



Children with Disabilities

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The Future of Children

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Children with Disabilities: Introducing the Issue

Janet Currie and Robert Kahn

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.”

Janet Currie is the Henry Putnam Professor of Economics and Public Affairs and the Director of the Center for Health and Wellbeing at Princeton University. Robert Kahn is an associate professor of pediatrics at the Cincinnati Children’s Hospital Medical Center and University of Cincinnati College of Medicine.

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

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.

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. 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.

The Changing Landscape of Disability in Childhood

Neal Halfon, Amy Houtrow, Kandyce Larson, and Paul W. Newacheck

Summary

Americans' perceptions of childhood disability have changed dramatically over the past century, as have their ideas about health and illness, medical developments, threats to children's health and development, and expectations for child functioning. Neal Halfon, Amy Houtrow, Kandyce Larson, and Paul Newacheck examine how these changes have influenced the risk of poor health and disability and how recent policies to address the needs of children with disabilities have evolved.

The authors examine the prevalence in the United States of childhood disability and of the conditions responsible for impairment, as well as trends in the prevalence of chronic conditions associated with disability. They find that childhood disability is increasing and that emotional, behavioral, and neurological disabilities are now more prevalent than physical impairments. They stress the importance of, and lack of progress in, improving socioeconomic disparities in disability prevalence, as well as the need for better measures and greater harmonization of data and data sources across different child-serving agencies and levels of government. They call on policy makers to strengthen existing data systems to advance understanding of the causes of childhood disabilities and guide the formulation of more strategic, responsive, and effective policies, programs, and interventions.

The authors offer a new and forward-looking definition of childhood disability that reflects emerging and developmentally responsive notions of childhood health and disability. They highlight the relationship between health, functioning, and the environment; the gap in function between a child's abilities and the norm; and how that gap limits the child's ability to engage successfully with his or her world. Their definition also recognizes the dynamic nature of disability and how the experience of disability can be modified by the child's environment.

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Notions of childhood disability have evolved over the past century in concert with changing conceptions of health and illness, in response to changing threats to children's health and development, and in relation to changing demands and expectations for child functioning. While the prevalence of parent-reported childhood disability has been steadily increasing over the past fifty years, the nature, severity, and consequences of disability for a child living in 1960s America are considerably different from those for a child with disability today. Until the 1960s, the iconic image of disability was a child with polio, pictured in leg braces and supported on crutches. If there were a poster child for today, it might be a child with autism. While the girl with polio wore her disability for all the world to see, the boy with autism represents the new and less identifiable face of modern disability, a range of ubiquitous and not as easily recognizable mental health and neurodevelopmental disorders.

All children, especially those living in poverty or with preexisting health conditions, are at risk for having a disability.¹ Disability in childhood can result in lifelong health, social, vocational, economic, and psychological impacts.² Children with disabilities tend to have more extensive health care needs, have greater rates of unmet needs for health and related services, and experience social and environmental barriers to full participation in life events.³ They are at risk for diminished health-related quality of life and for negative psychological and social impacts.⁴ Their families devote considerable time and effort to providing health-related care, and often experience financial burden, work loss, poor mental and physical health, and negative social consequences.⁵ For poor children with

disabilities and their families, these problems tend to be even greater.⁶ In addition, communities and health systems are often unable to provide the resources for children with disabilities and their families necessary to achieve optimal health and social outcomes.⁷

In this article we describe the changing nature of child health and childhood disability. We first address the changing context of childhood, health, and disability; how changing contexts of childhood influence risks for poor health and disability; and how policies focused on addressing the needs of children with disabilities have evolved over the recent past. We then examine the data on childhood disability. Using data from the U.S. National Health Interview Survey, we look at the prevalence of childhood disability and the conditions responsible for impairments, trends in prevalence of chronic conditions associated with childhood disability, and cross-national data comparing U.S. prevalence rates with those of other nations. We interpret our findings, considering explanations for trends that show increasing prevalence and for the changing distribution of childhood disability. We also address the importance of and lack of progress in reducing the social disparities in disability prevalence, as well as the need for better measures, more consistent definitions, better longitudinal data, and greater harmonization of data and data sources across different child-serving agencies and levels of government. After offering a new and forward-looking definition of childhood disability, one that reflects emerging and more developmentally responsive notions of childhood health and disability, we consider the potential for improving the understanding of trends and determinants of childhood disability and its consequences for the nation.

Changing Contexts of Childhood Health and Disability

Contemporary notions of childhood disability contend that the nature and severity of disability are not only a product of underlying medical conditions but also a function of the demands, expectations, and social roles that children assume in their daily lives. Championing an integrated biopsychosocial perspective, the World Health Organization (WHO) in 2001 developed the International Classification of Functioning, Disability and Health (ICF), which describes how health conditions interact with personal and environmental factors to affect functioning at the levels of the body, the person, and the person in social situations. “Disability” is the umbrella term for impairments at the body level, activity restrictions at the person level, and participation restrictions at the person-in-society level. The ICF defines impairments as “problems in body function or structure such as a significant deviation or loss,” activity limitations as “difficulties an individual may have in executing a task,” and participation restrictions as “problems an individual may experience in involvement in life situations.”⁸ Personal and environmental factors that influence functioning are considered contextual factors. In 2007 the WHO released the International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY) in response to the specific and unique aspects of disability in childhood. For children, disability is also explained in the context of delays, deviations, and variations in expected growth and development.⁹

Primarily a classification scheme, the ICF does not provide a formal definition of disability. Subsequent work by the UN Convention on the Rights of Persons with Disabilities led to the development and

adoption of a new definition of disability in 2010 that is built on the ICF framework. This definition is contained in Article 1 of the UN convention: “Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.”

The UN convention now has 149 countries as signatories, including the United States. Its inclusive definition of disability takes into account the impact of barriers created by the physical and social environments and emphasizes the importance of ensuring individuals’ equal participation in society. Although this definition does not incorporate a direct reference to the evolving developmental needs of children, the general principles contained in Article 3 include: “Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.”¹⁰

The ICF framework and the U.N. convention definition of disability represent a new synthesis of two previously competing disability models—the medical model and the social model. The medical model of disability is aligned with biomedical notions of health and disease, attributing alterations in function to pathological changes in the individual.¹¹ The biomedical understanding of disability reduces impairments to categories of disease and deficiencies. The focus is on patients instead of persons in their environments.¹² In the medical model, disability is defined by the manifestations of health conditions in the form of anomalies of structure or function. Biological dysfunction may be amenable to medical interventions.¹³ This model remains pervasive in medical care and persists as the basis for eligibility for many public programs.

In contrast, the social model perceives disability as a social construct defined by social role function, practices of inclusion and exclusion, and discrimination.¹⁴ In a perfect world where the physical environment is accessible to all and where social attitudes and public policies are embracing and inclusive of all individuals, regardless of impairment, the experience of disability would not exist.¹⁵ From this vantage point, society limits full participation of people with impairments through discriminatory policies, inadequate environmental adaptations, and social ostracism. From the social model perspective, the focus of study is not the individual but social and environmental barriers.¹⁶ By considering both the medical and social perspectives, the ICF framework and the UN convention conceive of disability as a manifestation of the interaction between individuals and the context in which they live. Instead of a simple dichotomy, disability is understood as a dynamic continuum, influenced by biology, social factors, environmental conditions, health services, and personal preferences.¹⁷

The Changing Context of Childhood and Impacts on Health

Over the past century, enormous shifts have affected the social and cultural scaffolding that supports children's development and have also influenced the occurrence of chronic health conditions that can result in disability. These shifts include changes in demographics, the decline of some environmental toxins and the rise of others, new media and information technology that affects human relationships and perceptions, and advances in medical care technologies that have changed patterns of mortality and morbidity.

