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Author(s):	*Coyle, Carter, Currie and Cragg*
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Family Strengths Improve the Well-Being of Family Members with Developmental Disabilities

Coyle, Carter, Currie and Cragg

Abstract

Persons with developmental disabilities (DD) and their families often cope with increased health, economic, and social risks. Effective family coping depends upon the overall health of the family coupled with each family member's ability to promote positive well-being for self and others. This paper will share findings from three family-centred, qualitative studies that examined the coping strategies of parents of young children with autism, parents of adult children with DD and a co-occurring mental illness (Dual Diagnosis) who live at home with their caregivers, and young-adult siblings of children with autism. Overall, these studies point toward five areas of family strengths which promote coping in families who have a member with DD: a) the ability to see positive aspects of disability, b) close family relationships, c) ability to access resources, d) supportive relationships from outside of the family, and e) the ability to effectively self-advocate for essential services and to educate the public and professionals about the impact of developmental disabilities. These findings support interventions which focus on enhancing family strengths in order to improve the well-being of persons with DD and their families and caregivers.

Persons with developmental disabilities (DD) and their families often cope with increased health, economic, and social risks. Effective family coping depends upon the overall health of the family coupled with each family member's ability to promote positive well-being for self and others. This paper will share findings from three family-centred studies that looked at coping strategies in unique ways. The first study examined how online self-help groups improved families' abilities to care for children with autism. The second study identified characteristics of resilience in young adult siblings of children with autism. The third study outlined positive coping abilities in parents who were caring for adult children with DD and co-occurring mental illness (Dual Diagnosis) who lived at home. When analyzed overall, these studies suggested five areas of family strengths which can promote the well-being of both caregivers and family members with DD.

Strengths in Families Who Have Members with Developmental Disabilities

A person with developmental disability has life-long "significant limitations in cognitive functioning and adaptive functioning" which commenced prior to age 18 and influence the person's "capacity to live independently as an adult" (Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008). Worldwide, approximately 13% of the population has a developmental disability (First Leadership Limited, 2008). Caregivers of persons with DD frequently report lack of social supports, a lower quality of life, and increased financial difficulties (Chou, Lee, Lin, Kroger, & Chang, 2009; Olsson & Hwang, 2008). The health and well-being of persons with DD is greatly influenced by family strengths and the accessibility of supportive services for children and families (World Health Organization, 2010). Additionally, the increased life span of persons with DD has increased the number of aging parents who are caring for their adult children (Chou et al., 2009). Needs and challenges for persons with DD and their families predictably change over individual and family life journeys, and thereby, the coping strategies and interventions need to predict and adapt to these changes (Esbensen, 2011).

James Coyle, PhD, RSW, is an Associate Professor Emeritus of Social Work at the University of Windsor.
Irene Carter, PhD, RSW, is a Professor of Social Work at the University of Windsor.
Beth Anne Currie, MASc, RN, is a Research and Program Evaluation Facilitator at the Southern Network of Specialized Care.
Stephanie Cragg, MSW, RSW, is a PhD student of Social Work at the University of Windsor.

Family members' capacities, hope, adaptability, and access to resources within and outside of the family unit are the basis for overcoming the challenges that can occur when caring for a family member with DD. Walsh (2006) suggests four areas of family strengths and resilience. First, positive beliefs, such as "we are able to work together to overcome this crisis," help families find meaning in hardship and recognize the potential for successfully addressing difficulties. Second, family structure that is cohesive and flexible helps families to support each other and amend family roles to adapt in times of crises. Third, families that are able to access effective communication and problem-solving skills can work together to respond to crises and ongoing challenges. Finally, accessible resources outside of the family can provide emotional and instrumental support that can enhance family coping and intervene when families become overwhelmed. Resources can include informal support from extended family, friends, neighbours, community groups, and churches as well as formal support services such as respite, educational/occupational training, residential options, and counseling services.

Research Methods

This paper examines the findings of three separate qualitative studies of families who had members with a developmental disability. Each study received approval from the Research Ethics Board at the authors' university. The studies all used semi-structured interviews to explore: a) self-help group experiences of 22 parents of children with autism (Carter, 2009), b) resilience characteristics of 14 young-adult siblings of children with autism, and c) coping abilities of 15 parents caring for adult children with DD and mental illness (Carter, Coyle, Currie, & Cragg, 2014). Researchers asked questions about demographic information, positive and negative experiences related to having a family member with DD, and strengths and resources influencing participants' coping and well-being. Research participants were recruited in southwestern Ontario through notices distributed at local agencies providing support services for people with DD and by word of mouth. Interviews were analyzed using qualitative techniques in which the researchers assigned codes and categories to significant statements in a line-by-line examination of the transcripts and then identified common themes across participants. This paper's findings represent themes occurring across all three studies.

