

FAMILIES OF CHILDREN WITH DISABILITIES: A REVIEW OF LITERATURE AND RECOMMENDATIONS FOR INTERVENTIONS

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Children with disabilities receive most of their support from families. While most family caregivers are mothers or fathers, grandparents are increasingly providing care for children with disabilities. In addition, family caregivers come from diverse cultural backgrounds that impact their views on disability. This paper reviews the literature on parent and grandparent caregivers of children with disabilities as well as the literature on parenting children with disabilities across cultures. Drawing from a literature review, the paper discusses emerging directions in intervention.

Key words: children with disabilities, parent stress, grandparent care, families and culture, intervention

Families are a critical source of support for children with disabilities. Family members absorb the added demands on time, emotional resources, and financial resources (Baker-Ericzen, Brookman-Frazee, & Stahmer, 2005) that are associated with having a child with a disability. Yet, rewards from having a family member with a disability, such as personal and spiritual growth, have also been noted (Scorgie & Sobsey, 2002).

The literature on disability in early childhood encompasses studies of a broad array of diagnoses. While a few diagnosis-specific differences exist, Stein and Jessop (1989) found that caregivers of children with all chronic conditions experience similar impacts, concerns, and needs for support. Thus, this paper will examine family impacts and approaches to intervention across a broad range of disabilities and developmental delays building on the assumption that these diagnoses affect families in similar ways.

An extensive amount of research has been conducted on the impact of childhood disability on parents, particularly mothers. The findings of this research have important implications for practitioners who are working with young children and will be discussed

below. While parents are the most common type of caregivers for young children with disabilities, there are a growing number of grandparents who are providing custodial care. The literature on custodial grandparenting is not as extensive, yet this population has some unique needs and it is important for practitioners to be aware of these. In addition, there is a growing recognition that families who care for children with disabilities differ cross-culturally. As our society is becoming increasingly diverse, it is important for practitioners to be aware that culture impacts the ways in which families perceive childhood disability.

Although much has been written on issues affecting family caregivers, we know of no other paper that has attempted to synthesize this literature and speak to the implications for clinicians working in early intervention. This paper begins with a review of the literature on parents; proceeds to a discussion of issues affecting custodial grandparents; gives special emphasis to the ways in which families differ across culture; and finally, discusses the emerging ideas in intervention that are relevant for these varied types of family caregivers.

PARENTS

The view that having a child with an intellectual or developmental disability creates negative family outcomes including added stress and parental depression has underpinned much of the research of the past three decades (see Baxter, Cummins, & Yiolitis, 2000; Hayden & Goldman, 1996 for a review). Yet, research on this subject has suggested varying outcomes for families. In support of the view that disability leads to negative outcomes, a couple of comparative studies have noted greater stress in parents of children with disabilities than parents of children without disabilities (Baker-Ericzen, Brookman-Fraze, & Stahmer, 2005; Dyson, 1997). Likewise, two studies, focusing specifically on mothers, have found that mothers of children with mental retardation experience more depression than those of typically developing children when compared using the Beck Depression Inventory (Olsson & Hwang, 2001) and the Center for Epidemiologic Studies Depression Scales (Blacher, Shapiro, & Fusco, 1997). Although these studies suggest a relationship between childhood disability and parent stress or depression, it is important to note that they did not control for variations related to the diagnosis or care demands associated with the disability.

When the parental experience has been examined across diagnoses, some differences have been noted. Parents of children with Down syndrome have been found to experience less stress (Ricci & Hodapp, 2003), depression (Abbeduto, Seltzer, Shattuck, Krauss, Orsmond, & Murphy, 2004), and pessimism (Lewis, Abbeduto, Murphy, Richmond, Giles, Bruno, et al., 2006) than parents of children with other diagnoses, particularly autism. In addition, childhood disability may not be as stressful for families as childhood illness. A comparative study of families of children with physical disabilities versus families of children with

cancer found higher stress levels in the families dealing with cancer (Hung, Wu, & Yeh, 2004).