Between 1900 and 2000, the population in the United States tripled, but the birth rate

dropped dramatically, from 32.2 to 14.4 births per 1,000 persons.¹⁸ Women are having fewer children, and first pregnancies are occurring at an older age.¹⁹ Demographically, children are more diverse, with several states now having or nearing a majority population that is of "minority" racial or ethnic background.²⁰ Children are now far more likely than ever before to reside in cities, live in smaller families, often with a stepparent and step- or half-siblings, and to spend part of their childhood with a single parent.²¹ More than 20 percent of children in the United States live in impoverished households, and nearly half live in low-income families that are stressed to meet the needs of the modern child.²² In sum, many children live in social environments that limit their full inclusion and participation in the social world.²³

Changing exposure to potentially toxic chemicals has also shifted the profile of risk for a range of health outcomes. Exposure to some environmental toxins such as lead, which can cause neurodevelopmental disorders, and air pollution, which is implicated in a range of maladies, has decreased over recent decades. But an expanding list of new environmental toxins has been implicated in the growing number of children with neurodevelopmental disorders.²⁴ Exposures to these toxins may occur during critical periods of development (prenatal, early childhood, adolescence) when children are particularly sensitive to the disruptive nature of these chemicals and may lead to alterations in functional potential that may be compounded in ways that amplify their consequences over time.²⁵

Changes in the cultural framework that guides children's growth and development may result from large-scale social changes, such as the introduction of television in the

Enormous shifts have occurred in the social and cultural scaffolding that supports children's development as well as their propensity for chronic health conditions that can result in disability.

1950s and the personal computer in the 1980s, or from more gradual changes, such as the progressive lessening of the amount of outdoor playtime that children experience. These subtle and not-so-subtle changes shape how children grow, develop, and function. Not only are today's children less active and spending less time outdoors, factors implicated in the rapidly rising rates of childhood obesity, but they are also exposed to a continuously increasing stream of information and electronic stimuli, giving them a wide range of experiences in a matter of weeks that their counterparts a century ago might not have experienced in a lifetime.

The dominant role that electronic media play in children's lives represents a tectonic shift in underpinnings of human health development. Researchers are just beginning to understand how various forms of electronic media are influencing and potentially disrupting neural development.²⁶ Studies document growing rates of exposure to TV and videos at earlier ages and for longer periods of time. Appropriate use of media clearly can have a positive influence on children's health development. But recent studies also

demonstrate that early and excessive viewing of television can have negative impacts on cognitive development and that playing certain kinds of video games is associated with changes in frontal lobe function, aggression, and impulse control, and is related to other behavioral problems.²⁷ With increasing numbers of children diagnosed with disabling mental and behavioral disorders, the role and impact of growing rates of exposure to all kinds of media are unanswered questions of growing concern.

Concurrent with dramatic shifts in the social, cultural, physical, and technological world of the modern child are rapid advances in health and health care. Large declines in infant mortality attributable to a combination of improved living conditions and health interventions such as vaccinations, prenatal care, and the use of antibiotics have decreased morbidity and increased life expectancy.²⁸ Medical and surgical advances, including improvements in neonatal care and management of previously fatal conditions such as congenital heart disease and cystic fibrosis, mean that more children with severe health conditions are surviving but also that many of them are at increased risk for chronic morbidity and disability.²⁹

Irrespective of these significant improvements in medical care and living conditions (or in some cases, perhaps because of these improvements), diagnoses of childhood chronic health conditions such as asthma, autism, attention-deficit/hyperactivity disorder (ADHD), and obesity have been rising over the past several decades. So too has there been an increase in the number of children designated as having a more generically defined "special health care need."³⁰ Many of the chronic health conditions children experience today are associated with

activity limitations and participation restrictions in their community, limitations that can profoundly influence children's lives.³¹ Advances in medical care have been associated with a broadening of the purview on what constitutes a health condition, the age when diagnoses are rendered, how diagnostic criteria are applied, and expectations for what constitutes healthy development.

Changes in the physical, chemical, social, psychological, cultural, and health care environments of children are continuous, dynamic, and cross-cutting. Epidemiologic studies and studies of basic mechanisms are attempting to determine the relationships between specific exposures and observed outcomes (for example, between organophosphates and autism, bisphenol and obesity, violent video games and antisocial behavioral disorders). As one considers the prevalence and impact of childhood disability, one must also consider these many and varied changes in children's environment as they relate either to the underlying health conditions that result in impaired functioning, or to the adaptive capacity of the child, family, and society to respond to distress and impairment.

The Social and Policy Response to Childhood Disability

As the constellation of risk and protective factors that influence child health and disability continues to evolve, so too does society's response. For centuries, disability was understood as a characteristic of an individual. In Western cultures, from ancient Greece until the rise of modern medicine, disability was often interpreted as evidence of God's dismay.³² Until the Enlightenment period, the birth of a disabled infant was perceived as a palpable sign of parental sin. Disability also fed into notions of biological fitness, and the social ills associated with "feeble

mindedness," or "degenerative and defective hereditary qualities," evolved in the early twentieth century into the rationale for eugenics and led to social policy that advocated forced sterilization of those considered unfit. As pathology, disability was deemed amenable to identification, characterization, and treatment for cure or management.³³ Children with disabilities were often shunned, removed from their families, and treated, and often warehoused, in specialized institutions. Not until the 1950s, when deinstitutionalization began, did children with disabilities begin to be viewed in a different light. Social forces such as the civil rights and women's movements and President John Kennedy's Panel on Mental Retardation in 1961 helped bring issues faced by people with disabilities to the national policy stage, ushering in a new era of understanding disability.³⁴ Inspired by his own family's experience with mental retardation, President Kennedy facilitated a new focus on the treatment and rehabilitation of individuals with mental retardation and other developmental delays. A federal law enacted in 1963, Public Law 88-156, provided new funding for children with mental retardation. In 1968 the Handicapped Children's Early Education Assistance Act (PL 90-538) provided funds for the first early intervention programs. The 1970s provided additional funding and focus for children with disabilities.

Social awareness of the challenges faced by children with disabilities and their families, coupled with advocacy by disability rights groups, continued to contribute to changes in disability policy at the federal and state levels in subsequent decades. Building on the Rehabilitation Act of 1973, the 1975 Education for All Handicapped Children Act (PL 94-142) provided the right to a full and appropriate education for all school-age children, regardless of the presence of

a disability (see the article by Laudan Aron and Pamela Loprest in this volume).³⁵ This law required public schools to evaluate all handicapped students and develop a plan, in conjunction with their parents, for educating these children in the same settings with typically developing children. At the time of enactment, more than 1 million children had no access to public education, and more than 3.5 million were segregated into special schools, often with no effective instruction.³⁶ In 1986 Congress extended the 1975 law to infants, toddlers, and their families and set the basis for developing state-level early intervention programs for children with or at risk for developing disabilities. In 1990, reflecting a change in conception and terminology, the 1975 law was reenacted as the Individuals with Disabilities Education Act. IDEA has since been reauthorized on several occasions, and in 2009–10 some 6.5 million children, representing more than 13 percent of public school enrollment, received special education services.³⁷

