

Introduction
Parents and Children, Children and Parents:
The Disability Context

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On March 22, 1998, it will 35 years that I have been the parent of a severely, profoundly retarded son. Prior to the birth of my youngest son, my understanding of disability was shaped by my paternal uncle who had polio as a child and used braces in order to walk and an adapted car in order to drive; by my two deaf second cousins who signed with what seemed like great emotion at family gatherings; and by my own congenital hip defect that caused surgery and a cast at a very early age and prevented me from full participation in at least the physical activities of childhood; by the illnesses and deaths of grandparents and by caring for my father prior to his death. I start with that in order to put the following discussion into perspective. As part of the life experience, I and most others, at some point in our lives, have participated in and observed the family dynamics when a family member is disabled. Disability is not an unknown to most of the population.

A discussion of parents and children from any perspective is a multi-faceted, multidimensional project. The relationship can be seen from the parent's experience, the child's experience, the experience of other immediate family or extended family observers, as well as the society's view which can include observations from various social institutions such as the church, the school, the neighborhood, the criminal justice system and so forth. An important mediator of the parent/child relationship is the age of the parent and the child. Frequently age and station in life influence the relative power and responsibility of the two members of the dyad, parent and child. While the parent is given control over and responsibility for an infant, roles change as we age and frequently children become the care givers and at times the custodians for aging parents. Disability of one of the parent/child dyad members, at any point in the life cycle, can impact that relationship, but is only one of the many factors that contribute to the dynamics of the relationship including gender, age, or personality of the individuals, and characteristics of the family, such as size, income, education and so forth. Much has been written about family relationships in a disability context. The purpose of this issue of DSQ is to provide an overview of the topic, reexamine the content of that research and to bring our focus to some of the policy issues and research questions that have direct relevance to the parent/child dyad in a disability context.

There are two things that stand out when I review just some of the literature that deals with the parent/child relationship or experience in the disability context. First, the work generally takes one perspective or the other, either the parent's or the child's. Very frequently that one-sided perspective is framed in terms of care giving (mostly by women) for the person with the disability, while the care receiver's perspective is less frequently investigated. Secondly, the literature is widely scattered. Gerontology literature looks primarily at care giving for the disabled elderly, while literature on developmental disabilities looks at parents of persons born with or acquiring a disability at an early age; and publications developed by persons with disability, such as *Disability Rag* (now named *The Ragged Edge*) and *Mouth*, reflect the perspective of the person with a disability. Concepts relevant in all three areas are not necessarily shared between or among these bodies of literature thus preventing an enrichment of all research that takes place on this subject.

Another thing I have noticed in the literature is that research on parents and children or children and parents in a disability context is sometimes an emotional exercise and often authors have difficulty separating analysis of research findings from the anger, emotional pain or political agendas of the population they are studying. Obviously first person reports by parents or children who report their lived experiences are richer for the emotion they bring to the telling of their stories. So this type of presentation will understandably reflect the emotion or pain of the situation. However, other types of research would do well to present a more balanced picture of the care giver/care receiver joint perspectives to improve our understanding of the parent/child relationship in the disability context.

Time and space does not allow for a review of parent/child, child/parent research, especially if one wanted to encompass the complete literature scattered across many disciplines. The variety extends from personal stories, such as those written by parents of children with developmental disabilities (Turnbull and Turnbull, 1985), to evaluations of territorial isolation as a parent's reaction to a disabled child (Weiss, 1997); from a feminist perspective that sees society as blaming the mother for all the things associated with their child's disability (Davis, 1987) to professionals' analysis of what parents of disabled children want (Westling, 1996). This is clearly a topic with many approaches, from many disciplines, with many ramifications for the individuals involved as well as for social policy development.

For this edition of *DSQ*, I have gathered three widely disparate articles that reflect a few of the facets of the literature on the parent/child relationship in the disability context. Gail Landsman's qualitative study examines the meaning of a disabled child and motherhood in a society which has come to view being a mother as an achieved status and procreation as production. Dr. Landsman adroitly captures the scientific perspective created by the new reproductive technologies which prescribe the

choices along the path to a "perfect product." She then examines the experiences of mothers whose outcomes are different than the innocent expectations the scientific method promised, and raises questions about how the child's problems may influence the mother's interpretation of her child and her role as mother. Her work is a sensitive examination of the development of mother/child bonding in the social cultural context of disability in America.

A second paper, written by April Barclay, looks at parents with a mental illness, and explores the effect of a disability of this kind on the developmental years of a child's life. Her work raises questions about the issues of the parent/child relationship when the parent with control and responsibility may not be able to play the ideal parent role (a reverse of the experience described in the Landsman piece). The last paper is a summary of a published report, from Berkley Planning Associates, that presents the findings from a survey of parents with disabilities. The survey, which includes responses from 1175 parents, examines the unique and ordinary needs parents with disabilities have when trying to raise children. This paper gives us insight into the types of programs and equipment, that if made available to parents with disabilities, could improve their capacity to raise and care for their children as other parents without disabilities are able to do.

In closing, I would propose that while there is an extensive multidisciplinary literature available that explores the parent/child relationship in a disability context, this continues to be a fundamental area of research. New attitudes toward independent living, new legal rights provided by the ADA, and new forms of support for care givers change the nature of the social context in which the parent/child relationship is taking place and provide meaningful issues for examination. However, I would also propose that attention to the effects and outcomes to both parties of the relationship along with cross fertilization between and among disciplines is necessary for this research to advance.

References

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