Behavior problems and care needs

Other studies indicate that it may not be the diagnosis, but rather the child characteristics associated with the diagnosis (e.g. behavior problems or care needs) that are the key predictors of negative family impact. When controlling for behavioral problems, Baker, Blacher, and Olsson (2005) found no differences in depression, well-being, and marital adjustment for families with and without children with disabilities. In addition to this comparative study, many non-comparative studies have noted poorer family outcomes associated with child behavior problems. Child maladaptive behavior has been associated with increased burden and stress (Heller, Hsieh, & Rowitz, 1997; Saloviita, Italinna, & Leinonen, 2003; Simmerman, Blacher, & Baker, 2001), poorer parenting efficacy (Kersh, Hedvat, Hauser-Cram, & Warfield, 2006), poorer parental mental health (Herring, Gray, Taffe, Tonge, Sweeney, & Einfeld, 2006), and poorer marital adjustment (Simmerman, Blacher, & Baker, 2001). These findings have important implications for practitioners working in behavioral intervention as they suggest that improvements in the child's behavior may lead to decreased parental stress and improved parental mental health.

Aside from behavior, other types of care demands can create stress and burden for families. Personal care needs (Neely-Barnes & Marcenko, 2004; Plant & Sanders, 2007; Warfield, 2001), adaptive behavior deficits (McCarthy, Cuskelly, van Kraayenoord, & Cohen, 2006; Saloviita et al., 2003), and medical needs (Neely-Barnes & Marcenko, 2004) have been associated with negative family impact, stress, and burden. Thus, research suggests that family outcomes may not be determined by simply the presence or

absence of a disability. Maladaptive behavior and care needs may be the more important risk factors for family impact and stress.

Marital adjustment and family functioning

In addition, the way the family functions in response to the child's disability has a critical relationship to family outcomes. Researchers have noted that marital and family functioning may be far more important predictors of parenting stress and depression than the presence or absence of childhood disability. Abbeduto et al. (2004) found that diagnosis-specific differences in parenting stress disappeared when child behavior, parental coping style, maternal education, family income, age of the child, and number of children in the family were controlled. Kersh, et al. (2006) found when controlling for marital quality, neither child functioning nor child behaviors were significant predictors of maternal and paternal depressive symptoms or parenting stress. Smith, Oliver, and Innocenti (2001) noted that although poor social skills in the child were a predictor of parent stress, family functioning was a much stronger predictor. The causal directions between stress and family functioning cannot be determined from these findings. Yet, these studies point to the need for practitioners to pay attention to parental relationships and overall family functioning because these can be important risk factors for parental stress.

Although several studies have examined the negative impacts of poor family functioning, Lustig (1997) found that most families of children with disabilities do not experience poor functioning. In a study of family typologies, Lustig found that most families of children with disabilities displayed either a coherent or flexible profile, and that only 7% of families exhibited a vulnerable profile which was characterized by a lack of functioning, coherence, resources, and adaptability. The results of Lustig's research suggest that families of children with a

disability may not experience more difficulties with functioning than other families. Thus, practitioners should not equate poor family functioning with childhood disability. While poor family functioning may be a risk factor for stress when it is present, many families function quite well.

Parental self-efficacy and cognitive appraisal

Several studies have pointed to the importance of parental cognitions and coping styles in predicting outcomes for families. Hastings and Brown (2002) found that when controlling for parental self-efficacy, the relationship between child behavior problems and parental stress was non-significant. In other words, the parents' belief that they could manage the care giving tasks was more important in predicting stress than the child's behavior. In addition, Plant and Sanders (2007) noted that when controlling for cognitive appraisal of care giving responsibilities, the relationship between child adaptive behavior and caregiver stress was no longer significant. When the parents' cognitive appraisal was accounted for in the study, only difficulty of care giving tasks significantly predicted caregiver stress. Likewise, Lustig (2002) found that families who could re-frame the disability in a positive way and perceived themselves as competent rather than passive had better family adjustment. Weinger (1999) found that mothers with a more positive perception of the child with a disability rated their family functioning higher. Finally, research indicates that how each parent copes with the disability may impact the spouse's coping. Hastings, Kovshoff, Ward, degli Espinosa, Brown, and Remington (2005) noted that spousal depression was a significant predictor of stress in both mothers and fathers. Thus, the literature suggests that practitioners need to pay close attention to how families define their experience of caring for a child with a

disability. Negative cognitions about the disability may represent risk factors for families.

