



Encyclopedia of Family Health

Intellectual Disability in the Family

Contributors: Wendy M. Nehring

Edited by: Martha Craft-Rosenberg & Shelley-Rae Pehler

Book Title: Encyclopedia of Family Health

Chapter Title: "Intellectual Disability in the Family"

Pub. Date: 2011

Access Date: January 16, 2017

Publishing Company: SAGE Publications, Inc.

City: Thousand Oaks

Print ISBN: 9781412969185

Online ISBN: 9781412994071

DOI: <http://dx.doi.org/10.4135/9781412994071.n224>

Print pages: 672-675

©2011 SAGE Publications, Inc.. All Rights Reserved.

This PDF has been generated from SAGE Knowledge. Please note that the pagination of the online version will vary from the pagination of the print book.

The birth of a child with a disability often changes the lives of all family members. Of course, this is true for any birth, but the birth of a child with a disability comes with challenges that are often not present with the birth of a child without disabilities. This is not to say that this experience for family members is negative. It is true that early literature does speak of negative family experiences, but in the past generation, this attitude has changed and the models of family life are painted with themes of adaptation and resilience. A historical review of the literature starts this entry and is followed with a review of the literature on the current themes of research on family life and specific literature on mothers and fathers, siblings, and grandparents. A final section covers policy and future research goals.

Historical Review of Family Literature

Institutions for the care and housing of persons with disabilities, in particular, intellectual disabilities, were prevalent from the late 1800s through the 1970s. It was felt that the birth of a child with a disability was a stigma on the family and the child needed to be placed outside of the home. Research conducted on families in this period of time was limited to the small percentage of families who chose to keep their child at home often with few community supports. Research involving the family where the member with a disability was residing in the home entered a new phase after the period of deinstitutionalization in the 1970s and after the influence of the Kennedy years with the passage of the Education for All Children Act of 1975 (Public Law 94–142).

Early research on family responses to a member with a disability was conducted by Bernard Farber. He examined family integration when a child had an intellectual disability. His research looked at marital happiness and sibling adjustment. He did find marital discord and was one of the earliest researchers to discuss how younger siblings without a disability would become the dominant sibling if an older sibling had an intellectual disability. It has been questioned whether these findings were influenced by the presence or absence of community supports. Other researchers found that the siblings without a disability could be very influential in assisting their sibling with an intellectual disability to socialize outside of the home.

Up until the 1990s, the theoretical approach to the examination of these families was psychological. The pathology of the parental response to the birth of a child with a disability was often discussed. This early research often centered on parental feelings of guilt, loneliness, stress, anger, denial, and/or chronic sorrow. *Chronic sorrow* was defined as the ongoing sadness of not giving birth to the ideal child. *Novelty shock* was another term used to describe the initial sense of shock that parents experience at the birth of a child with a disability and that those feelings will be affected across time based on their experiences with family, friends, and health care professionals.

Books were written by parents to illustrate their personal stories of having a child with a disability, and these books examined the prevailing view of society and the lack of social and educational supports available to these families during that time. The stigma of having a child with a disability as well as the stressors on family members is told in detail.

By the 1990s, researchers were painting a more positive perspective and lived experience of families with a child with a disability. Rather than lives filled with unhappiness, sorrow, guilt, and stress, researchers spoke of adaptation and resilience in the families. More sources of support were available to these families due to public policy and legislative changes, media exposure to the lives of children with disabilities (e.g., TV series *Life Goes On*), and changing

societal attitudes.

Current Research Themes on Family Responses

The major themes of family research encompassing the life span are adaptation and stress. In the past 10 to 15 years, researchers have examined stressors and the process of adaptation. In recent years, resilience is replacing adaptation as the construct to explain family reaction.

