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# Children with Disabilities: Introducing the Issue

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*Janet Currie and Robert Kahn*

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This issue of *The Future of Children* explores childhood disability—its prevalence, nature, treatment, and consequences. With unprecedented numbers of U.S. children now being identified as having special medical and educational needs and with the nation’s resources for addressing those needs increasingly constrained, the topic is timely.

Public discussion of childhood disability, by the media, parents, scholars, and advocates alike, tends to emphasize particular causes of disability, such as autism, asthma, cystic fibrosis, or attention-deficit/hyperactivity disorder (ADHD). In this volume, however, we focus not on individual disabilities, but rather on cross-cutting themes that apply more broadly to the issue of children with disabilities.

To this end, we commissioned a group of experts to review research on childhood disability, including its definition (itself a challenge), its prevalence and trends over time (likewise), and the costs it imposes both on the individual child and on the child’s family. Our contributors also consider disability within the context of the nation’s educational, health insurance, and medical systems; the impact of emerging technologies on the experience of disability; and the definition of

health care quality. The volume concludes with a discussion of the prevention of childhood disability.

## **Themes of the Volume**

Out of the research presented in this volume, five broad themes emerge. These themes are related to defining and measuring disability; trends in disability; the growing importance of mental relative to physical health; the importance of families; and the fragmentation of services for children with disabilities.

## **Defining Disability and Other Measurement Issues**

First, it is remarkably difficult to point to a consensus definition of disability. In the opening article of the issue Neal Halfon and Kandyce Larson, both of the University of California–Los Angeles, and Paul Newacheck and Amy Houtrow, both of the University of California–San Francisco, make the case for a definition that highlights the relationship between health, functioning, and the environment. Specifically, the authors propose that a disability be defined as “an environmentally contextualized health-related limitation in a child’s existing or emergent capacity to perform developmentally appropriate activities and participate, as desired, in society.”

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Defining disability as a limitation rather than a health condition per se highlights the social and technological context of the individual. In a world with electric wheelchairs, for example, a child with impaired mobility will be less disabled than he or she would be otherwise. It follows then that home and school environments can shape disability and that new technologies can either mitigate or exacerbate disability, as Paul Wise, of Stanford University, discusses in his article on the role of technology. The definition proposed by Halfon, Houtrow, Larson, and Newacheck also emphasizes that disability exists along a continuum and varies across children's ages and functional domains.

Until now empirical work on the prevalence of childhood disability has been based on a variety of simpler and more concrete definitions. National surveys that collect information about childhood disabilities, for example, generally ask questions about limitations on activities of daily living; they also usually classify children as disabled if they are receiving services for their limitations. Although the logic behind this latter definition is apparent, it can mean that the number of children counted as having disabilities may expand or contract along with the provision of services. In a similarly problematic way, expanding the number of children with disabilities who are covered by insurance may increase the number of children who have been diagnosed with a particular condition without actually changing the number who suffer from the condition. Many studies reviewed by contributors to this volume, such as those discussed in the articles by Liam Delaney, of University College Dublin, and James P. Smith, of RAND, and by Mark Stabile and Sara Allin, both of the University of Toronto, take into account only the presence or absence of specific health conditions, making that alone

the measure of disability. Research based on historical data (which analysts use to examine disability over the life course) consists almost entirely of information about the presence or absence of specific conditions. Clearly, there is little uniformity across time periods or studies in the definition of disability.

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Beyond the challenge of defining and measuring disability, many of the articles in the volume highlight ancillary measurement issues. For example, Peter Szilagyi, of the University of Rochester, addresses the challenge of comparing how well different children with disabilities are covered by insurance given the tremendous variation in types of insurance policies available. Typically, a researcher exploring insurance and children with disability knows whether an insurance plan is private or public and perhaps whether it involves "managed care." But such a crude characterization reveals little about what it is the plan actually covers.