There are many ways in which parents can reframe the disability experience into a positive one. In qualitative studies, parents have reported that their child's disability has given them an increased sense of purpose (Stainton & Besser, 1998); personal growth (Scorgie & Sobsey, 2000; Stainton & Besser, 1998); improved relationships and social networks (Scorgie & Sobsey, 2000; Stainton & Besser, 1998; Taunt & Hastings, 2002); increased spirituality (Stainton & Besser, 1998; Taunt & Hastings, 2002); increased tolerance and sensitivity (Scorgie & Sobsey, 2000; Taunt & Hastings, 2002); and a more positive future outlook (King, Zwaigenbaum, King, Baxter, Rosenbaum, & Bates, 2006). A positive outlook on childhood disability correlates with decreased feelings of stress and burden (Ylven, Bjorck-Akesson, & Granlund, 2006). Assisting families in finding a positive meaning to their child's disability may prove to be an important intervention in alleviating parent stress. However, further research is needed to understand what types of positive appraisals are the strongest predictors of positive coping and how the stress affects parents' behaviors or relationship behaviors such as the frequency of positive reinforcement used.

MOTHER/FATHER DIFFERENCES

Research suggests that mothers and fathers may experience different impacts of childhood disability and have different needs related to coping with the disability. In comparison to fathers, mothers of children with disabilities have been found to exhibit increased symptoms of depression (Hastings et al., 2005; Olsson & Hwang, 2001), increased caregiver burden (Heller et al., 1997) and increased stress (Dellve, Samuelsson, Tallborn, Fasth, & Hallberg, 2006; Herring,

Gray, Taffe, Tonge, Sweeney, & Einfeld, 2006). Looking comparatively at mother-father differences in families of children with and without developmental disabilities (DD), Oelofsen and Richardson (2006) found that mothers with children with DD experienced increased stress, weaker sense of coherence, and poorer health than their husbands while the comparison group (with children without DD) experienced no mother-father differences. Conversely, one study reported that mothers have more positive perceptions of care giving than fathers (Hastings, et al., 2005). However, smaller studies of approximately 30-40 mother/father pairs did not find significant differences on measures of stress (Dyson, 1997; Keller & Honig, 2004; McCarthy, Cuskelly, van Kraayenord, & Cohen, 2006), family support (Dyson, 1997; McCarthy, et al., 2006), family harmony (measured with the Family Environment Scale) (Keller & Honig, 2004), marital adjustment (McCarthy, et al., 2006), or family quality of life (Wang, Summers, Little, Turnbull, Poston, & Mannan, 2006). The lack of significant findings in smaller studies suggests that differences between mothers and fathers may be small.

Mothers and fathers may also differ in what contributes to their stress. Keller and Honig (2004) found that for fathers, acceptance of the child with the disability and family harmony reduced stress. While mothers were also affected by family harmony, lower socio-economic status and greater care demands predicted stress. These differences may represent important differences in the way practitioners should intervene with mothers versus fathers. Further research is needed to better understand what contributes to maternal and paternal stress.

While most of the stress and burden research focuses on parental mental health, the economic burden of raising a child with DD has also been examined. This economic burden has a particular impact on mothers. Comparative studies of parents with and

without disabilities have noted that mothers of children with disabilities work fewer hours and have lower earnings than mothers of typically developing children (Olsson & Hwang, 2006; Parish, Seltzer, Greenberg, & Floyd, 2004). In addition, mothers report spending more time caring for the child with the disability than fathers (Heller, Hsieh, & Rowitz, 1997) and that the care giving demands associated with the child's disability lead to increased work absenteeism (Warfield, 2001).