Despite the growing understanding of disability as a dynamic, socially constituted, and culturally mediated process that pivots on each individual's capacity to engage in culturally constituted social roles and realize his or her multidetermined developmental potential, many laws, policies, and programs related to disability require the identification of a specific medical condition for eligibility. For example, IDEA defines a child's eligibility for special education on the basis of thirteen disability condition categories; a child who is not diagnosed with one of these conditions is not eligible for special education, even though in other settings she might be considered as having a disability.³⁸ Similarly, many states with special health care need programs for children use condition lists as a key determinant of eligibility for services. On the federal

level, until 1990 individuals were eligible for assistance under the Supplemental Security Income (SSI) program only if they had one of a narrow set of specific impairments as determined by a medical examination. This requirement changed after a Supreme Court ruling in 1990 in the case of *Sullivan v. Zebley* added consideration of a child's developmental functioning as a criterion for eligibility for SSI benefits.³⁹

Prevalence and Trends of Disability for U.S. Children

Information on the prevalence and trends of childhood disability is needed to formulate effective policies for preventing new cases of disability and ameliorating the impact of existing cases. Various national surveys collect information on the prevalence of chronic conditions, impairments, and disabilities among children. These include the National Survey of Children's Health, National Survey of Children with Special Health Care Needs, National Health and Nutrition Examination Survey, Medical Expenditure Panel Survey, and National Health Interview Survey, or NHIS, from the U.S. Department of Health and Human Services as well as Census Bureau surveys such as the American Community Survey and the Survey of Income and Program Participation. Each survey is conducted for a different purpose, and some have been used to measure the broader concept of special health care needs, but all incorporate at least some general measures of disability based on different combinations of items that capture functional or activity limitation. These surveys share certain limitations such as reliance on subjective parental reports, exclusion of individuals living in institutional settings, and lack of a standardized measure of childhood disability that fully captures the multidimensional nature of disability. Table 1 shows recent prevalence

Table 1. Disability Prevalence Estimates in Childhood

Survey	Year	Measure of disability or related concept	Prevalence estimate (and age group)
National Health Interview Survey ^a	1992–94	Disability: a long-term reduction in ability to conduct social role activities, such as school or play because of a chronic physical or mental condition	6.5% (under 18)
National Health Interview Survey on Disability ^b	1994	Limitations in learning: Limitations in communication: Limitations in mobility: Limitations in self-care:	10.6% 5.5% 1.3% 0.9% (5–17)
National Longitudinal Survey of Children and Youth (Canada) ^c	1994	Activity-limiting conditions: limited or prevented from participating in play, school, or other age-appropriate activities because of a long-term condition or health problem	3.6% (6–11)
Medical Expenditures Panel Survey ^d	1999–2000	Disability: the presence of a limitation in age-appropriate social role activities, such as school or play, or receipt of specialized services through the early intervention or special education programs	7.3% (under 18)
National Survey of Children's Health ^e	2003	Functional limitation: how often the child's medical, behavioral, or other health condition or emotional, developmental, or behavioral problems affected his/her ability to do the things children of the same age can do. Affirmative if answered sometimes, usually, or always	3.7% (under 18)
Family Resources Survey (United Kingdom) ^f	2004–05	Disability: the presence of a physical or mental illness or disability that limits the child and creates significant difficulties with any of the following areas of life: mobility, lifting/carrying, manual dexterity, continence, communication (speech, hearing, vision), memory/ability to concentrate or understand, recognize if in physical danger, physical coordination, or other problem/disability. Children could also be considered disabled if their conditions were managed by medications without which they would be expected to have significant limitations in one or more life areas.	7.3% (under 18)
Survey of Income and Program Participation ^g	2005	Disability among children 0–5 years: developmental delay; difficulty walking, running, or playing; difficulty moving arms or legs. Disability among children 6–14 years: uses a wheelchair, cane, crutches, or walker; has difficulty with one or more activities of daily living; has one or more specified conditions: a learning disability or some other type of mental or emotional condition; has one or more specified conditions: autism, cerebral palsy, mental retardation, or another developmental disability; has difficulty performing one or more functional activities (seeing, hearing, speaking, walking, running, or taking part in sports)	1.9% (under 3) 3.8% (3–5) 12.8% (6–14) Aggregate: 8.8%
National Survey of Children's Health ^h	2007	Functional limitation: limited or prevented in the ability to do the things most children the same age can do by any medical, behavioral, or other health condition that has lasted or is expected to last for 12 months or longer	4.3% (under 18)
National Health Interview Survey ⁱ	2009	Activity limitation: a child is considered to have a limitation if he or she has difficulty seeing, even when wearing glasses or contact lenses; has difficulty hearing without a hearing aid; has an impairment or health problem that limits his or her ability to crawl, walk, run, or play; has been identified by a school representative or health professional as having a learning disability; has been identified by a school representative or health professional as having ADD/ADHD; or needs the help of other persons with bathing or showering	8.0% (under 18)
American Community Survey ^j	2010	Disability for children under age 5: deaf or serious difficulty hearing; and/or blind or serious difficulty seeing even when wearing glasses. Disability for children aged 5–17 years: as above plus a cognitive difficulty, an ambulatory difficulty, and/or a self-care difficulty	0.8% (under age 5) 5.2% (age 5–17 years)

Sources:

- a. P. W. Newacheck and N. Halfon, "Prevalence and Impact of Disabling Chronic Conditions in Childhood," *American Journal of Public Health* 88, no. 4 (1998): 610–17.
- b. D. P. Hogan and others, "Improved Disability Population Estimates of Functional Limitation among American Children Aged 5–17," *Maternal and Child Health Journal* 1, no. 4 (1997): 203.
- c. J. McDougall and others, "Chronic Physical Health Conditions and Disability among Canadian School-Aged Children: A National Profile," *Disability and Rehabilitation* 26, no. 1 (2004): 35–45.
- d. P. W. Newacheck, M. Inkelas, and S. E. Kim, "Health Services Use and Health Care Expenditures for Children with Disabilities," *Pediatrics* 114, no. 1 (2004): 79–85.

- e. C. Bethell and others, "What Is the Prevalence of Children with Special Health Care Needs? Toward an Understanding of Variations in Findings and Methods across Three National Surveys," *Maternal and Child Health Journal* 12, no. 1 (2008): 1–14.
 - f. C. M. Blackburn, N. J. Spencer, and J. M. Rea, "Prevalence of Childhood Disability and the Characteristics and Circumstances of Disabled Children in the U.K.: Secondary Analysis of the Family Resources Survey," *BMC Pediatrics* 10, no. 21 (2010).
 - g. M. W. Brault, "Americans with Disabilities: 2005," *Current Population Reports*, P70–117 (U.S. Census Bureau, 2008).
 - h. National Survey of Children's Health, "Data Query from the Child and Adolescent Health Measurement Initiative (2007)" (www.childhealthdata.org).
 - i. Child Trends Data Bank, "Children with Limitations" (www.childtrendsdatabank.org/?q=node/73).
 - j. U.S. Census Bureau, "Disability Characteristics," 2010 American Community Survey 1-Year Estimates, American FactFinder (http://factfinder2.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=ACS_10_1YR_S1810&prodType=table).
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estimates derived from different national surveys and the various ways disability has been measured by survey methodologists and researchers. As the table shows, measurement of childhood disability in the United States has lagged behind the development of the conceptual models described here. Instead, most measures incorporated in current national surveys continue to use modified medical approaches.