Adaptation/Resilience

Adaptation is influenced by sources of support, including information, informal and formal support, and resources. Information is the most requested form of assistance, and the type of and form for delivery changes across time and by family members. This need for information may be a factor in the reason that parents of children with Down syndrome appear to have more positive adaptation, since more is known about this condition than other disabilities. Before families participate in social activities, they need to feel that there are informal and formal supports available to the member with a disability. If such supports are not available, then the families either will not participate or they will separate so that some members can partake of the activity and the member with a disability is not left alone. These and other family demands, problem-solving abilities, and resources are the primary factors in ascertaining a level of adaptation. In addition, adult community services must also be flexible so as to meet the unpredictable way of life of the families who use their service. Variability of services is further found by etiology.

Adaptation is also affected by each family member's belief system and the meaning the member with a disability has for them and their family. These belief systems are felt to be the most important determinant for resilience and successful adaptation. The McCubbin and McCubbin resilience model of family stress, adjustment, and adaptation has been widely used in research involving families with a child with a disability.

Several researchers have identified that parents initially have negative experiences and feelings, including depression and distress, but in most cases, these negative experiences diminish and are replaced with increasingly positive outcomes. For such positive adaptation to occur, it is essential that these parents develop a sense of hope, a positive view of the future, and coherence. Researchers have found that parents develop increased compassion, patience, and tolerance; enhanced spiritual values and beliefs; and realization of what is most important in life. Parents often speak of altering their original parenting plans rather than maintaining feelings of guilt and sorrow. There is a need to redefine the importance of achievement and focus on the child's strengths. Other factors to keep in mind are cultural beliefs related to disability and the severity of the child's condition. Each can greatly affect the belief systems of each individual family member.

Stress

Stress in parents with a child with a disability is most often studied through the examination of a specific condition. For example, parents of children with Down syndrome have been found to experience less stress than parents of children with autism spectrum disorder, other conditions resulting in intellectual disabilities, and neurological disabilities. In general, the usual areas of stress for families of children with a disability are psychosocial and physical needs, costs of care, communication problems between the child and parent, and day-to-day

activities, such as bathing, feeding, and dressing. In the following sections, research involving individual members is highlighted.

Research on Mothers

Mothers assume the greatest role in the caretaking of a child with a disability. Therefore, the majority of research on individual family members has been done on mothers. The majority of this research has involved maternal well-being with a consensus that raising a child with intellectual disabilities increases stress levels, negatively affects family functioning, and increases depression. These findings are increased if the child has coexisting behavioral problems. Such findings have been fairly consistent across countries but are affected by culture and family and social support services. Family functioning and acceptance have also been found to be positively related to the degree that a mother views the situation as positive. The specific condition often affects emotional well-being in mothers, and the more that is known about a condition and the less the stigma of the condition corresponds to less emotional distress.

Research on Fathers

Less has been written about the responses of fathers to having a child with a disability. In early studies on families, fathers were found to be disappointed if their boy had a disability. More recent research has not shown this result. Fathers initially show less emotion at the birth of a child with a disability but are concerned with the long-term concerns. In contrast, mothers are much more emotional and worry about whether they can care for their child with a disability. In some cases, these reactions are reversed.

Research on Siblings

In general, the sibling relationship when one sibling has a disability has been positive and, in some cases, involved less conflict than when both siblings were healthy. Yet as mentioned earlier, the healthy sibling often takes on the role of caregiver, and this sibling is usually a sister. When the healthy sibling was a brother, the sibling with a disability was more social and less shy if the relationship was good. If the healthy sibling was a sister, the sibling with a disability was less assertive and showed more aggression. Healthy sisters were more supportive, and healthy brothers were closer to a brother with a disability than they were if the sibling with a disability was a sister. In the case where a sibling has autism, researchers have found small negative psychological effects (i.e., depression, anxiety, anger, aggression, and fear) that became more obvious at different times in the healthy sibling's life. Behavior problems have also been noted in siblings who have a brother or sister with a disability. Maternal negativity and family conflict and disorganization negatively impacted healthy siblings. This contrasts to a general examination of sibling relationships where one sibling has a variety of disease conditions. Further, researchers have found no significant differences in perceived competence or self-concept in healthy siblings who have a sibling with a disability.

The research on siblings in families in which there is a child with a disability is void of a theoretical framework. There is a need for the development of theories that examine age differences, personalities, developmental stages, spacing, and multiple siblings.