GRANDPARENTS AND GRANDCHILDREN WITH DISABILITIES

Grandparents are also being called upon to serve as caregivers for their disabled grandchild(ren). An aging caregiver is often thought of as an aging parent caring for an adult child with a disability. Instead, a new and growing population is beginning to garner the attention of researchers and is being referred to as the "skip-generation" (Janick, McCallion, Grant-Griffin, & Kolomer, 2000) caring for grandchildren and in some cases, great-grandchildren. Caregivers of grandchildren with disabilities are overwhelmingly female (e.g., greater than 90%), primarily minority (e.g., African-American, Latino), mostly in their late 50's to early 60's, with some high school education or a high school diploma, and from urban areas (Burnette, 2000; Force, Botsford, Pisano, Holbert, 2000; Janicki et al., 2000). In addition, one study indicates that these grandparent caregivers provide daily care for the grandchild for an average of 7 years (Janicki et al., 2000). Most of the children, who are cared for by their grandparents, are male (59%) with an average age of 4.83 years (Janicki et al., 2000). Most of the grandchildren have multiple problems or disabilities. The most common problems are learning disabilities, developmental delays, attention deficit hyperactivity disorder, intellectual

deficits, speech or hearing problems, and neurological problems (Janicki et al., 2000; McCallion, Janicki, & Kolomer, 2000).

The most common reason for grandparent custody is parental child abuse and neglect (Dubowitz, Feigelman, Harrington, Starr, & Zuravin, 1997; Janicki et al., 2000). Grandparent custody is often sought as an alternative to foster placement. Other reasons included teen mothers not being able to care for their child, AIDS, homelessness, unemployment, poverty, maternal imprisonment, and substance abuse (Burnette, 2000; Janicki et al., 2000; Pinson-Millburg, Schlossberg, & Pyle, 1996).

McCallion et al. (2000) identified five challenges for grandparents trying to care for their grandchildren. One issue was related to guardianship. Many families had informal agreements regarding child placement and legal guardianship had not been established, therefore making it difficult for the grandparents to access formal services (e.g., medical care or school support services). A second issue was financial. Many grandparents had difficulty accessing public assistance or emergency cash and Medicaid. A child staying in a home with a care-giving relative most often falls outside the formal child welfare system making them ineligible for some public benefits such as Temporary Assistance to Needy Families (TANF) (Hegar & Scannapieco, 2000). A third issue with aging grandparents was the lack of time off or respite from the grandchild. A fourth issue surrounded the need for emotional support for the grandparents as many grandparents had not addressed their own feelings about the death, drug addiction, or imprisonment of the absent parent. The fifth issue was that grandparents had difficulty navigating the maze of the educational, judicial, and social service systems. For grandparents caring for children with disabilities, this maze of service systems can be particularly complex. Thus, it will be important for clinicians to assess these

five factors when completing a comprehensive assessment.

Prevalence of burden and stress in custodial grandparents

Similar to the findings concerning depression in mothers, grandmothers, who make up 90% of grandparent caregivers, are also susceptible to depression when they are the primary care taker of a disabled grandchild, due to the additional stress of caring for the child (e.g., Dellmann-Jenkins, Blankemeyer, & Olesh, 2002; Kelley, Yorker, Whitley, & Sipe, 2001; Fuller-Thomson & Minkler, 2000). Scales used for measuring depression include the CES-D (Center for Epidemiological Studies Depression Scale (Fuller-Thomson & Minkler, 2000) and the depression subscale of the Brief Symptom Inventory (Kelley, et al., 2001). Other predictors of stress and burden included being African-American, having lower family income, having lower levels of social support, and not receiving welfare support (Burnette, 2000; Kolomer, McCallion, Janick, 2002; Mills et al., 2005).

However, it is not clear if caring for a grandchild with a disability exacts a greater burden for the grandparent than caring for a grandchild without a disability. In a comparative study of grandparents who were raising a grandchild with a disability to grandparents who were raising a child without a disability, few differences were found between perception of health status and depression (Force et al., 2000). Both groups of grandparents had high average scores on the Center for Epidemiologic Studies-Depression (CES-D) scale (13.9 for the disabled child grandparent and 15.8 for the non-disabled child grandparent, with the clinical cutoff score being 16). One difference found was that grandparents of children with a disability were more likely to need help with school. This makes sense as there is a greater likelihood that a child with a disability needs special support services. Two important

themes that have been previously identified that were confirmed by this study: both groups of grandparents experienced low access to potentially useful services and low levels of financial supports. This parallels the McCallion et al. (2000) grandparent study.