Although less than ideal, the concept of limitation of activity used in the NHIS offers the most inclusive approach to measuring disability among the existing national surveys. The NHIS measure is designed to identify children who experience limitations in developmentally appropriate activities. Like disability measures in other national surveys, it does less well in capturing the participation dimension of disability. The NHIS measure offers the advantage of being continuously collected over the past fifty years, albeit with some changes in measurement methodology. Because of its inclusiveness and longevity, we use it here to describe prevalence and trends in childhood disability.

The NHIS measure of limitation in usual activities is a composite of several developmentally appropriate items that capture social role limitations (play for preschool-age children and school for older children). In recent years these items have been complemented with several measures of functional

status (activities of daily living and difficulties with mobility and memory). A catch-all item is meant to identify any other limitations. Using this approach, any child under age eighteen is initially classified as being limited in usual activities if he or she is reported to receive special education or early intervention services; experience difficulty walking without equipment; experience difficulty remembering; or have any other limitation. Children under five are also considered to be limited in usual activities if they experience limitations in the kinds or amounts of play activities done by other children, as are children aged three and older who need help with personal care including bathing, dressing, eating, getting in and out of bed and chairs, using the toilet, and moving around the home.

When a child meets any of these criteria, the respondent is then asked to identify the condition(s) causing the limitation. Reported conditions are classified by the data collection agency as "chronic," "not chronic," or "unknown if chronic." In this section we report on the prevalence of limitation in usual activities due to one or more chronic conditions. We use the terms "limitation in usual activities due to one or more chronic conditions" and "activity limitations" interchangeably.

Current Prevalence Estimates from the NHIS

The prevalence of activity limitations overall and for subgroups of the population is shown

Table 2. Prevalence of Limitation in Usual Activities due to Chronic Conditions, by Sociodemographic Characteristics, U.S. Children under Age Eighteen, 2008–09

Category	Estimated number of cases	Number of cases per 1,000 children	Standard error
Overall	5,666,000	76.8	1.8
Child age			
Under 6	1,175,000	46.5	2.2
6–11	2,260,000	94.7	3.3
12–17	2,231,000	90.4	3.0
Child gender			
Male	3,711,000	98.4	2.5
Female	1,955,000	54.1	2.1
Race/ethnicity			
White, non-Hispanic	3,535,000	84.1	2.6
Hispanic	934,000	57.8	2.8
Black, non-Hispanic	969,000	84.0	3.7
Asian, non-Hispanic	116,000	36.5	5.2
Other, non-Hispanic	112,000	120.3	20.3
Family income, as % of federal poverty level			
Under 100	1,390,000	108.1	4.9
100–199	1,296,000	87.9	4.5
200–299	768,000	75.7	4.4
300–399	616,000	84.3	5.5
Over 400	967,000	57.5	3.3
Highest parent education			
Less than high school	688,000	76.4	4.3
High school diploma	1,260,000	82.5	4.1
Some college	1,865,000	84.6	3.3
B.A. degree or higher	1,546,000	63.5	3.0
Family structure			
Two biological/adoptive parents	2,126,000	60.5	2.4
Two-parent stepfamily	501,000	86.3	6.5
Single mother	1,107,000	110.0	5.2
Single father	81,000	64.5	11.2
Other	1,842,000	86.1	3.7

Source: Authors' tabulations of data from the 2008–09 National Health Interview Survey.

Note: Total sample size = 43,676. Sample size is 16 percent lower for family income, 5 percent lower for parents' education, and 2 percent lower for family structure.

in table 2 and is based on NHIS data for 2008–09. On average for the two years, the prevalence of activity limitations for children younger than eighteen was 7.7 percent. Nationally, an annual average of 5.7 million children was estimated to have an activity limitation in 2008–09. Data from other sources indicate that these children represent a relatively small subset of the population of children with chronic conditions. Studies conducted with data from the late 1980s

indicate that more than 30 percent of children experience one or more chronic conditions over the course of a year.⁴⁰ More recent national survey data indicate that up to half of all children experience chronic conditions over a multiyear period.⁴¹

The prevalence of reported activity limitations varies by demographic and socioeconomic characteristics (see table 2). For example, children aged six through eleven have double

the prevalence of activity limitations as children under six. This tendency has been observed in past studies from the NHIS and likely reflects the added demands placed on children as they enter school and possibly increased recognition of certain conditions such as learning disabilities. Prevalence does not vary much across age groups once children are of school age. Boys are almost twice as likely as girls to be reported as having a limitation. Activity limitations are reported less frequently for black and white children than for Hispanic and Asian children. There is a substantial, though somewhat uneven, income gradient; children living in families with incomes below the federal poverty level (FPL) are almost twice as likely to be reported with activity limitations as children in families with incomes at 400 percent or more of the poverty level. Children in families where the highest parental educational attainment is less than college were more likely to be reported with activity limitations than those with one or more parents who had completed college. Finally, children in single-mother families were more likely to be reported with activity limitations than children in other household types. For the most part, these demographic and socioeconomic differences are consistent with past reports.⁴²

Conditions Associated with Limitations in Usual Activities

Prevalence estimates for individual diagnostic categories are presented in table 3. The first column displays the average annual prevalence of chronic conditions reported as causes of activity limitations in 2008–09. The conditions in table 3 reflect main and secondary causes of activity limitations, hence, the sum of condition prevalence estimates exceeds 100. In fact, an average of 1.4 conditions was reported for each child with activity limitation. The top five conditions are

primarily developmental, emotional, and behavioral. Speech problems, learning disability, and ADHD were each cited by more than one in five parents as contributing to their child's activity limitation. The most common physical health condition was asthma, which was reported as a cause of activity limitations for 8 percent of all children with limitations. Most of the other conditions listed in table 3 affected comparatively small numbers of children.

The dominance of developmental, emotional, and behavioral conditions over the traditional physical conditions as causes of childhood activity limitations has important implications for the design of effective prevention and intervention programs. When most of the current programs serving children with disabilities were designed, the most prevalent causes of disability were physical conditions. This epidemiological shift and its implications are discussed in more detail later in this article.

Trends in Childhood Activity Limitations Due to Chronic Conditions

A growing body of studies has documented an increase in the prevalence of a variety of reported childhood chronic conditions over time, including increases in asthma, autism, and behavioral conditions such as ADHD.⁴³

An analysis of data from the *Digest of Education Statistics* shows a near doubling of the share of students with diagnosed disabilities between 1976 and 2005, with a modest decline between 2005 and 2009.⁴⁴ Past studies have also demonstrated substantial increases in the prevalence of reported childhood activity limitations. One analysis, for example, documented a doubling in the prevalence of activity limitations for children under age seventeen between 1960 and 1981,

Table 3. Prevalence of Conditions Associated with Limitations in Usual Activities due to Chronic Conditions, U.S. Children under Age Eighteen, 2008–09

Chronic condition	Number of cases per 100,000 children	Standard error	As a share of all disability cases
Speech problem	1,815	87.5	23.6
Learning disability	1,775	86.8	23.1
ADHD	1,715	74.7	22.3
Other mental, emotional, or behavioral problem	1,452	75.9	18.9
Other developmental problem	779	57.1	10.1
Asthma/breathing problem	632	48.4	8.2
Other impairment/problem	431	36.5	5.6
Birth defect	423	35.7	5.5
Bone/joint/muscle problem	260	31.0	3.4
Hearing problem	256	29.9	3.3
Vision problem	244	27.1	3.2
Mental retardation	207	25.9	2.7
Epilepsy/seizures	173	24.6	2.3
Injuries	76	16.4	1.0

Source: Authors' tabulations of data from the 2008–09 National Health Interview Survey.