Research on Grandparents

Little research has been done on grandparents. Maternal grandmothers have been identified as providing the greatest amount of support and availability, followed by maternal grandfathers, and finally, the paternal grandparents. Mothers were less stressed and experienced less emotional distress when the maternal grandmother was supportive after the birth of a child with a disability. In addition, fathers were less stressed if they received support from their mothers. Grandparent support is also found more often than support from friends and other relatives, and grandparent practical support decreases across time. Finally, fathers experienced less stress when they knew that their wife was being supported and as a result was feeling less stress.

Policy Influences

There have been a number of laws and statutes passed that have influenced the lives of persons with a disability, but the Developmental Disabilities Assistance and Bill of Right Act (42 U.S.C. Secs. 15001 et seq.) is the only statute that is specific to individuals with developmental disabilities and their family members. This Act provides for individual supports and community services that allow self-determination, inclusion, and independence. Family support programs provide either direct or indirect reimbursement for different forms of support to enable persons with a disability to remain at home. Medicaid also provides funding for medical expenses.

In 2003, The Arc of the United States and the American Association on Mental Retardation cosponsored a national meeting of leaders in research, education, and service, as well as self-advocates, to identify a research agenda. The overarching goal of the group that focused on families was to support families with a member with an intellectual disability and to provide supports to maintain the family unit. The group also listed five goals, which focused on partnerships, accessible community supports and services, sufficient sources of funding, and knowledge and best practices that are readily disseminated. The group further discussed pressing issues that will impact supports for families, and these included federal and state economies, cultural diversity, demand for services, concerns related to the workforce, and improved collaboration between agencies and programs. In an effort to address these issues and meet the goals outlined above, current and future research must provide the evidence for change.

Future Research Goals

Much research is needed to understand the quality of life and supports needed for successful adaptation and resilience in families with a child with a disability. There is a need to understand how families identify their needs, strengths and challenges, and celebrate their resilience across time. Knowledge is needed about the internal and external processes in adaptation that the family undertakes across time, in what areas change takes place, and how these processes change, if they do, at different points in the parent's versus child's life. There is also a need for research on the effects of developmental transitions and research to understand cultural and generational differences.

Research is further needed to examine sibling relationships. Little research has been done on adult siblings. It is important to understand the meaning of a sibling with a disability to the healthy sibling across their life span and to compare that meaning to the meaning between another sibling pair without a disability. In addition, it is important to understand the sibling relationship across time and to ascertain if there are developmental periods that are better or

worse and what factors contribute to or hinder relationships at these times (e.g., culture, parental beliefs, services, health). Researchers need to examine how parents influence the sibling relationship based on gender, age, and spacing.

In addition, future research should involve blended families, race, religion, ethnicity, fathers, and multiple siblings, and the perspective of the sibling with a disability.

In conclusion, the birth of a child with a disability affects each family member. Each day, there will be positive, negative, and mixed feelings depending on internal and external factors, and these feelings will be influenced by culture and socioeconomic status. Theoretical development and further research is needed to better understand these factors and how professional supports and services can be delivered.

- children with disabilities
- siblings
- disability
- families of children with disabilities
- intellectual disability
- sibling relationships
- resilience

Wendy M.Nehring

<http://dx.doi.org/10.4135/9781412994071.n224>

See Also:

- [Adult Child With Disability: Planning for by Parents](#)
- [Caregivers of Adults With Developmental Disabilities](#)
- [Caregiving: Adults With Developmental Disabilities](#)
- [Disabilities and Family Management](#)
- [Life Span: Care Coordination for Chronic Illness/Disabilities and the Family](#)
- [Resilience in Families With Health Challenges](#)

Further Readings

Blacher, J., & Baker, B. L. Positive impact of intellectual disability on families. *American Journal on Mental Retardation*, 112, 330–348. (2007)

Emerson, E., Hatton, C., Llewellyn, G., Blacker, J., & Graham, H. Socio-economic position, household composition, health status and indicators of the well-being of mothers of children with and without intellectual disabilities. *Journal of Intellectual Disability Research*, 50, 862–873. (2006)

Farber, B. Effects of a severely mentally retarded child on family integration. *Monographs of the Society for Research in Child Development*, 24 (2, Serial No. 71). (1959)

Farber, B. Family organization and crisis: Maintenance of integration in families with a severely mentally retarded child. *Monographs of the Society for Research in Child Development*, 25 (1, Serial No. 75). (1960)

Featherstone, H. (1980). *A difference in the family: Life with a disabled child*. New York: Basic Books.