In another comparative study, Burnette (2000) compared Latino grandparents who were caring for a child with special needs to Latino grandparents who were caring for a grandchild without special needs. Those who were caring for a child with special needs reported greater levels of depression and more unmet service needs than the grandparents who were not caregivers of special needs children. However, the results of this study need to be interpreted cautiously due to the high number of comparisons and the risk of an inflated alpha yielding a statistically significant difference due to chance. Considering these studies together suggest that caring for a grandchild is stressful, but the results are mixed regarding the level of distress experienced if the child has a disability.

Research has typically focused on the negative aspects or burden to the grandparents and its effects on their psychosocial functioning or health. An equally important area of focus is the positive benefits to raising a grandchild with a disability. Positive benefits include greater love and intimacy, finding meaning in the experience of care giving, personal growth, and improved relationships (Gardner, Scherman, Efthimiadis, & Shultz, 2004; Toseland, Smith, & McCallion, 2001).

It is still unclear whether a grandparent raising a child with a disability experiences more stress and burden than a grandparent raising a grandchild without a disability. Borrowing from the parent research, what may be most important is how the grandparent views the care giving experience. Thus grandparents who are able to reframe the situation in a positive way and are more accepting of the disability could experience

less stress and burden. However, research with grandparents is still needed to substantiate this assumption.

CULTURE AND DISABILITIES

There is an increasing understanding among disability scholars that disability is a social construct, which is defined variably across cultures (Ferguson, 2001; Olkin, 1999). Culture has implications for how families define and experience disability, how families experience their interactions with the formal service system, and how parental child rearing values develop. While many examples of cultural differences around disability could be given, we will give a few that highlight issues that practitioners need to consider.

Culture influences the way families define disability. Two examples, the first one coming from one of the author's clinical experience, illustrate how families from India and China might define a specific condition very differently than a clinician native to the United States. For example, a clinician from an early intervention program, targeting children from birth to age 3 with developmental delays or disabilities, was referred to a family who recently emigrated from India. The presenting problem was that the child was not walking, or even crawling very well. During the assessment, the worker noticed that the child had extra digits on both hands and feet. When asked when they planned to schedule surgery to remove the extra digits, the mother indicated that no surgery would be scheduled as several of their extended family members had extra digits and were not hampered or hindered by being polydactyl. The clinician identified being polydactyl as a disability based on her culture, while the family identified the condition as a family trait based on their culture.

A study conducted in China also illustrates how culture can influence how a problem is defined. Families may experience different

levels of social stigma related to disability depending on their cultural context. For instance, "There are many people in China who continue to think that any child who develops in a non-typical fashion is a *shazi* – an idiot." (McCabe, 2007, p. 48). A study focused on children with autism found that children and their families experienced discrimination, limited educational opportunities, and limited support.

Culture and stress

Cultural influence can also be a mediator of stress. For example, a study examining the relationship between Panamanian grandmothers and their disabled grandchildren (Gardner et al., 2004) indicates less emotional distress was experienced by the grandmothers related to the birth of a grandchild with a disability than by American grandmothers. The Panamanian grandmothers focused less on personal loss, grief, and stigma related to having a grandchild with a disability and more on the current needs and resources for the disabled child as compared to their American counterparts. In addition, only about 10% of the grandmothers expressed fear about their grandchild experiencing social rejection or discrimination from the Panamanian community. The birth of a disabled child is viewed as less of a life altering event by grandmothers in the Panamanian community and the focus is more on the needs of the child and less on the status of the grandmother and thus the perception and reaction to the disability is related to the amount of stress and burden experienced.

