

Topic: Build child, family and community relationships that promote child development and learning.

Arnold, C. K., Heller, T., & Kramer, J. (2012). Support needs of siblings of people with developmental disabilities. *Intellectual and Developmental Disabilities, 50*, 373-382.

Context

Research on the needs of siblings of individuals with disabilities is scant and is of utmost importance as siblings often become the next generation of caregivers when aging parents can no longer fill this role (Heller & Kramer, 2009). Inquiry in this area could help guide the development of support programs and services to assist all family members, not just parents.

Research that does exist in this area, however, focuses on interventions used with siblings when they are children. For instance, targeting nondisabled siblings for interventions to teach interaction skills and strategies was found to increase sibling play and interactions (Celiberti & Harris, 1993; Clark, Cunningham & Cunningham, 1989; James & Egel, 1986). An evaluation of Sibshops, a support project for brothers and sisters of people who have special health, developmental, or mental health concerns, indicated that it has had an enduring positive effect throughout the lives of participants (Johnson & Sandall, 2005).

Purpose of Study

The purpose of this qualitative study was to provide descriptive information about the support needs of siblings of individuals with developmental disabilities and to suggest resources to address these needs. Information provided is useful for parents, professionals, and policymakers and has implications for future policy and research. The findings support the arguments that more opportunities are needed for siblings of people with developmental disabilities to connect and share information and resources and that siblings are an important resource for the disability field as future caregivers and potential advocates for their siblings with disabilities.

Method

Selected items were analyzed from a previously conducted survey of 139 adult siblings of people with developmental disabilities (Heller & Kramer, 2009). The Supporting Siblings Survey included 59 questions focusing on, among other topics, the relationship of the individual with a disability to their siblings and the family's future plans. In 41% of the families, the individual with a disability lived at home with parents, in 24% the individual lived in a residential facility, in 11% the individual with a disability was living with a spouse or independently, in 8% the individual lived with their nondisabled sibling, and in 7% he or she was living with other family members. Items selected for this study focused on open-ended questions in which siblings were able to write thoughts and ideas relevant to support needs.

Results

Siblings expressed that they felt more support was needed and that professionals working with individuals with disabilities and their parents sometimes neglected to include siblings in conversations about how they might be feeling or what information they might be seeking. One sibling shared that the first time they felt normal was when they found an Internet sibling group.

Siblings shared that they needed to be included in the definition of family and to be able to take part in the services offered to families. They expressed the need for education and training opportunities particularly in the areas of advocating for the rights of their siblings and how to transition from parent to sibling as caretaker.

Improvement of the formal disability service system was a need also voiced by siblings who found it often difficult to navigate. They hoped for better and more consistent service

coordination, choices for residential living, and service providers who encouraged sibling involvement. The need for funding sources and financial support was also indicated by siblings.

Discussion

Responses from siblings of individuals with disabilities were organized into the following three themes: (a) the need for inclusion as a family member, (b) the necessity for information, and (c) the importance of improving formal support systems to address sibling needs.

One source of information provided in this article is titled *The Future is Now* and is described by the authors as a “future-planning curriculum that includes siblings and has tested outcomes” (Factor, DeBrine, Caldwell, Arnold, Kramer, Nelis, & Herrero, 2010, p. 379). Another source of information and networking cited was an online listserv, called SibNet, where adults who have a brother or sister with a disability can connect. [www.siblingsupport.org/connect/the-sibnet-listserv]

The Sibling Leadership Network (SLN) is also mentioned as providing “siblings of individuals with disabilities the information, support, and tools to advocate with their brothers and sisters and to promote the issues important to them and their entire families” (Heller, Kaiser, Meyer, Fish, Kramer, & Dufresne, 2008). Because, currently, family support policy does not specifically include siblings, the SLN developed a policy white paper with key recommendations that can help address the support needs of siblings in this study. This paper can be downloaded at the following two websites:

<http://siblingleadership.org/policy-advocacy/expanding-the-circle-of-support-through-policy-and-advocacy-brothers-sisters-and-caregiving-for-individuals-with-developmental-disabilities/> and

<https://docs.google.com/file/d/0B-0A69WPAaAXNzlmZGM5ODQtMDdkZC00MzFILW14MTItMmYyZWY5NmQ0MjU0/edit?pli=1>.

The SLN has partnered with the national Self Advocates Becoming Empowered (SABE) to ensure that they are working with and learning from people with disabilities. The authors suggest that this approach models how siblings can work as a team to improve the system for their entire family. They are also advocating for the specific inclusion of siblings in the definition of family on the reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act of 2000.

About Research-to-Practice Briefs

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About The ACCEPT Project

The ACCEPT (Advancing Community College Efforts in Paraprofessional Training) Project is a federally-funded cooperative agreement between the U. S. Department of Education Office of Special Education Programs (OSEP) and the University of North Carolina at Charlotte College of Education. The focus of this effort is the inclusion of special education content in the coursework and experiences provided within the associate degree program in early childhood education at targeted state-supported community colleges in North Carolina.

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