Ferguson, P. M. A place in the family: An historical interpretation of research on parental reactions to having a child with a disability. *Journal of Special Education*, 36, 124–130. (2002)

Grossman, F. K. (1972). *Brothers and sisters of retarded children: An exploratory study*. Syracuse, NY: Syracuse University Press.

- Hodapp, R. M., Urbano, R. C., & Burke, M. M. Adult female and male siblings of persons with disabilities: Findings from a national survey. *Intellectual and developmental disabilities*, 48, 52–62. (2010)
- Hornby, G. Fathers' views of the effects on their families of children with Down syndrome. *Journal of Child and Family Studies*, 4, 103–177. (1995)
- McConkey, R., Truesdale-Kennedy, M., Chang, M-Y., Jarrah, S., & Shukri, R. The impact of mothers of bringing up a child with intellectual disabilities: A cross-cultural study. *International Journal of Nursing Studies*, 45, 65–74. (2008)
- McCubbin, H. I., & McCubbin, M. A. (1993). Family coping with health crises: The resiliency model of family stress, adjustment, and adaptation. In C. Danielson, B. Hamel-Bissell, & P. Winstead-Fry (Eds.), *Families, health, and illness* (pp. 21–64). St. Louis, MO: C. V. Mosby.
- Nehring, W. M. Cultural considerations for children with intellectual and developmental disabilities. *Journal of Pediatric Nursing*, 22, 93–102. (2007)
- Olshansky, S. Chronic sorrow: A response to having a mentally defective child. *Social Casework*, 43, 190–193. (1962)
- Orsmond, G. I., & Seltzer, M. M. Brothers and sisters of adults with mental retardation: Gendered nature of the sibling relationship. *American Journal on Mental Retardation*, 105, 486–508. (2000)
- Seligman, M., & Darling, R. B. (2007). *Ordinary families, special children* (3rd ed.). New York: Guilford.
- Seltzer, M. M., Greenberg, J. S., Floyd, F. J., Pettee, Y., & Hong, J. Life course impacts of parenting a child with developmental delay/mental retardation. *Nursing Research*, 44, 38–44. (2001)
- Seltzer, M. M., Greenberg, J. S., Orsmond, G. I., & Lounds, J. Life course studies of siblings of individuals with developmental disabilities. *Mental Retardation*, 43, 354–359. (2005).
- Seltzer, M. M., Krauss, M. W., Walsh, P., Conliffe, C., Larson, B., and Birkbeck, G. et al. Crossnational comparisons of ageing mothers of adults with intellectual disabilities. *Journal of Intellectual Disability Research*, 39 (5), 408–418. (1995).
- Stoneman, Z. Siblings of children with disabilities: Research themes. *American Journal on Mental Retardation*, 43, 339–350. (2005)
- Trute, B. Grandparents of children with developmental disabilities: Intergenerational support and family well-being. *Families in Society: Journal of Contemporary Human Services*, 84, 119–126. (2003)
- Turnbull, A. P., Turnbull, R., Agosta, J., Erwin, E., Fujiura, G., and Singer, G. et al. (2005). Support of families and family life across the life-span. In K. C. Lakin, & A. Turnbull (Eds.), *National goals & research for people with intellectual and developmental disabilities* (pp. 217–256). Washington, DC: American Association on Mental Retardation.
- Turnbull, H. R., III, Stowe, M. J., Agosta, J., Turnbull, A. P., Schrandt, M. S., & Muller, J. F. Federal family and disability policy: Special relevance for developmental disabilities. *Mental Retardation and Developmental Disabilities Research Reviews*, 13, 114–120. (2007)