James Perrin, of Harvard Medical School and Massachusetts General Hospital, highlights the need for improved measures of the quality of medical care. His concerns dovetail with those of Halfon, Houtrow, Larson, and Newacheck in that he emphasizes that quality measures should focus on improvements in a child's functioning and outcomes rather

than on physiological measures or processes of care alone. He argues that collaboration across medical sites that treat children for similar conditions can improve the measurement of the quality of care (by, for example, pooling data to yield larger sample sizes) and ultimately the quality of care itself.

### **How Big Is the Increase in Childhood Disability?**

Although differences in definitions and measures may seem arcane, they directly impinge on researchers' ability to address one of the most controversial issues in the field of childhood disability studies—the huge increase in recent years in the number of children who are considered to have a disability. The measured prevalence of disability for children under age eighteen in the National Health Interview Surveys (NHIS) doubled from 3.8 percent in 1981 to 8.0 percent in 2009. Over the past half century, the estimated prevalence of measured childhood activity limitations has increased fourfold.

What to make of this remarkable rise is a second theme of this volume. The sensitivity of these numbers to the way disability is defined is clear from the quite different estimates contained in other surveys. For example, the National Survey of Child Health (NSCH) classifies only 4.3 percent of children as disabled. The NSCH focuses strictly on limitations relative to other children of similar age; its classification system is not based on medical care, activities of daily living, or receipt of special education services. So, for example, the NSCH would not count as disabled children whose well-controlled asthma does not limit their daily activity. By contrast, the NHIS classifies children as disabled if they receive special education services. The higher NHIS numbers may thus be attributable not only to increases in the prevalence of

disabilities among children but to increases in the numbers and shares of children receiving special education services over the past four decades (see the article by Laudan Aron, of the National Research Council, and Pamela Loprest, of the Urban Institute).

In sum, researchers' efforts to track trends in disability and understand the meaning of the recent increase in numbers have been seriously complicated by changes over time in definitions of disability, in screening for disability, in services for disability, and in the extent to which particular conditions are considered to be actually disabling. Several researchers whose work is highlighted here see an increasing epidemic of childhood disability that may stem from factors such as increasing exposure to dangerous chemicals (see the article by Stephen Rauch and Bruce Lanphear, both of the Child and Family Research Institute in Vancouver). Children today, for example, are exposed to many widely used chemicals, such as pesticides and phthalates, which are found in our diet and are thought to be linked with neurological disorders and disruption of the endocrine system. Indeed, most Americans have metabolites of pesticides and phthalates, as well as of DDT and PCBs, in their blood or urine. These researchers argue that chemicals may interact in synergistic ways to create disease and that by the time medical researchers definitively know the mechanisms by which the chemicals do their damage, many children may have been harmed. Other researchers whose work is reviewed in these pages point to the tremendous reduction in infant and child mortality over time, the immunization-linked decrease in the incidence of many disabling diseases, and the reductions in childhood exposure to air pollution, smoking, and lead, and wonder why these improvements are not reflected in disability statistics. The

rise of morbid obesity among children also suggests that new disabling conditions can arise over time.

In the absence of consistently collected statistics about the incidence of childhood disability over time, it is difficult to resolve the controversy over how much of the increase in disability reflects changes in the underlying incidence of disabling conditions. Careful research on some specific conditions, such as autism and asthma, does suggest increasing incidence. What this controversy over a fundamental fact about disability highlights is the need for researchers to arrive at a consistent definition of childhood disability so that they can accurately track trends over time.

### **Mental Health Issues**

A third theme that permeates the volume is the growing role of mental health issues in 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 2008–09, the top five limiting conditions of children were behavioral or developmental. More than one in five parents reporting a child with a disability cited ADHD as an underlying condition; another 19 percent cited other mental, emotional, or behavioral problems. Today ADHD is almost three times more likely than asthma to contribute to childhood disability.

Moreover, both the Delaney and Smith and the Stabile and Allin articles highlight the significant lifetime costs of mental health disorders for children. In fact, mental health disorders in childhood generally have larger impacts than childhood physical health problems in terms of adult health, years of schooling, participation in the labor force, marital

status, and family income. Aron and Loprest document the high prevalence of childhood mental illness and neurodevelopmental disorders in educational settings. For example, autism affects 6 percent of all special education students, up from 2 percent over the past decade. Emotional disturbances affect 6 percent of special education students as well.