A comparative study of Latina mothers and Anglo-American mothers with children with developmental disabilities found depression was higher and morale was lower with the Latina mothers, but the two groups did not differ on parenting stress ratings (Blacher & McIntyre, 2005). Latina mothers reported both greater depression and greater positive impact than Anglo-American

mothers. This finding is similar to the finding of Hastings et. al. (2005) that regardless of race and ethnicity, mothers report both greater depression and greater positive impacts than fathers. While these dynamics are not fully understood, it is important to note that parents can experience both greater positive and negative outcomes simultaneously.

Culture, parental values, and access to care

Culture and personal experiences influence child-related parental values (Arcia & Johnson, 1998). Taken a step further, researchers found that acculturated Mexican-American mothers were more similar to non-acculturated Mexican mothers in their child rearing beliefs than to American mothers (Arcia, Reyes-Blanes, Vazquez-Montilla, 2000). This suggests that parental child rearing values may be influenced more by the context of the family than the social environment. Therefore, it is important to identify parental definitions and values, and not assume that the family has mainstream American values, even when the parent seems to have acculturated to the Anglo-American culture.

Culture can also influence access to care. A study examining Asian mothers and Malay Muslim mothers with children with intellectual disabilities, found some interesting differences that the researchers attribute to differences in culture. The behavior of Muslim mothers appears to be guided by Islamic syariah (laws) (Ow, Tan, & Goh, 2004). Roles of the father and mother are clearly stipulated and support from within the family and community are viewed as sufficient. Conversely, Asian mothers believe they have options for support beyond the family (Ow, Tan, & Goh, 2004). This has direct practice implications in that Asian mothers may be more willing to seek out formal supports while Muslim mothers may not.

The examples in this section highlight the significance of culture and its affect on how

childhood disability is defined and experienced. It is important for clinicians to assess how the family defines the child's disability or the child's behavior. Considering the examples given above, clinicians should be aware of the many different ways that families might view a presenting problem. The family's assessment is an important consideration in how an intervention proceeds. Culture also influences how families, primarily the mothers, seek help and support. It is important for clinicians working with families of young children to recognize that families from other cultures may not be aware of school policies, school culture, and social service agency culture within the United States. In addition, families from other cultures may have different traditions regarding their relationships to school and agency authorities (e.g., only the father speaks to authorities on behalf of the family or extended family members are invited to school meetings as well as parents). Clinicians need to be open to the ways in which families communicate with them about their needs. At the same time, clinicians need to be willing to orientate families to U.S. school culture and policies.

INTERVENTION

The review of literature points out that caregivers experience different impacts of having a child with a disability and different needs for support related to the needs of the child, the relationship of the caregiver (e.g. father, grandmother), and the cultural context. One of the needs of caregivers is to be given opportunities to nurture healthy family functioning and find positive meaning in their care giving experience. As one special educator and sibling of a person with a disability points out, professionals need to allow families to "be a family first, and then do programming after that". He further explains:

“[H]ave you ever lived with a person with severe disabilities? There isn’t time to do all these [in-home] programs. You know, I would prefer to have a healthy family, one that can sit at a dinner table... When I talk with [families] about that, it’s amazing how much guilt is released to be able to...be a family first...have some fun with your children” (Marks, Matson, & Barraza, 2005, p. 214).

Another need is for caregivers to have the opportunity to deal with other family issues aside from the disability. Families of children with disabilities have all the joys and stresses of a typical family. Clinicians need not assume that all family problems are related to the child’s disability. For example, poor marital and family functioning have been linked to parental stress in families of children with disabilities (Kersh, et. al., 2006; Smith, et. al., 2001). Yet, because these studies of parenting stress and family functioning are not comparative to families of children without disabilities, we do not know if these issues are unique. The occurrence of poor family functioning in a family with a child with a disability may not always be attributable to the disability. Clinicians need to be aware of the fact that the child’s disability may not always be the presenting problem.