Note: Categories are not mutually exclusive—more than one condition could be reported as contributing to the child's activity limitation.

from 1.8 percent to 3.8 percent, using data from the NHIS.⁴⁵ More recent NHIS data show that the upward trend in activity limitations has continued (figure 1). The prevalence for children under age eighteen again more than doubled, from 3.8 percent in 1981 to 8.0 percent in 2009 (the age range used to define children in the NHIS was changed from under seventeen to under eighteen in 1982). Overall, the data in figure 1 indicate a fourfold increase in prevalence of childhood activity limitations during the past half century. Figure 1 also shows some of the major programmatic initiatives enacted during this period along with the dates of major revisions to the NHIS survey questionnaire. Because the activity limitations are defined in part by the receipt of services, the extent to which increases in reported disability may be driven by increases in service provision is an open question. These trends are discussed in more detail later.

Trends by Social Class

Monitoring the magnitude of social disparities in health across time is an important way to determine if the country is meeting public health goals to reduce these disparities. A comparison of prevalence ratios for childhood activity limitations due to chronic conditions, as measured by the NHIS over a forty-five-year period, indicates that the magnitude of the differential between the poor and the nonpoor remained roughly the same, even as children in both income groups experienced a near fourfold increase in prevalence during the period. In 1964 poor children were one and a half times more likely than those in nonpoor families to have an activity limitation attributable to chronic conditions (3.1 percent versus 2.0 percent).⁴⁶ These ratios held nearly constant at 1.41 in 1978 (5.2 percent vs. 3.7 percent), 1.68 in 1992–94 (9.6 percent vs. 5.7 percent), and 1.50 in the 2008–09 NHIS (10.8 percent vs. 7.4 percent).

Trends by Condition

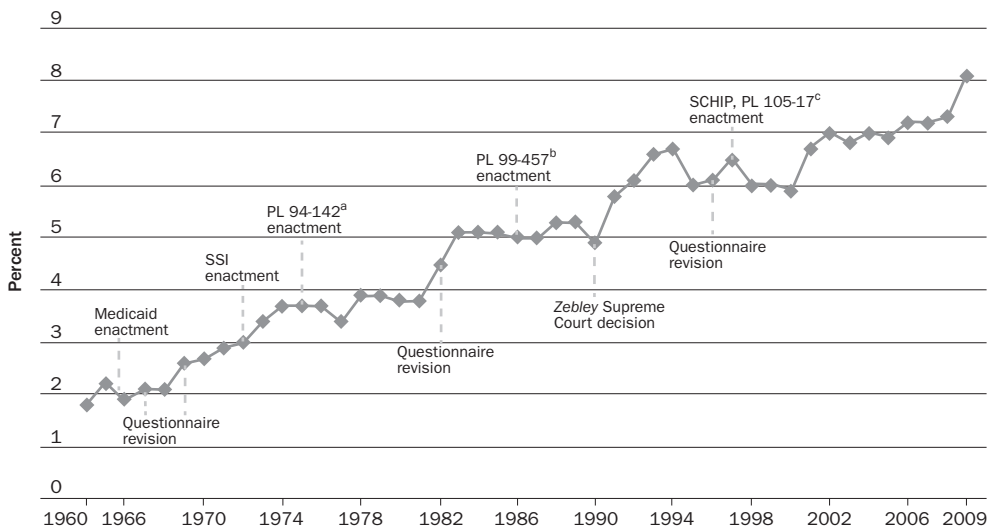
As indicated earlier, the leading conditions associated with activity limitations in 2008–09 were largely developmental, emotional, and behavioral in nature. Comparison with earlier time periods is made difficult by changes in the way condition data are collected and coded in the NHIS. Before 1996 respondents were asked to name the main and secondary causes of activity limitation. Trained diagnostic coders at the National Center for Health Statistics then categorized reported conditions into detailed International Classification of Disease codes. The NHIS no longer distinguishes main and secondary causes, and only the broad categories of conditions shown in table 3 are collected for children. Nevertheless, some conclusions, albeit provisional, may be drawn concerning changing patterns of conditions. The leading causes of activity limitation for 1979–81, 1992–94, and 2008–09 are shown

in table 4. Over this thirty-year period, the composition of activity limitations has changed dramatically, with physical health conditions, formerly dominant, receding in importance as developmental, emotional, and behavioral conditions became the leading causes of childhood activity limitation.

Cross-National Comparisons

Given increasing trends in childhood disability in the United States, it is useful to consider how the United States compares with other nations with similar social and economic conditions. Cross-national comparisons of child health and education outcomes are often used to assess how differences in culture, geography, health, and social systems shape child outcomes. Comparing U.S. data on the prevalence and trends in childhood disability with those of other nations is also quite revealing regarding similarities

Figure 1. Trends in Limitation of Activity due to Chronic Conditions for U.S. Children, 1960–2009, with Major Programmatic Initiatives in Health, Education, and Public Assistance



Source: National Health Interview Survey.

Note: Under 17 years of age for 1960–81; under 18 years for 1983–2009; no data available for 1982.

a. Education for All Handicapped Children Act of 1975.

b. Education of the Handicapped Act Amendments of 1986.

c. Individuals with Disabilities Education Act Amendment of 1997.

Table 4. Leading Causes of Limitation in Usual Activities due to Chronic Conditions, U.S. Children

1979–81	1992–94	2008–2009
1. Diseases of the respiratory system	1. Diseases of the respiratory system	1. Speech problems
2. Impairment of speech, special sense, and intelligence	2. Impairment of speech, special sense, and intelligence	2. Learning disability
3. Mental, nervous system disorders	3. Mental, nervous system disorders	3. ADHD
4. Diseases of the eye and ear	4. Certain symptoms, ill-defined conditions	4. Other emotional, mental, behavioral problems
5. Specified deformity of limbs, trunk, and back	5. Deafness and impairment of hearing	5. Other developmental problems
6. Nonparalytic orthopedic impairment	6. Nonparalytic orthopedic impairment	6. Asthma/breathing problems

Sources: For 1979–81 data, P. W. Newacheck, N. Halfon, and P. P. Budetti, “Prevalence of Activity Limiting Chronic Conditions among Children Based on Household Interviews,” *Journal of Chronic Disease* 39, no. 2 (1986): 63–71; for 1992–94 data, P. W. Newacheck and N. Halfon, “Prevalence and Impact of Disabling Chronic Conditions in Childhood,” *American Journal of Public Health* 88, no. 4 (1998): 610–17; for 2008–09, authors’ tabulations of data from the 2008–09 National Health Interview Survey. Note: The age range is under 17 for the 1979–81 data but under 18 for 1992–94 and 2008–09. Includes main and secondary causes of activity limitations.

and differences. A recent report from the Organization for Economic Cooperation and Development (OECD) attempts to harmonize the results of different data collection efforts in member countries.⁴⁷ This analysis reveals that the United States is similar in many ways to other OECD countries but has higher rates of autism and twice the rate of speech and language difficulties. This latter difference, however, appears to be driven by differences in classification schemes between the United States and Europe.⁴⁸ The larger proportion of children classified with autism in the United States may be the result of several factors, including recent changes in the U.S. diagnostic rubric for autism.