### **The Importance of Families**

A fourth theme highlighted in this volume concerns the fact that children live in families. Childhood disability poses major costs for families as well as for the children themselves. If we take a broad definition of disability, then the way that children are able to function within their families should be considered a key indicator of the extent to which any particular health problem results in disability. Moreover, families are important advocates for children, often serving as the only effective coordinators of care.

Four articles in the issue address the role of the family in some detail. Mark Stabile and Sara Allin lay out a framework for measuring the economic costs to families and children; they consider medical costs, indirect costs to families in terms of lost work time (especially for mothers), and costs in terms of losses to the child's future productivity. (They do not take into account the costs paid by private insurance or the cost of decreased well-being of families.) Liam Delaney and James Smith consider U.S. data from the Panel Study of Income Dynamics that track children and families over time and allow researchers to measure the impact of childhood disability on adult outcomes and show that the consequences can be profound. Peter Szilagyi points out that the costs to families often depends on the type of health insurance available to them. Insured children with disabilities are more likely than uninsured

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children to have a usual source of care and to get necessary care. Such care may or may not lower costs, but is likely to improve the child's, and hence the family's, functioning.

James Perrin argues that assessments of quality of care need to consider disability, as well as the impact of interventions on children's functioning, in the context of their families. He stresses going beyond the purely "medical home" model of coordinated care that is often cited as an ideal in discussions of the quality of care to include the child's family home as well.

Another recurring theme is the importance of family advocacy for children with disabilities. Very often it is the family that coordinates care for the child and ensures that medical practitioners consider the child's functioning in various contexts. Thus, children with effective family advocates receive care that is likely to be of significantly higher quality than children whose families are less able to take on this role.

### **The Fragmentation of Disability Services**

The fifth theme is the fragmentation of services for children with disabilities. One

indication of the severity of the problem is that even as mental disabilities make up a growing share of children's disabilities, a disproportionate share of services for the disabled is still targeted at physical disabilities. Likewise, systems set up to deal with medical problems such as clinics for children with disabilities, or public insurance programs, are not coordinated with services at schools. And as the article by Laudan Aron and Pamela Loprest shows, even within the educational system itself many services are delivered in isolation from or even at cross purposes with each other. For example, children receiving services for disabilities funded by special education before entering formal schooling are not automatically connected to special education services once in school. Nor are services for high school students with disabilities linked with supportive services for adults with disabilities. High schools are required to deliver services designed to help students transition to adulthood, but no one has the responsibility to track children as they go out into the community and assess whether these services are effective.

One reason that health services for children with disabilities are delivered in a fragmented manner is that many children have only episodic health insurance coverage. Ironically, most children with disabilities who lack insurance are actually eligible for Medicaid or the Child Health Insurance Program (CHIP). Hence, as Szilagyi argues, the fact that the majority of uninsured children are actually eligible for either Medicaid or CHIP only emphasizes that universal coverage for all children would actually be an incremental step to more efficiently use the health care system, and not a major overhaul of the health care system. Szilagyi also supports searching for and enrolling more eligible children through enhanced outreach, as well as the concept of

the medical home (to be used to integrate services, but broadened to include the family, as Perrin emphasizes). Broadening the concept of the medical home in this way would help to connect medical services to support services for families of children with disabilities and recognize the key role of families in the coordination of care.

## Findings of the Issue

At this point a few comments about the individual articles are in order.

### The Changing Landscape of Disability in Childhood

In addition to offering a new and forward-looking definition of childhood disability, Neal Halfon, Amy Houtrow, Kandyce Larson, and Paul Newacheck devote serious attention to documenting and interpreting trends in disability. They note that Americans' perceptions of childhood disability have changed dramatically over the past century and that demands and expectations for child functioning have also changed. The authors explore the ways in which all these changes have influenced the risk of poor health and disability and how policies focused on addressing the needs of children with disabilities have evolved over the recent past. They stress the importance of (but lack of progress in) reducing socioeconomic disparities in disability prevalence.