Cognitive-behavioral techniques, problem-focused coping, and empowerment

While much literature has examined the risk of stress, burden, and depression in families of children with disabilities, less literature has examined interventions that are aimed at ameliorating that stress. Hastings and Beck (2004) conducted a literature review and found a few limited, but promising approaches for parental stress. Most of the studies of interventions for parental stress utilized some form of cognitive (e.g., enhancing problem solving, cognitive restructuring, setting goals) and behavioral techniques (e.g., operant conditioning,

reinforcement, punishment, extinction) delivered in both groups and individual formats. The aim was to improve child behavioral management techniques, which ultimately led to decreased parental stress. Other interventions including case management services and respite care also show some benefit (Chan & Sigafos, 2001).

Another area of research relevant to improving parent well-being involves an understanding of problem-focused coping. Problem-focused coping includes the use of cognitive and behavioral problem-solving in order to manage the source of stress. That is, with problem-focused coping the person takes some action to reduce their stress. For example, the person can develop a problem list and then prioritize the problem list starting with the most pressing issue. Conversely, emotional focused coping seeks to change a person’s negative emotional state by focusing on moderating the negative emotion. These could include such techniques as using relaxation techniques, rethinking the problem in a more positive light, and denial. Essex, Seltzer, and Krauss (1999) found that mothers who coped with their child’s disability using problem-focused coping experienced less burden and depression than those who employed emotion-focused coping, which simply seeks to manage the emotions surrounding the source of stress. However Essex et al. (1999) found that fathers did not get the same benefits from problem-focused coping and only experienced decreases in burden when they refrained from emotion-focused coping. Similarly, Ylven et al. (2006) point out that emotion-focused coping is only beneficial in situations that are beyond the caregiver’s control. These findings suggest that clinicians may be able to decrease caregiver stress by helping the caregiver to focus on aspects of the disability that are under his/her control (such as asking for assistance and advice when needed or advocating for the child’s needs).

Another intervention concept closely related to problem-focused coping is the parent's sense of empowerment. Empowerment has been defined as "a person's (1) access to and control over needed resources, (2) decision-making and problem-solving abilities, and (3) acquisition of instrumental behavior needed to interact effectively with others to procure resources" (Dunst, Trivette, & Deal, 1988, p. 3). Interventions that involve empowerment hold promise for helping families deal with the stress of having a child with a disability. Yet, little empirical work has been done to establish the benefits of empowerment. Dempsey and Dunst (2004) found that families experience greater empowerment when they experienced greater comfort and autonomy in their relationships with professionals. In considering the outcomes of empowerment approaches, Neely-Barnes, Graff, Marcenko, and Weber (2008) have found that when families make more decisions, they receive more services and experience greater satisfaction. More research is needed to determine if there are other ways in which empowerment improves outcomes for families. However, for practitioners, it is important to note that preliminary research suggests that giving families more control over their services and creating a greater sense of comfort and autonomy is beneficial.

Future and long-term planning

As discussed in the literature review, an increasing number of grandparents are caring for children with disabilities. This increase in the number of older caregivers creates a need for information about long-term planning. Most long-term planning programs address both financial planning and living arrangements and provide caregivers with a step-by-step guide. For example, the Planned Lifetime Advocacy Network (PLAN) explains to caregivers how to help the person with a disability build informal relationships; how to

plan for residential stability; how to deal with guardianship and assist the person with a disability with life choices; and how to develop a will and plan an estate (Etmanski, 2000). Many programs for aging caregivers have been created. Although few of these programs have been evaluated, most anecdotal reports on long-term planning suggest that these approaches are helpful (Heller, 2000). In addition, one small controlled study of long-term planning indicated that older families who participated in a program were more likely to establish special needs trusts, to look into residential placement, and to put their desires for the future of the person with a disability in writing (Heller & Caldwell, 2006). Practitioners working with young children should know that these types of programs are available and may be particularly beneficial to older families.

Interventions specific to gender, age, and ethnicity of caregiver

Another consideration in planning interventions for caregivers is whether all family caregivers will benefit from the same types of interventions. As the review of literature suggests, fathers may have very different concerns and needs from mothers and grandparents may have different needs from parents. Parents may have different needs across cultures. Interventions such as support groups that are specifically for custodial grandparents, fathers, or parents of a particular cultural group may have particular value.