Surveying the Landscape and Moving Forward

This brief survey of childhood disability in the United States has revealed several important and interrelated findings that deserve additional consideration. First, the reported prevalence of disability has increased steadily since the 1960s, and at the same time the underlying health and environmental conditions associated with reports of disability have

also substantially changed. Second, despite increases in prevalence, and the implementation and expansion of social programs to prevent and ameliorate childhood disability, social class disparities in disability have persisted at virtually the same level for the past fifty years. Third, the measures of disability used in national surveys lag behind current thinking about disability and its relationship to the environment. In addition, most available data on disability have come from cross-sectional surveys, that is, surveys that take a snapshot of the situation at a point in time and do not follow individual respondents over time, leaving gaps in our knowledge base about the dynamics and trajectories of disability as children with disabilities age. We take up each of these issues in turn, discussing their significance and implications for the future.

Increasing Prevalence over Time

Trend data from the NHIS demonstrate that the prevalence of activity limitations reported by parents across all condition categories has steadily increased over the past half century. There is no simple explanation for why rates

of childhood disability have increased so dramatically. Indeed, the upward trend might be explained by a number of factors, including changes in survey procedures, increased exposures to risks and declines in resistance, changes in diagnoses, changes in access to health and educational services tailored to identify and treat children with disabilities, or other significant cultural shifts including expectations of what a typically developing child “should” be able to do.

Some of the increase in prevalence is attributable to changes in the NHIS data collection process. In particular, the questions used to identify activity limitations have changed over time. Significant changes in survey procedures and questionnaire items related to activity limitations occurred in 1967, 1969, 1982, and 1996. In some cases the questionnaire wording was broadened to be more inclusive (1967, 1969), and in other cases the emphasis shifted. For example, in 1996 the questions for school-age children shifted from an emphasis on limitations in ability to engage in school activities to enrollment in special education programs owing to health conditions. Conservatively assuming that all of the increases in prevalence occurring in those years were attributable solely to changes in survey procedures and questionnaire revisions, about one-third of the upward trend between 1960 and 2009 can be attributed to changes in the survey.

Large-scale improvements in access to health care also occurred during the study period through the enactment and implementation of programs such as Medicaid, the federal and state health care program for the poor, and the federal-state Children’s Health Insurance Program (CHIP) for children in low- and moderate-income families. These programs made large numbers of children eligible

for screening, diagnosis, and treatment of physical, developmental, and behavioral problems. Public assistance programs for families of children with disabilities also grew during this period through the enactment and subsequent broadening of the federal Supplemental Security Income program following the Supreme Court’s *Zebley* ruling.⁴⁹ Enrollment in SSI also confers automatic eligibility for Medicaid. As described earlier, landmark legislation for the education of school-age children with disabilities was enacted in 1975, followed in 1986 by legislation that provided states with funds to establish a comprehensive statewide, interagency, multidisciplinary approach for expanding evaluation, special education, and early intervention services to disabled children from birth to age three. Enactment dates for these programs and rulings are shown in figure 1. In reviewing the figure, readers should keep in mind that complete implementation of new programs often occurs years after the enactment of legislation, and the programs may never be fully funded.

Advances in medical care, treatment, and diagnosis are likely to have contributed to the rise in prevalence. For example, access to and improvements in the delivery of specialized care have resulted in a growing number of survivors of complex congenital disorders, prematurity, and cancer.⁵⁰ Greater access to medical and dental screening through Medicaid’s Early and Periodic Diagnosis and Treatment Program is likely to have led to increased identification of previously “hidden” conditions. Better tools to diagnose chronic conditions, particularly emotional and behavioral conditions, may also contribute to the upward trend in prevalence. Concepts of health and disease, and definitions of what constitutes a childhood chronic illness have also changed.⁵¹ As noted, the narrow medical

and programmatic focus on physical defects during the “crippled children” era of the 1930s to the 1960s has evolved to include an expansive range of physical, developmental, emotional, and behavioral conditions.⁵²

Besides improvements in access to health care services over the past half century, there have also been tectonic shifts in how the education system views and responds to children with mental, behavioral, and developmental problems. As a result of federal and state programs, more children have access to special education and early intervention services focused on mental, behavioral, and developmental conditions; thus, questions in the NHIS that identify the presence of a limitation in activity based on the provision of special education and early intervention services would be expected to mechanically increase reported prevalence.

Teasing out the contributions of each of these factors to the increase in prevalence is a daunting but critical task and beyond the scope of this brief article. However, considering trends in some of the major condition categories associated with the rising prevalence of limitation of activity can provide a useful starting point for a more careful and detailed examination.

A growing number of children are reported to suffer disability stemming from emotional, behavioral, and neural developmental conditions such as ADHD, autism, learning disabilities, and speech and language disorders. This trend could reflect a real change in the incidence of conditions caused by changing risk exposures during pregnancy and early childhood, or it could result from changes in recognition, screening, and diagnostic criteria. For example, autism, which was previously more narrowly defined and based on more

severe symptoms, has been expanded to include a spectrum of pervasive developmental disorders that includes Asperger’s Syndrome and other related disorders. The ongoing controversy regarding the validity of increased reports of childhood autism is indicative of the challenges inherent in attempting to understand the factors contributing to increased prevalence of childhood disability. Reported prevalence rates for autism have increased by several orders of magnitude in the past twenty years. Yet changes in recognition, diagnostic criteria, and incentives for early identification and intervention alone do not account for the increased prevalence.⁵³ Several studies have also documented the relationship of higher rates of autism to age of parents at birth, birth spacing, breast feeding, and other social factors, as well as to exposures to a range of environmental toxins.⁵⁴ Others have argued that increasing rates of autism, as well as of ADHD, are the result of a confluence of small but important changes in children’s exposure to the combined influence of demographic changes, environmental toxins, toxic stress associated with poverty, and the instability associated with a lack of adequate resources for child rearing.⁵⁵

The trend for childhood asthma is a special case in which the prevalence of disability owing to asthma increased dramatically over several decades only to apparently plateau since the turn of the century. Analysis by the Centers for Disease Control and Prevention showed that between 1980 and 1995 asthma rates in children were increasing at a rate of 5 percent a year.⁵⁶ An analysis of NHIS data by two of the authors, Paul Newacheck and Neal Halfon, showed that between 1969–70 and 1994–95, the prevalence of asthma-related disability increased 232 percent, whereas disability in general from all other

conditions increased by a much smaller 113 percent over the same period.⁵⁷ These rapid increases in rates of disability related to childhood asthma were paralleled by rising hospitalizations and other indicators of the growing burden of asthma in children across the United States.⁵⁸ Since 1997, however, the number of children with disabling asthma has leveled off and seems to be decreasing somewhat. The reasons for the spike in and subsequent plateauing of asthma rates are not clear, with hypotheses ranging from changes in infectious disease patterns to changes in activity levels, with more sedentary lifestyles that led to greater indoor exposures and less outdoor play time.⁵⁹ The plateauing and declining rates of disabling childhood asthma also coincide with reductions in air pollution that have resulted from changes mandated by the Clean Air Act and its amendments. The absence of reliable longitudinal data makes this trend difficult to unravel.

