

At a time when the nation's resources for addressing social needs are increasingly constrained, unprecedented numbers of U.S. children are being identified as having special medical and educational needs. This issue of *The Future of Children* explores childhood disability—its prevalence, nature, treatment, and consequences.

Although discussions of childhood disability tend to emphasize particular causes of disability, such as autism, asthma, or cystic fibrosis, this volume focuses not on individual disabilities, but on cross-cutting themes that apply more broadly to the issue of children with disabilities. Contributors to the volume review research on childhood disability, including its definition, its prevalence and trends over time, and the costs that disability imposes both on the individual child and on the child's family. They consider disability within the context of the nation's educational, health insurance, and medical systems and examine the impact of emerging technologies on the experience of disability.

Themes of the Research

Out of the research presented in this volume, five themes emerge. The themes are related to defining and measuring disability, trends in disability, the increasing incidence of mental health disabilities, the role of families in managing disability services, and the fragmented nature of those services.

***Pointing to a consensus definition of disability is remarkably difficult. One reason for the lack of consensus is that disability is often defined simply by the presence or absence of specific health conditions. The opening article of the issue makes the case for a more wide-ranging definition that stresses the relationship between health, functioning, and the environment.

***Although the estimated prevalence of childhood disability has increased dramatically over the past few decades, the inability of researchers to arrive at a consensus definition complicates efforts to track trends in disability and understand the meaning of the recent increase. A major research goal is to assemble reliable data about incidence of childhood disability.

***Over the past several decades, the incidence of disability and its underlying health conditions has shifted away from physical disorders toward mental health disorders. In the past few years, the top five limiting conditions of children have been behavioral or developmental. Childhood mental health disorders can be even more problematic than physical disabilities in terms of adult health, years of schooling, employment, marital status, and family income. And even as mental health disorders make up a growing share of children's disabilities, the growth in services for these children has not kept pace.

***Childhood disability poses major costs for families as well as for children. The medical costs of disability to families, which can depend heavily on the type of health insurance available to them, are dwarfed by the indirect costs in terms of lost work time (especially for mothers) and the indirect costs to the children themselves in terms of lost productivity. Moreover, these personal costs translate into costs to society as a whole in terms of lower tax revenues and higher outlays for social programs. Families are important advocates for children, often serving as the only effective coordinators of care. But some families are less able than others to take on this role.

***Services for children with disabilities are fragmented. Service systems that are set up to deal with medical problems are not coordinated with services at schools. Researchers have conducted far too few rigorous evaluations of the effect of special education programs on children’s educational prospects and trajectories. Many children with disabilities have only episodic health insurance coverage even though most who lack insurance are actually eligible for Medicaid or CHIP.

Research and Policy Recommendations

The five themes of the volume lead naturally to recommendations for researchers and for policy makers.

***First, researchers must focus attention on developing workable definitions of disability that can be implemented in national surveys and maintained over time. Only in this way can they interpret accurately the rising numbers of disabilities among children. But regardless of why the number of special needs children is growing, policy makers should be mindful that many children must live with a diagnosed disability. These children merit attention.

***Second, both researchers and policy makers must be aware of, and respond aggressively to, the shift in the nature of childhood disability from problems that are physical in nature to those that involve a mental health disorder—one that often has more severe consequences than many physical health conditions.

***Third, the fragmented nature of services for children with disabilities places a tremendous burden not only on children but also on their families, and those families struggle at great cost to fill the gaps. Any policy measure that effectively increases coordination between the home, the doctor’s office (or offices), and the school would tremendously improve the lives of children with disabilities, as well as their families.

***Fourth, one problem highlighted by this review is a relative lack of attention in the research to the special problems of minority and low socioeconomic status children with disabilities. As one example, as technology enhances the ability of medical professionals to improve health outcomes, access to technology becomes more important. Health outcomes may improve for those who can afford the technology, but not for others. Unless access to technology is provided equitably, technology could expand disparities in outcomes for children with disabilities rather than reduce them.

***Finally, in this time of budget shortfalls, it is important to keep in mind that even given the large run-up in the number of children with diagnosed disabilities, medical care for children with disabilities still accounts for only about a nickel of every dollar of health care costs as a whole. As a society, our concern with the increasing prevalence of disability should not be primarily about reducing the medical costs of treating disability, but about improving the quality of life for children and their families.



The Future of Children is a collaboration of the Woodrow Wilson School of Public and International Affairs at Princeton University and the Brookings Institution. For more information on *The Future of Children* please visit: www.futureofchildren.org.