For example, one controlled study examined a specific intervention for grandparents caring for a child with a disability. This intervention focused on support groups, which provided both support and education about services available to children with disabilities. The support groups were effective in reducing depressive symptomology and improving a sense of mastery as compared to the control group

(McCallion, Janicki, & Kolomer, 2004). Another study regarding grandparents raising grandchildren, but not necessarily children with a disability, found multimodal, home-based intervention with monthly support groups significantly reduced stress and improved the level of public benefits the family received. This intervention can serve as a model for future study with grandparents raising children with disabilities (Kelley et al., 2001). Both of these studies suggest potential avenues of intervention and research with grandparents. In addition, research is needed to evaluate the value of support groups for fathers or for specific ethnic minorities.

Financial and respite support

Caregivers of children with disabilities benefit from concrete services such as stipend programs and respite care. In two studies of a cash subsidy program, Herman (1991; 1994) found that parents rated the cash subsidy as helpful, as improving their overall family life and ability to care for their child with a disability, and that they were able to get more respite care and professional services due to the subsidy. Similarly, Meyers and Marcenko (1989) found that cash subsidies reduced family financial stress and led to fewer families anticipating out of home placement. Chan and Sigafos (2001) found that respite care reduced short term stress for mothers and had a particularly positive effect on mothers of younger children in their review of the respite care literature. Herman and Marcenko (1997) found that the respite care had an indirect effect on maternal depression mediated by adequacy of time and adequacy of babysitting resources. When mothers received respite care, they felt they had more time and more adequate babysitting resources. These more positive perceptions in turn led to a decrease in maternal depression. Since mothers bear the brunt of the economic impact of having a child with a disability, it is not surprising that stipend and respite care

programs would be particularly beneficial to mothers. Although concrete services are beneficial to families, they are often underfunded and difficult for families to access. Clinicians can assist families by advocating that they get adequate services.

FUTURE DIRECTIONS

This review of literature points to several future directions for both researchers and practitioners. First, it points to the need for more research into the impact of caregivers positive perceptions of their child with a disability. While we know that family members have positive perceptions, we do not know what types of positive perceptions improve family coping. More information about the benefits of positive perceptions would assist practitioners, particularly those who employ cognitive-behavioral interventions with caregivers. This line of research could also clarify whether positive perceptions differ for mothers versus fathers and whether gender moderates the relationship between positive perceptions and parental coping. Research on this topic might also clarify whether different interventions are needed for mothers versus fathers.

We need more research into the cultural competency of our interventions with parents of children with disabilities. Although we know that families differ across cultures, little research has examined the cultural competency of interventions. In particular, studies of interventions that address needs of specific ethnic or cultural groups would be a much needed addition to the literature. In addition, future research could examine whether the cultural competency of practitioners improves family and child outcomes.

Additional research is also needed into interventions with grandparent caregivers. It is difficult to draw full and valid conclusions due to the limitations of the research. Similar to the parent research, most of the studies

utilized availability sampling, thus making generalizations difficult. Another significant limitation of the research is the reliance on self-report measures. For instance, grandparents reported their grandchild's diagnosis. There were no reliability or validity data pertaining to the accuracy of the self-reported diagnosis. Finally, there was only one controlled study found examining a specific intervention for this population. Previous researchers have done well to identify a "new" population of need, but further research is needed to fully understand the scope of the problem and how best to intervene. Further research could clarify whether interventions that work with parents would also be effective with grandparents.

Most importantly, this review of research points out that there is a large variation in the experience of caring for a child with a disability. Practitioners need to be aware of the fact that care giving produces both positive and negative experiences. Parents and grandparents may react to the care giving experience in many different ways. In addition, practitioners need to keep in mind that caregivers and other family members have needs for support in addition to the needs of the child with the disability. This review of literature points out that healthy family functioning is important and that practitioners need to support the needs of the entire family and not just the needs of the child with a disability. Finally, the research suggests that the way family members perceive their care giving experience may be just as important for their coping and functioning as the actual day-to-day demands of care giving. Practitioners working with young children can play an important role in helping family members reframe their care giving experience in positive ways and assisting family members in feeling like they have the knowledge, skills, and ability to successfully advocate for what their children need.

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