Another trend of note is the rise in the number of preterm births. Long-term trends show that preterm rates peaked sometime in the mid-1960s and then steadily decreased over the next twenty years. From 1990 to 2006, however, rates of preterm birth increased from 10.6 per 1,000 live births to 12.8 per 1,000, with recent declines to 12.3 in 2008.⁶⁰ While rates of preterm births for black mothers have remained persistently high (ranging between 18 and 19.5 per 1,000 for much of this period), rates for white mothers have increased from 8.0 to 10.2 per 1,000. Trends in most high-income countries are similar to those in the United States.⁶¹ Much of the overall increase for white mothers is attributable to an increase in late preterm deliveries by caesarean section. Between 1994 and 2007, the percent of children born via C-sections increased by 53 percent, from 21 percent of all births to 32

percent.⁶² Children born preterm are at risk for a number of short- and long-term neuro-developmental disorders including cerebral palsy, intellectual impairment, sensory impairments, and ADHD.

Changes in perceptions, acceptance, and advantage associated with childhood disability may also help explain increased reporting of childhood disabilities. Over the past several decades, perceptions about the nature, impact, and mutability of behavioral, developmental, and emotional disorders such as ADHD have shifted significantly. Several factors, including the revolution in brain science and better understanding of the biological and developmental origins of behavioral, developmental, and emotional disorders, have served to reduce the stigma and encourage the acceptance of more aggressive early intervention, diagnosis, and treatment. ADHD, for example, once known as minimal brain dysfunction, was renamed and reframed after extensive natural history and epidemiologic research. That work now suggests that ADHD is not just a disorder of school-age children but a symptom complex that afflicts a growing number of individuals across the lifespan.⁶³

Some commentators have questioned whether increased performance demands placed on children and young adults, particularly in school settings, are contributing to a growing reported prevalence of ADHD. A portion of the observed increase may be a response to a societal shift in perceptions and expectations of what is appropriate child behavior and greater acceptance of the ADHD diagnosis. While minimal brain dysfunction may not have been a condition that one would like to talk about at cocktail parties, ADHD has much less stigma and might also provide access to medications that can prove beneficial for

achieving the next rung on the education or employment ladder. Greater demand for pharmacological interventions to enhance school performance is coincident with diminishing opportunities and fewer educational and career paths for children who do not succeed in gaining entry into traditional four-year colleges, creating growing pressure on families to do whatever they can to help their children succeed in school.

Other potential advantages come with a diagnosis of a specific developmental disability, including opportunities to receive early intervention and special education services. Children with a diagnosed learning disability also become eligible for “accommodations” when taking college admission tests. For those children attending private and parochial elementary and high schools, similar accommodations are often made both for admissions testing and even routine classroom quizzes and tests. Whether these accommodations also provide incentives for families to seek out such a diagnosis and designations is yet to be determined. In addition, the enactment and subsequent expansions of the SSI disability program for children and other public benefit programs have created other advantages for carrying diagnosed disability.

The Social Gradient

While the upward trend in childhood disabilities has shifted from physical and medical conditions to neurodevelopmental and behavioral conditions, the social gradient in prevalence of childhood disability is little changed. In other words, the country appears to have made no progress in reducing socioeconomic disparities in disability over the past half century. Lower socioeconomic status can adversely influence development, and severity of childhood disabilities as well

as their potential for remediation. A growing body of literature documents not only the role that socioeconomic status plays in shaping preconditions of childhood disability, such as rates of prematurity, but also the likelihood that lower-income children will suffer from significant developmental delays, behavioral problems, and conditions such as ADHD.⁶⁴

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Research also demonstrates that the relationship between income and health gets stronger with age, and that children from low-income families often experience more health problems and have more difficulty recovering from those health shocks.⁶⁵ Families with fewer resources also experience more barriers to receiving appropriate health and educational services and other necessary resources that can play a significant role in the capacity of the child and family to successfully adapt to or overcome the disability. The impact of socioeconomic status on the natural history of disabilities has been illustrated in cohort studies from England that compare cognitive and behavioral outcomes of low-birth-weight children and children born in the normal weight range. These longitudinal data show that low-birth-weight babies start life with greater rates of developmental delay, but that low-birth-weight babies from higher-income families surpass the function of even

normal-birth-weight babies from low-income families.⁶⁶ Better longitudinal data on the trajectory of developmental disabilities would go a long way toward understanding the role that social disadvantage plays in the origins, development, persistence, and resolution of disabilities in children.

Measurement of Disability and the Need for Better Data

Measures of disability are derived from conceptual models. Given the recent nature of the evolution of disability models from biomedical to those that are multidimensional and ecological, it is not hard to understand why there are gaps in how the origins, determinants, prevalence, trends, and trajectories of childhood disability are measured. The biomedical paradigm of disability measurement has dominated the field, and while the newer conceptual approach embodied in the WHO's international classification system and the UN Convention on the Rights of Persons with Disabilities is gaining ground, it has yet to be incorporated in national surveys in the United States. Moreover, the assessment of disability is plagued by the use of a hodgepodge of different definitions and measures. Current estimates thus tend to vary across surveys that are conducted by different organizations and agencies to fulfill very different measurement surveillance and administrative goals (see table 2).

Furthermore, most population-based data on disability are derived from cross-sectional surveys. To date, few longitudinal surveys, that is, surveys that follow the same individuals over time, have been conducted. Such surveys are needed to understand how disability develops, evolves, and potentially remits in U.S. children. The dynamics of disability in the child population is one of the areas where there has been a paucity of data.

Without better data on the natural history of childhood disabilities, including changes in biological and clinical manifestations, as well as environmental adaptations and response to various types of interventions designed to treat and manage disability, health researchers will find it difficult to understand the difference between children who have severe and relatively static disabilities and those who might have moderate or mild disabilities that may be quite responsive to prevention, early intervention, and rehabilitation. For disabilities that arise as a result of major and often life-threatening health shocks (major illness, accidental or intentional injury) or through the cumulative impact of a series of smaller health shocks, the natural history of a disability will depend not only on disruptions to health and biological function but also on the capacity of the child, family, and their immediate and broader communities to respond. A young child with sufficient developmental plasticity or enough biological or behavioral reserves will respond quite differently to a health shock than will a child who has limited personal, familial, or community capacity or resources. For example, children who are born prematurely with neurodevelopmental vulnerabilities and respiratory dysfunction may follow a path of continued and increasing functional limitations, or they may be afforded the kinds of adaptive interventions that help them overcome their biological deficits and achieve normal developmental function. These alternative paths will depend on the nature of their biological deficit as well as on the ability of the family, the health system, and other community resources to rally in service of their adaptive developmental goals.

Going forward, a strategic measurement system that responds to the necessity for better and more actionable data is sorely

needed. Such an approach must not only incorporate newer conceptualizations of disability but also respond to life-course models of how health develops so that better measurements of life history pathways, transitions, and turning points are routinely used. In creating this measurement strategy, it will be important to measure the origins, onset, and developmental trajectories of disabilities; to measure the risk factors that enhance the likelihood of developing chronic and disabling health conditions or factors that protect a child from experiencing those risks or actively promote optimal health development; and to include better measures of socioeconomic disparities and how those disparities develop over time. In addition, it is important to understand differences in individual disability development pathways as a basis for designing effective individual and population-based interventions aimed at preventing the development of disabilities in the first place and ameliorating the impact of those that do develop.

Improving Understanding of Childhood Disability

Different models of health, disease, and disability are influenced by and must respond to the dominant operating logic that organizes the structure and function of the larger health and health care system. The biomedical model of disability arose when health was narrowly defined by the absence of disease and the contributions of psychosocial factors were rarely considered or addressed. The ICF and UN convention focus on the role of environment and the importance of social participation reflects the ascendance of biopsychosocial models of human health and disability development that first emerged in the 1970s and have only recently gained prominence. This evolution in thinking has helped to broaden not only the conceptual

understanding of disability but what constitutes appropriate measurement.