### Disability and Health Trajectories over the Life Course

Liam Delaney and James P. Smith compare the lifetime trajectories of individuals with and without disabilities. Because addressing this question requires tracking individuals over time, they devote considerable attention to new retrospective data on a large sample of children and their siblings, which can be used to examine the effects of childhood health conditions on future outcomes. They also

note that researchers examining past disability have no choice but to focus on specific conditions in the absence of conceptual definitions along the lines of those proposed in the first article.

Delaney and Smith explore the complex relationship between childhood health and the socioeconomics of adulthood, focusing especially on the long-term effects of mental health problems in childhood. They also examine evidence regarding the efficacy of early mental health treatment for children in terms of promoting good health later in life.

### Economic Costs of Childhood Disability

Mark Stabile and Sara Allin provide a comprehensive overview of the literature on the economic costs of disability, together with a conceptual framework to organize their review. The most striking finding of their article is that the medical costs of disability are dwarfed by the costs to families and to the children themselves in terms of things like 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.

The authors examine evidence about three kinds of costs—direct, out-of-pocket costs incurred as a result of the child's disability; indirect costs, often involving employment, incurred by the family as it decides how best to cope with the disability; and long-term costs associated with the child's future economic performance. These negative effects appear to be much greater, on average, for children with mental health problems than for those with physical disabilities.

### Disability and the Education System

In their overview of the treatment of childhood disability within the educational system,

Laudan Aron and Pamela Loprest document a dramatic shift from exclusion to inclusion in U.S. law governing the education of children with disabilities. Before passage in 1975 of the Individuals with Disabilities Education Act (IDEA), only one in five children with identified disabilities attended public schools. Of the 3.5 million such children who did attend school, many received little or no effective instruction. By the 2004–05 school year, almost 7 million children were receiving special education services through IDEA.

The special education system has provided not only far better access to public education for students with disabilities, but also an established infrastructure for educating children with disabilities, earlier identification of disabilities in children, and greater inclusion of these children in classrooms with peers without disabilities. Concerns remain, however. Certain groups—African Americans, in particular—may be over-represented among children identified as having disabilities. Special education students still lag behind their nondisabled peers in educational achievements, are often held to lower expectations, are less likely to take the full academic curriculum in high school, and are more likely to drop out of school. And researchers have conducted far too few rigorous evaluations of the impact of special education programs on children’s educational prospects and trajectories.

### **Disability and Health Insurance**

In his survey of how health insurance, or the lack of it, shapes the lives of children with disabilities, Peter Szilagyi concludes, not surprisingly, that children with disabilities fare far better when they are insured. By one estimate, nearly two of every five special needs children are either uninsured or inadequately insured. Compared with these children,

those with insurance are more likely to have a primary care provider, to be able to reach a specialist, and to have access to supporting services. They also have fewer unmet medical and oral health care needs and receive care more quickly.

Szilagyi compares benefits provided by private insurance and by public insurance (such as Medicaid) and finds that although public plans offer more comprehensive benefits for special needs children, their lower reimbursement rate tends to make some providers reluctant to take on these patients. He stresses the urgency of providing adequate health insurance to all children with disabilities and of developing a set of best practices in health insurance to cover important services needed by this population.

### **Disability and Health Care Quality**

James Perrin provides an overview of the research on disability and health care quality. He offers an especially informative discussion of the way in which health care quality has been improved through the collaboration of specialized medical settings focusing on specific diseases such as cystic fibrosis. The numbers of patients being treated in any particular medical setting are often too small for practitioners to be able to judge whether a new treatment is effective. Pooling information over a broad network makes it possible for them both to understand more rapidly whether a treatment is working and to make the treatment available to more patients. The most successful networks have focused on improving a child’s functionality, which gives them a clear goal and a metric for judging success.

