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DISABILITIES AND FAMILY MANAGEMENT

Disability can be understood as the experience of a limitation in one's ability to do the things other people of the same age can do. The 2000 U.S. Census counted more than 41 million children and adults in the United States as chronically disabled. These individuals are limited by the way their bodies function, the way they are able to carry out activities, or in the way they are able to fulfill social roles and participate in life events. The medical model of disability highlights the importance of diseases and individual consequences. In contrast, the social model rejects the idea that disability is an individual characteristic and postulates that if the physical world was fully accessible and society's attitudes were accepting, the experience of disability would not exist. Most scholars, health professionals, and people with disabilities understand disability to be an interaction between the

individual and his or her environment. This biopsychosocial model of disability is used by the World Health Organization (WHO) and is the basis of their International Classification of Functioning. Because each person's and every family's experience with disability is unique, the biopsychosocial model of disability is an appropriate framework for understanding how families experience disability. This entry provides historical and current perspectives of disability and the family.

History

The number of people living with disabilities is on the rise. This situation can be attributed to major improvements in public health and medical treatment. The social history of disability has also changed over time. Up until the late 19th century, childhood disability was believed to be related to the sins of the parents. A disabled child was the burden to bear for breaking social and moral codes. Acquired disability later in life was thought to be the punishment for not leading a good and moral life. As medical science blossomed, the etiologies of the conditions associated with disability were described. Still, the stigma of disability was quite pronounced. Until the disability rights movement took hold in the mid to late 20th century, families were encouraged to institutionalize their children with disabilities. In general, individuals with disabilities were excluded from daily life and felt to be a burden on society. In recent decades, policies and social views about disability have shifted. There are now expressed goals and policies to foster community living and participation for all individuals with disabilities. The shift from institutionalization to community living has served to increase demands on families. Now essentially all children with disabilities are living with their families, and a majority of adults live with their families of origin or with spouses.

Family Functioning and Management

The ways in which families function after a baby is born with a disabling condition or someone in the family develops a disability vary considerably. Families report both positive and negative impacts of caring for a family member with a disability. Some of the typically identified positive impacts are improved self-esteem, resilience, and enhanced

advocacy skills. Some of the negative consequences include caregiver stress, loss of employment, financial burden, and social isolation. Many studies identify the added work of caring for someone with a disability. This work includes daily care and assistance; advocating for and arranging health, school, and community services; balancing the needs of the family; and planning for the long-term needs of the individual with the disability.

There are a multitude of factors that can contribute to how families function. Just as disability is understood as the interaction of the individual with his or her environment, the effects on families should be understood as the interaction of the family with factors in their environment. These factors can be conceptualized as occurring at the levels of the individual with the disability, the family, the community, and society. For example, at the level of the individual, the type and severity of the disability contribute to how families are affected. At the family level, a family's cohesiveness and stability affect how they are able to adapt and function with increased care needs. Research investigating the importance of community-based supports clearly indicates that access to community resources positively affects how families function by providing external sources of support. At the society level, laws, policies, and social acceptance all interact with families' experiences and contribute to how families provide care.

Families manage their lives in a variety of different ways. Dealing with stressful situations and unexpected events is a normal part of family life. For many families caring for a child or an adult with a disability, the dominant way of managing and understanding their lives is through a process of normalization. Families see their daily routines and experiences through a lens of normalcy and therefore engage in activities that are consistent with their assessment of themselves as normal. Families incorporate the extra caregiving activities into their lives and adapt to challenges as they arise. Kathleen Knafl and colleagues described five basic family management styles of families raising a child with chronic health problems: thriving, accommodating, enduring, struggling, and floundering. These patterns of family management reflect a continuum of difficulty. Families who are thriving or accommodating tend to see the world through a normalcy lens. On the other end of the

spectrum, families who are struggling or floundering tend to experience their situations as burdensome and tragic and identify them as such. In all cases, family management techniques may become more or less successful as situations and impacting factors change over time. Families also adjust and alter their management styles in response to various influences.

Families of children with disabilities want for their children to be as happy and healthy as possible. In addition, other family members should be able to enjoy life to the fullest. Participation in life events is a goal for children with disabilities and their families. Families should actively work toward balancing their lives to incorporate all aspects of life that help them to be successful, happy, and healthy. Families may need to get assistance from community agencies, mental health professionals, and support groups to optimize their situations. Some families may need financial assistance, whereas others might need respite care or emotional support. Needing extra help or assistance is common because raising a child with disabilities is often more complex and time-consuming than raising typically developing children. If a family is struggling, they should express their concerns to their physician, social worker, or community agency representative. Once a problem is identified, the family and health and community support agencies can work together to improve the situation. Identifying resources in the community can often offset some of the negative impacts associated with caring for a child with a disability.

Conclusion

Disability is a universal experience. How individuals and families function depends on a wide array of factors. Some of these factors are intrinsic to the individual with the disability and his or her family, whereas other factors are extrinsic. When working with families, it is important to remember that they are providing extraordinary amounts of care that make it possible for individuals with disabilities to live successfully at home. Providing services that address the needs of the individuals with disabilities and their families is essential to promote the well-being of families.

Amy Houtrow

See also Adult Child With Disability: Planning for by Parents; Adult With Disability Living at Home; Americans with Disabilities Act and the Family; Birth Defects and the Family; Caregiving: Adults With Developmental Disabilities; Community Resources for Families Related to Health; Coping Management Styles in Families; Families Experiencing Chronic Physical and Mental Health Conditions; Health Management in Families

Further Readings

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