

FAMILY SUPPORT RESEARCH AND OUTCOMES

Recently a group of family support researchers reviewed twenty years of literature to report about the state of research and overall findings on family support. Kyzar, Turnbull, Summers & Gómez, (2012) reviewed quantitative studies published between 1990 and 2010 to discuss how family support is conceptualized across research studies (and how the definition can be sharpened), how families can benefit from family support, and to what extent do families benefit.

The authors argue that during the last 10 years, an ecological perspective of disability has gradually replaced the deficit-within-the-person model. The ecological perspective examines the match between a person's individual capacity and environmental demands; and introduces supports where functioning is compromised. A corollary of the support paradigm is the importance of the family as a primary means of support, and the impact of disability on the family. This recognition of the role of the family is fixed in federal policy as part of the Developmental Disabilities Assistance and Bill of Rights Act (DD Act)

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which includes the family support goals of enabling families to nurture and enjoy their children at home, and preserving, strengthening, and maintaining the family. The Act further authorizes family support activities: access to childcare services, respite care, training and leadership, self-advocacy, and self-determination.

Despite the recent broad acceptance of family support, the resources provided to families have not increased. This is in spite of evidence that need to support families is growing as individuals are cared for outside of institutional settings. Thus, 78% of individuals with disabilities live with family members, and more severe disabilities correlate with more serious needs, and reduce parent's satisfaction with the quality of life.

There is also a need for guidance. While there has been much written about better policies to support families, and how medical providers and other professionals should include families in decisions, planning,

Family Support is defined as a set of strategies directed to the family unit but that ultimately benefit the individual with ID/DD. Family Support strategies are intended to assist family members, who have a key role in the provision of support and guidance to their family member with I/DD. These strategies are designed, implemented and funded in a flexible manner that addresses the emotional, physical and material well-being of the entire family.

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and providing services to the individual, there has been very little research about what support is effective for families.

Kyzar and her colleagues searched literature published between 1990 and 2010, looking for quantitative studies of outcomes for families of a child from birth to 22 with moderate to severe disabilities. They used a four part definition of family support: *emotional support*; *physical support* including health and daily living activities; *material support* including financial resources and assistance with tasks; and *informational support*.

Fourteen studies met all criteria for inclusion in the review. The studies were a mix of journal articles and PhD dissertations. The majority included the mother only as the respondent (79%), and the respondents were more likely to be married and have education beyond high school. Two thirds of the studies were from the US, with the rest from Canada, Australia, and the UK. The study sample sizes averaged 72, except for one with 880 participants. Family stress was included as an outcome in 10 of the 14 studies, with a smaller number of studies reporting family functioning (4), family satisfaction (2) and family quality of life (1).

On the whole, the articles reported a positive relationship of family support to family outcomes. One study found a significant relationship between support and family quality of life, but they also found that the relationship was mediated through a reduction on parent stress. Two studies found significant effects of support on family satisfaction and well-being. Seven studies found a beneficial effect of mother's social support on reduced stress. One study reported a significant effect of father's social support on reducing stress.

There was variation in the measures of the independent variable – family support – both in terms of the sources of support (family, friends, professionals), and the types of support provided (emotional, physical, material, informational). This probably stems from the lack of an accepted operational definition of “family support.” Because of this variation, the article does not suggest any conclusions about the effect of any specific type of support, although the majority of studies were looking at informal sources of support.

The authors conclude that there is a positive association between family support and outcomes. Family support was associated with a positive effect on family quality of life, family functioning, and family satisfaction and lowered family stress. Fourteen studies over a period of 20 years indicates the need for more research. The authors also note that the research includes a wide range of types and sources of

Types of Family Support

Emotional support – Assistance related to improving psychosocial functioning in terms of reducing stress and improving a positive orientation of feelings

Physical support – Assistance related to improving physical health (e.g., health checks, nutrition) or daily living skills of the family member with a disability (e.g., helping child with toileting, eating, moving around their environment)

Material/instrumental – Assistance related to improving access support to adequate financial resources and the completion of necessary tasks (e.g., transportation to doctor's appointments, child care enabling the parents to work, assistance with housework so the family can spend time together)

Informational support – Assistance related to improving knowledge from verbal or written materials presented either online, through print, or video that leads to improved decision-making

Kyzar, Turnbull, Summers & Gómez, 2012

support. As an agenda for research, the authors offer a definition of family support, types and sources of support, and expected outcomes.

Since the Kyzar et al. paper was published, there have been more quantitative studies of family support. Replicating the method of the earlier search, we found six studies from 2011 to 2014 which are summarized here.

Social support can help reduce the feeling of stress that can impact the health of caregivers. Cantwell, Muldoon, and Gallagher (2014) found in a study comparing 109 families caring for a child with developmental disabilities to 58 families without, that the stress of caring for a child with special needs impacted the health of the caregiver. The perception of stress, and its effect on health, was moderated for those parents who reported higher levels of social support. Controlling for everything else, parents with more social support felt less stress, and reported better health. Similarly, Gallagher and Whiteley (2012) compared 35 parent caregivers with 30 parents of children without disabilities and found poorer psychosocial functioning and higher systolic blood pressure. Again, these effects were positively moderated by variations in social support.

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Several studies confirmed the role of social support in moderating the effect of stress on families of children with special needs. Migerode, Maes, Buysse, and Brondeel, (2012) studied 132 parents and 111 adolescents with developmental disabilities. They found the impact on the quality of life of the parents was fully mediated through the parents' resilience and the quantity of social support. Smith, Greenberg, and Seltzer, (2012), in a social network analysis of 269 mothers caring for children and adults with ASD, found that the psychological well-being of the mothers was influenced by the quantity of support they received. They found more improvements over an 18-month period for mothers with larger social networks. They also found that social support was a stronger predictor of caregiver well-being than was the behavior problems of the child. Plumb (2011) in a study of 50 parents of children with ASD found clinically high levels of stress in most of the families, and families with more resilience experienced lower stress. Surprisingly, in her study, higher social support was associated with greater stress, which could indicate that some social "support" can create situations that lead to stress, at least in the short run.

Kutash, Duchnowski, Green, and Ferron, (2011) report the effects of a parent-to-parent support program for caregivers of school-age children with mental health diagnoses (ED). The Parent Connections program was based on phone calls from trained support parents. They found the program to be feasible based on the 70% rate of participants they engaged in sustained conversations over time (averaging 305 minutes of contact over the school year). They also found moderate effects over time for the intervention on parent empowerment and use of mental health services, and greater effects over

time for the subgroup of highly strained parents. Student school attendance increased significantly in the treatment group (17 more days per year than the comparison group).

Conclusion

There is a modest-sized literature base about the effect of family support on quality of life, family functioning, and stress. Research of the past twenty years has consistently shown a positive association between family supports and the families' ability to foster resilience, maintain the health of the caregiver, reduce stress, and overcome the effect of stress.

What the research does not say is anything about the different effect of the different types of support, or differences in who provides the support – whether service providers, community members, or family. Not enough studies have been done that specify the types of support (emotional, physical, material, or informational) to enable conclusions about the effectiveness of types of support. Emotional and informational support seem to be the predominant types of support represented in the existing studies. With a set of specified types of family support, and attention to the different providers of support, research of the next twenty years can tell us more about the differential effects of types and combinations of support. There is a need to add to the amount and specificity of studies linking family support to outcomes.

The current body of research, however, is enough to indicate that family support is a prudent resource to meet the needs of families caring for the 13.9% of US children (Boyle et al, 2011) with intellectual and development disabilities.

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