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Impact of Child Disability on the Family

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Abstract

Families with disabled children represent a sizeable share of all American households. Living with a disabled child can have profound effects on the entire family, which in turn can affect the health and well-being of the child who is disabled. A small but growing literature has studied these effects at the population level, but much more needs to be learned about how children's health affects their parents, siblings, and other family members and about how resources modify those associations. Numerous programs and organizations provide resources for disabled children and their families, but the system is extremely fragmented and difficult to navigate. This commentary reviews what is known about the effects of child disability on the family, provides an overview of the complex needs of and multitude of resources available to families of disabled children, and concludes with suggested directions for practice, research, and public policy.

Keywords

child disability; family

Numerous forces have come together to increase the rates of families living with disabled children. Advances in neonatal care technology have dramatically increased the survival rates of very low birthweight infants and infants with severe birth defects who are at high risk for long-term health problems or cognitive deficits. Diagnoses of autism and attention deficit disorders have multiplied. De-institutionalization, the Americans With Disabilities Act, the Individuals with Disabilities Education Act, and improvements in assistive technology have resulted in greater proportions of disabled and chronically ill children being mainstreamed--that is, living at home and attending school. For some or all of these potential reasons and perhaps for others, families with disabled children now represent a sizeable share of all American households.

The number of disabled children in the United States is an extremely difficult figure to ascertain due to definitional ambiguities and because adequate data by which to derive estimates are sorely lacking. The terms "chronic illness," "disability," and "chronic condition" tend to be used interchangeably and are often proxied by measures of activity limitations. Disability can be defined broadly, to include most types of physical,

developmental, and emotional disorders, or it can be defined more narrowly in terms of specific conditions and degrees of severity. Because a national health information database does not exist for the U.S., estimates of the prevalence of and changes in rates of disabled persons are generally based on survey data. Estimates are therefore subject to potential biases stemming from non-response, limitations and changes in question wording, and respondent reporting. Regardless of data source, trend analyses are subject to confounding by changing patterns in diagnosis.

Based on the best U.S. data sources currently available, disability rates of non-institutionalized children have at least doubled since 1960. Thus, regardless of the exact definition or magnitude, it is clear that disabled children constitute a sizeable fraction of all children (between 6% and 18%, depending on the definition and data source), and that a large and growing number of families now include children with some type of disability.¹

Implications for the Family

Living with a disabled child can have profound effects on the entire family—parents, siblings, and extended family members. It is a unique shared experience for families and can affect all aspects of family functioning. On the positive side, it can broaden horizons, increase family members' awareness of their inner strength, enhance family cohesion, and encourage connections to community groups or religious institutions. On the negative side, the time and financial costs, physical and emotional demands, and logistical complexities associated with raising a disabled child can have far-reaching effects as we describe below. The impacts will likely depend on the type of condition and severity, as well as the physical, emotional, and financial wherewithal of the family and the resources that are available to them.

For parents, having a disabled child may increase stress, take a toll on mental and physical health, make it difficult to find appropriate and affordable child care, and affect decisions about work, education/training, having additional children, and relying on public support. It may be associated with guilt, blame, or reduced self-esteem. It may divert attention from other aspects of family functioning. The out-of-pocket costs of medical care and other services may be enormous. All of these potential effects could have repercussions for the quality of the relationship between the parents, their living arrangements, and future relationships and family structure. Having a disabled child may also affect parents' allocation of time and financial resources to their healthy and unhealthy children, their parenting practices, their expectations of healthy siblings in terms of achievement, responsibility, and short- and long-term contributions to the household, and the siblings' health and development. Finally, having a disabled child in the family may affect the contributions of time and financial resources on the part of the child's grandparents or other extended family members, the relationships of those individuals to the core family, and the financial, physical, and emotional wellbeing of those family members. All of these potential effects on families have implications for the health and well-being of disabled children.