### **Emerging Technologies and Their Impact on Disability**

Paul Wise examines the relationship between technology and childhood disability. He



shows how technological change has transformed the nature and functional impacts of child disability, as well as the scale of social disparities in child disability. He discusses the impact of preventive and therapeutic interventions on disability in childhood, access to emerging technologies, and the relationship between technical innovation and the social determinants of health in shaping patterns of child disability.

Technology, says Wise, can reduce or widen social disparities in health care for children with disabilities. 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 will likely expand disparities in child outcomes rather than reduce them.

### Prevention of Disability

The final article, by Stephen Rauch and Bruce Lanphear, focuses on preventing disability. The heart of their argument is that societal choices can shift the curve of child health outcomes to increase the probability that some children will be moved from a nondisabled to a disabled state. Exposure to chemicals in the environment, for example, may decrease the attentiveness of all children, but in a subset of more vulnerable children, the exposure may lead to symptoms and impairment that warrant an ADHD diagnosis. The implication is that society should pay attention to shifting the entire distribution of health outcomes in a positive direction and that doing so will reduce the toll of childhood disability. Such a public health focus on prevention is a useful complement to the usual medical focus on improving technology or the quality of medical care for children who already have disabilities.

## Research and Policy Recommendations

The five themes of the volume that we have highlighted lead naturally to recommendations for researchers and for policy makers. Most important, researchers must pay attention to how disability is defined and develop workable definitions that can be implemented in national surveys and maintained over time. Only in this way can they learn whether the increasing numbers of children with disabilities represent an exploding epidemic or an emerging, more nuanced understanding of what it means to be disabled. (For information on key data sets for children with disabilities and on selected federal programs serving these children, please go to [www.futureofchildren.org/futureofchildren/publications/journals](http://www.futureofchildren.org/futureofchildren/publications/journals). Then click on volume 22, number 1 (2012), and look for Appendixes 1 and 2.)

Second, although understanding trends in disability is scientifically important and helpful in terms of identifying causes of disability, policy makers should be mindful that whether or not the number of special needs children is growing, large numbers of children must live with a diagnosed disability. These children merit attention.

Third, both researchers and policy makers must be aware of, and respond aggressively to, the change in the nature of childhood disability in recent years. Several decades ago the problems that most children with disabilities confronted were physical in nature. Today childhood disability more often involves a mental health disorder—one that often has more severe consequences than many physical health conditions. A key goal for society today is to devote resources to preventing, diagnosing, and managing these conditions to improve children's functioning and trajectories.

Fourth, the fragmented nature of services for children with disabilities places a tremendous burden not only on the children but also on their families, who struggle at great cost to fill the gaps. The concept of a medical home that coordinates care is a useful starting point for policy makers (though far from a reality for many children with disabilities), but it must be expanded to include families and educators as well. Our view is that 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 the lives of their families. Moreover, the different programs and services available to children with disabilities must be evaluated to determine whether they effectively promote children's functioning.

In conclusion, both researchers and policy makers must pay more attention to children with disabilities who are also socially disadvantaged because of poverty or discrimination. It is important to know whether these children are being adequately served by the available programs, and whether their outcomes differ from those of other children with disabilities.

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. Although poor and minority children are more likely than other children to have

disabilities, as emphasized in the opening article by Halfon, Houtrow, Larson, and Newacheck, most research on disparities highlights differences in access to care, but does not go further to consider possible differential impacts of disability on children of different backgrounds. The possibility that minority and low socioeconomic status children with disabilities are at "double jeopardy"—both more likely to have disabilities, and more likely to suffer from a given disability, is one that merits more attention. Similarly it would be useful to look further at whether health care quality improvements for children with disabilities affect minority or disadvantaged children differently than other children (for example, these children might be less likely to receive the latest treatments and might have more difficulty gaining access to specialists to treat them). The article by Wise emphasizes new technology's capacity both to expand and to reduce disparities in child health.

Finally, in this time of budget shortfalls, it is important to keep in mind, as Szilagyi reminds us, that even given the large run-up in the number of children with diagnosed disabilities, caring for children with disabilities still accounts for only about a nickel of every dollar of health care costs as a whole. Thus, 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.