Results

The study of parents of young children with autism (Carter, 2009) found that self-help groups were important sources for connecting with others, receiving information about autism and intervention, and providing tools for promoting advocacy. Parents of adult children with DD and mental illness (Carter et al., 2014) identified several areas of parents' strength, noting their adult child's interests and interactions, staying hopeful, and overcoming social stigma. Siblings of children with autism reported challenges related to living with a sibling with autism and also the factors which improved coping, such as positive beliefs, support from parents and extended family particularly during childhood, and supportive relationships with friends, particularly during adolescence and early adulthood.

Overall, the three studies suggested five areas of family strengths which positively impact families and family members with DD. First, the ability to see the positive aspects of disability improves family coping and supportive family relationships for family members with DD. For example, a parent of an adult child stated that "he's learning to handle things a little better and I'm proud." A sibling research participant said that:

> As I've grown up I felt I care less about what people think and I feel like my brother has had a pretty big impact on that … I guess my brother pushes me more, seeing him struggle with a lot of things kind makes me realize that I can push myself and I need to be thankful.

Second, close family relationships provide support for parents, siblings, and family members with DD. A parent of an adult child reported that one of her other sons "looks after a lot of the paper work that needs to be filled out … We talk to him about our problems, and it's very helpful that way in terms of moral support." A sibling of a child with DD said "my parents would just take note of things that … [we] were interested in. They would really try to encourage us to build on that." Additionally, supportive relationships with friends, extended family, and from self-help groups is a third area of strength. These relationships improve family members' coping ability, which in turn improves supportive relationships between caregivers and family members with DD. For example, a parent of an adult child with DD stated, "I would not have been so happy if I hadn't met them [other families that had children with DD] … [I] am still in touch with these people. … I feel very fortunate to know these people." Moreover, a sibling research participant explained, "I have always had really good even-keeled friends, and I have always had really strong relationships with other people because, I don't know, it's just what is important. … I always had an escape with my friends."

Fourth, the ability to access resources, such as appropriate financial assistance, educational or vocational training, and residential care options for adult children decreases the stressful impact on all family members. A parent of an adult child with DD noted that "[respite services have] been fantastic with helping me financially to get that little time to myself," and a sibling participant suggested, "I think outside support is the biggest thing, whether it's through a trained organization, or your friends or community, church, whatever, just don't do it alone."

Fifth, the ability to effectively advocate for needed services and to educate the public and professionals about DD can lead to a more supportive community for people with DD and their families. A parent of a child with autism explained that using the internet or email to promote needed services was "a very good way to feel like … a community advocating together," while a parent of an adult child emphasized that "there needs to be new training [for teachers] to learn what the children need … They need more workshops to come and explain …"

Discussion

These findings support interventions that enhance family strengths in order to improve the well-being of persons with DD across the life span. Specifically, positive outlooks about disability and emotionally supportive relationships serve to improve family coping skills and by extension families' ability to provide instrumental and emotional support for members with DD. Parents need help with advocacy and with accessing outside and community resources. Parents of young children with DD reported the need for timely assessment, educational and vocational training, and respite services. Parents of adult children with DD mentioned the need for enhanced employment opportunities and access to appropriate supportive housing resources for the time when they are no longer able to care for their adult children. Siblings need emotional support from parents, and supportive relationships with friends are particularly important for adolescent siblings. Nurturing family relationships improve coping for all family members, as do supportive relationships outside of the family, including self-help groups, friends, and neighbours.

Parents and family members have stories which can educate the general public and supportive service professionals about the challenges and the benefits of caring for persons with DD while encouraging the provision of essential resources that foster the positive growth and development of persons with DD and their families. Increasing community understanding and support is an important step for reducing isolation and stigma faced by persons with DD and their families (First Leadership Limited, 2008; Sylvester, Donnell, Gray, Higgins, & Stalker, 2014) and for increasing financial resources, services, and community support which can improve the quality of life for persons with DD and their families. Professionals who support persons with DD can improve their service plans by enhancing and building on these family strengths.

The studies did have some limitations. Even taken together, the sample size is small, and this limits generalizability of the findings. In addition, the studies had slightly different aims, and some of the common themes were supplementary to these aims. Identifying these themes could be influenced by the researchers' attempts to interpret findings for practical application. However, finding common elements in three different studies does strengthen the overall results.

The three studies examined in this paper found common concerns and needs reported by parents of young children with DD, parents of adult children with DD, and young adult siblings of children with DD. They identified family strengths which assist coping and well-being of persons with DD and their family members. Interventions which bolster family strengths are an important asset for helping persons with developmental disabilities.

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