Surprisingly little is known at the population level about the ripple effects of child disability on the family. Studies in the psychology literature indicate that a number of specific child

health conditions are associated with poor mental health outcomes of parents and siblings, but empirical research on the impacts of child disability on resources, hardship, and physical health of family members is scant. Studies indicate that having an infant in poor health increases the likelihood that parents divorce^{2,3,4} or live apart;^{4,5} that the mother does not work outside of the home;^{6,7} and that the mother relies on public assistance.⁸ It also leads to a reduction in the father's work hours.⁹ Another study found that parents with disabled children have lower rates of social participation than parents without a disabled child and that they are less likely to have large families.¹⁰

A recent meta-analysis indicates that peer activities and cognitive development scores are lower for siblings of children with a chronic illness compared to controls.¹¹ Virtually nothing is known about siblings' long-term economic, demographic, and physical health outcomes. Another potentially important but under-explored area is how child disability affects the wellbeing of grandparents and other extended family members and how the responses of those individuals to having a disabled child in the family affect the child's parents.¹² A third crucial gap involves the extent to which resources modify the effects of children's health status on families. A recent study found that low socioeconomic status and maternal depression increase the negative financial impacts and caregiving burdens associating with raising an extremely low birthweight infant.¹³ Overall, much more needs to be learned about how children's health affects their parents, siblings, grandparents, and extended family members.

Resource needs

Most children grow up, leave the household, and become independent. For some disabled children, however, care may be life long—extending in some cases beyond the parents' death. Even when a disabled child is able to transition to independence soon after reaching adulthood, enormous resources may be required to get to that point. On top of the competing demands of raising their other children, holding down jobs, and sometimes even caring for their own aging parents, adults raising a disabled child can face a host of daunting challenges.

The most obvious resource needs involve health care. Disabled children require not only high quality primary care, but they often require multifaceted specialized care on a long-term basis. Ideally, children with complicated cases will have a team of specialists who work together in a coordinated fashion. If the condition is rare or difficult to diagnose, the family may need to consult specialists on a regional or national level. Even routine transportation may become a problem when the child has mobility issues, especially for poor or inner-city families who rely on public transportation. The family's dwelling may be inadequate to accommodate the child's physical limitations and expensive modifications may be necessary.

Disabled children often have complex educational and child care needs as well as unique recreational and social needs. They may need early intervention programs for physical, developmental, and/or emotional rehabilitation. Later, specialized education programs or facilities may be needed. Into the teen years and adulthood, transition programs and

specialized job training can help many disabled individuals become independent, although supported employment on an ongoing basis may be necessary. Specialized child care is often needed, as are appropriate recreational and social activities for the disabled child.

Resource availability

The good news for families is that there are numerous programs and organizations that provide resources that their children need. Medical care may be financed by private insurance companies, Medicaid or the State Children's Health Insurance Program when the family is eligible, state Medicaid waiver programs for specific types of disabilities, state programs for children's catastrophic illness, state and local departments of disability, and charitable organizations and programs at various levels of government that provide assistance for medication, medical or assistive devices, home modifications, or services such as physical, occupational, and speech therapy. General financial or in-kind assistance may be available from the Supplemental Security Income program or from need-based programs such as Temporary Assistance to Needy Families, the federal Food Stamps program, public housing, and the Supplemental Nutrition Program for Women, Infants, and Children. Programs such as the Special Olympics and the Ronald McDonald summer camp provide opportunities for children with special needs to get exercise and socialize. Resources that help family members directly include respite care, counseling, parent and sibling groups, and support groups surrounding specific types of diagnoses, as well as national clearinghouses (often provided by foundations focusing on specific diseases) for information about available resources.

The Individuals with Disabilities Education Act (IDEA) requires states to implement early intervention programs that provide therapeutic, educational, and case management services from infancy through age 2 for children with, or at risk for, developmental delays. These can be administered by state departments of education, health, or human services. It also requires school districts to provide handicapped preschool programs beginning at age 3 and a free and appropriate education in the "least restrictive environment" when the child reaches school age (parents and school districts may not always agree about what such an environment would entail)¹⁴. School districts vary in the quality of services they offer to disabled children, and it is all too common to hear of families relocating, when they are able, to areas with school districts that offer better services for their children. Head Start, a completely separate program under the Department of Health and Human Services, provides grants to local public and private agencies to provide early intervention and preschool programs for children age 0 to 5 years and some additional services for participants and their families. The goal of Head Start is to increase the school readiness of disadvantaged children, broadly defined to include children with disabilities.¹⁵ However, the services discontinue after age 5 and are not necessarily coordinated with the services that states and school districts are required to provide under IDEA.

