 family members, 53 professionals
	McKeever & Miller (2004)	Bourdieu	Interview/observation	107 mothers
	Middleton (1998)	None	Focus groups/interview	19 social workers, 9 parents
Religion	Todd & Jones (2003)	None	Interview	30 mothers
	Dollahite (2003)	Generative theory of fathering and faith	Interview	35 fathers
	Marshall et al. (2003)	None	Interview	32 parents
	Poston & Turnbull (2004)	None	Focus groups/interview	187 PWDs, families, professionals
Policy	Skinner, Correa, Skinner, & Bailey (2001)	None	Survey/interview	250 parents
	Heyl (1998)	None	Interview/text analysis	Unspecified
	Kagan, Lewis, Heaton, & Cranshaw (1999)	None	Interview	40 parents
	Redmond & Richardson (2003)	None	Interview	17 mothers
	Steyn, Schneider, & McArdle (2002)	None	Interview	32 carers

Note. Each study is listed only once. Superscripts indicate additional foci of studies: (1) well-being; (2) resources/SES; (3) culture/minorities; (4) intervention; (5) extended families; (6) siblings; (7) professional relationships; (8) religion; (9) policy. SES = socioeconomic status; PWD = persons with disabilities.