The bad news is that in trying to address the often complex needs of their disabled children, parents must interact with and coordinate benefits from a variety of disjointed public and private institutions. This represents a challenge under the best of circumstances, but can be particularly onerous while also caring for a disabled child. The availability and generosity

of assistance can vary greatly from one locale to another and over time. There is no single source of information on the resources available for disabled children, who represent a heterogeneous group—with different ages, conditions, and degrees of impairment. Families of children without definitive diagnoses may need the most help negotiating the system, since it is rarely clear that their children qualify for particular programs and the burden of proof often falls upon them. For each program or service, parents need to be aware of its existence, go through a program-specific application process, sometimes re-apply for services or benefits annually, and often have to wait months or years to be offered services, at which time their children may be too old to receive the services. Programs are not always implemented as intended. Family support services are generally available on an ad hoc basis.

Successfully navigating the idiosyncratic and shifting landscape of disability benefits requires parents to be proactive and enterprising or to have the means and awareness to hire a child disability lawyer or consultant. Anecdotes of families' difficulties abound. A poignant example is that of a professional couple who assumed care for the wife's adult disabled brother after the siblings' mother died. These two highly educated individuals, both in health-related professions, describe the administrative hurdles, redundancies, inconsistencies, and frustrations they experienced when relocating the brother from one state to another and trying to secure needed services.¹⁶

Three recent legislative changes may have created additional obstacles for families with disabled children, particularly those who are poor: The Personal Responsibility and Work Opportunity Reconciliation Act of 1996, which dramatically restricted eligibility for cash assistance by establishing time limits on the receipt of welfare, expanding work requirements for those receiving welfare, and allowing states to impose stricter sanctions for non-compliance with work requirements or other guidelines; the No Child Left Behind (NCLB) legislation of 2001, which requires states to implement statewide standards in reading and mathematics, annual testing for students in grades 3–8, and accountability systems to ensure that students reach proficiency within 12 years; and the Deficit Reduction Act of 2006, which makes U.S.-born children of illegal immigrants no longer automatically entitled to health insurance through Medicaid. NCLB, while well-intentioned, may result in a shift in focus from children's individualized goals (under IDEA) to preparing for the standardized test, a shift in resources away from the most cognitively impaired children (school districts are penalized for poor test performance of non- and moderately-disabled children, but not those who are severely cognitively impaired), or divert resources from preschool and outreach programs in order to achieve test score goals.

Moving forward

More attention to the plight of families with disabled children is clearly warranted—in clinical practice, in research, and in the policy arena. The general message for clinicians is to be aware of the complex needs of families with disabled children, which start from the moment they receive a diagnosis or impairment is suspected. Skotko¹⁷ offers specific recommendations on how to deliver the diagnosis of Down Syndrome in a sensitive and balanced fashion that may apply to disabilities more generally. Another recent study found that children with special health care needs have lower access to health services because

their parents do not recognize the need for those services.¹⁸ Clinicians should inform parents that their children will need a range of services and that the system may be extremely difficult to navigate. Whenever possible, they should provide referrals to local support and advocacy groups, national organizations focusing on specific conditions, and websites such as those of the National Dissemination Center for Children with Disabilities¹⁹ and the Parent Advocacy Coalition for Educational Rights²⁰ that provide comprehensive listings of services.

In terms of research, a consensus needs to be reached on how to label, define, and measure child disability, and better data are needed to study the effects of child disability on health, economic, and demographic outcomes of parents, siblings, and grandparents. The ideal would be a national longitudinal multigenerational health database with detailed economic and demographic data, ample sibling information, and rich data on service use. Additional high quality studies using existing data are needed as well.

The implication for public policy is that the only way to equitably and efficiently provide services to disabled children and their families may be through a national coordinating system. The Social Security Advisory Board, in a recent report focusing primarily on education and employment, acknowledges the glaring deficiencies of the current patchwork system of supports for disabled children and urges for a coordinated and purposeful approach, with case managers and “life progression plans.”²¹ The UK, which has a child disability rate on par with that in the U.S., recently established a new Office for Disability Issues and a major initiative to integrate services in order to better meet the needs of disabled individuals. One of the four key areas is improving support for families with young disabled children that are “centered on disabled children and their families, not on processes and funding streams (p. 7),” with key workers, or case managers, as an integral component.²² This type of system has the potential to substantially improve the lives of disabled children and their families while more efficiently and equitably allocating resources.

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