It has been argued that health systems are evolving toward a new era of health where the operating logic of the health and health care system will focus on optimizing the health of the entire population.⁶⁷ As health researchers attempt to understand the causes of disability, explanatory models are becoming more sophisticated, shifting their focus from single and multiple risk factors to more dynamic, complex, and emergent factors organized around the development of health over the life course.⁶⁸ Concepts of child health are also evolving beyond biopsychosocial constructs to embrace ideas from systems and complexity theory to describe the evolving qualities of health, disease, and disability as they develop dynamically. In 2004 the Institute of Medicine proposed a new definition of health in childhood: the extent to which children are able or enabled to “a) develop and realize their potential, b) satisfy their needs, and c) develop the capacities that allow them to interact successfully with their biological, physical, and social environments.”⁶⁹ This new definition describes health as a developmental capacity that enables individuals to achieve specific goals. This developmental definition, coupled with the UN convention definition, which highlights the interactional nature of disability, leads us to consider how best to define disability in children. We propose the following definition:

A disability is 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.

This definition highlights the developmentally contingent relationship between health, functioning, and the environment; the gap in function between the child's abilities and the norm; and how this gap limits the child's ability to engage successfully with his or her world. Consistent with the ICF-CY and the UN convention, this more developmentally focused definition recognizes the dynamic nature of disability and how the experience of disability can be modified by factors in the child's environment. Also consistent with the newer framing of disability, our proposed definition does not require a specific diagnosis. It does require consideration of the continuum of health (from thriving to poor) as well as the continuum of disability (from enabled and flourishing to limited in all domains and functions). By incorporating notions of developmental potential and plasticity into considerations of disability, new strategies for intervention, remediation, adaptation, and accommodation can be considered even in the face of significant biological loss. Advancing this definition and conceptual approach will also provide new and better ways of understanding how children move along a health continuum from disability to flourishing, promoting ways for children to meaningfully engage in relationships, educational opportunities, and other activities that allow them to achieve happiness and life satisfaction.⁷⁰

Challenges for the Future, Opportunities on the Horizon

Although the causes remain unclear, data on childhood disability suggest that the proportion of children experiencing disability is steadily increasing, and that the conditions underlying those disabilities are shifting from a dominant mix of traditional medical conditions and orthopedic impairments to a preponderance of mental, behavioral, and

developmental conditions. Questions remain about how much of this increase in prevalence is "real" and what proportion results from changes in recognition, diagnosis, availability of health care services, and the way that disability in children is measured. Nonetheless a large, and potentially growing, number of children are limited in their ability to engage in age-appropriate activities and face reduced opportunities to participate in social and educational offerings. These children are likely to become adults with chronic and disabling health conditions; as such they represent not only a burden for families, schools, and other institutions but also an enormous loss of human capital, with implications for ongoing health care, their economic well-being, and social welfare. The data presented here suggest a continuing challenge to the nation's public health system. Yet, clear data are lacking on the nature of the causes, consequences, and costs of disability.

There is obviously a need for better information, more complete data, and more up-to-date, comprehensive, and integrated measurement. Currently there exists a host of different surveys and data collection mechanisms that use different concepts, definitions, and measures. The resulting data are difficult to interpret, cross-link, and harmonize. These survey data sets also provide very little information about the causes, dynamics, trajectories, and burdens of disability, making it very difficult to develop effective prevention, intervention, or accommodation strategies. The Federal Interagency Forum on Child and Family Statistics, the National Academy of Science, or some similar neutral and cross-cutting organization should develop a plan to correct the deficiencies in the national data infrastructure and ensure that clear, complete, and comprehensive data on childhood

disabilities are available to address key policy questions, including trends in prevalence, changing distributions, and long-term consequences of childhood disability.

Several major changes are occurring in the health care system and in health measurement that are likely to influence future trends in the prevalence and impact of disabilities on U.S. children. First, as health systems incorporate forward-looking programs designed to optimize the health of all citizens, the measurement of positive health development and health potential is becoming ever more important. For example, the inclusion of new measures of healthy development in the 2011 National Survey of Children's Health will provide additional opportunities to understand the factors that are associated with more optimal outcomes for children, including those with disabilities. Ultimately, better measures should result in a greater emphasis on connecting the dots across the life course, thus enhancing understanding of mechanisms that determine how at-risk families, toxic environments, and other social factors literally get under the skin, influence genetic predispositions and the development of biobehavioral pathways, and also produce resilience in the face of adversity.

One of the great opportunities to better understand the prevalence, determinants, and trends of childhood disability is the National Children's Study (NCS), sponsored by the Eunice K. Shriver National Institute for Child Health and Human Development. When fully implemented, this study will follow at least 100,000 children across the United States from preconception through the first twenty years of life. This study holds the promise of being able to measure many of the risk, protective, and promoting factors associated with a range of child outcomes,

including those associated with the development of a range of impairments. The design of the NCS and its focus on multiple levels of dynamic interaction between children and their environment will also permit a more finely tuned analysis of how impairment manifests and the factors that influence differing levels of participation in normal daily activities.

Given the enormous investment in the NCS, and its potential capacity to address many (but not all) of the current information and data gaps, steps should be taken to consider linking the NCS measurement development process with other existing and ongoing data monitoring efforts. Such coordination could ensure greater harmonization of data elements and greatly improve the ability to cross-link data on health and disability in the future. While it is tempting to make the NCS the "great data hope" of the future, much can be done to make better use of existing data, including finding ways to upgrade periodic national health surveys with better and more explanatory questions about childhood disability, as well as linking health and education surveys with other program administrative data from special education, early intervention, and disability treatment programs. As the nation builds an electronic health information infrastructure, there will also be growing opportunities to collect new and different information on child health and disability and to take advantage of the power of electronic health records to better link data. This effort will not happen on its own, however, and requires a strategic design, leadership, and financial support.

Conclusion

Current data indicate that the number of children with disabilities is increasing and that the nature and type of health conditions

responsible for these impairments is dramatically changing. Despite improvements in recognition, early intervention, diagnosis, and a range of treatment and intervention programs, significant social disparities persist. Lack of long-term longitudinal cohort data and of appropriate measures of the array of potential influences that could be responsible for these worrisome trends hamper our ability to fully understand their causes and inhibit formation of more strategic, responsive, and effective policies, programs, and interventions. The negative implications

for health care, dependency, and educational costs of a growing number of disabled children lend urgency to the need to better understand and address this growing health, economic, and social liability. We call upon policy makers at all levels of governance to engage in a process that will strengthen existing data systems and lead to the development of programmatic enhancements to reduce the prevalence and severity of childhood disability. Special attention should be given to eliminating long-standing disparities in the prevalence of disability.

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Childhood Health: Trends and Consequences over the Life Course

Liam Delaney and James P. Smith

Summary

This article first documents evidence on the changing prevalence of childhood physical and mental health problems, focusing on the development of childhood health conditions in the United States. Authors Liam Delaney and James Smith present evidence on the changing prevalence of childhood chronic conditions over time using recalled data as well as contemporaneous accounts of these childhood health problems. The raw data from both sources show sharp increases in the prevalence of most childhood physical health problems (such as asthma, allergies, respiratory problems, and migraines) over time. However, inferring trends is difficult because such data are also consistent with improved detection of childhood disease, and many of the causes of childhood disease have not worsened over time. Conclusions about rapidly rising rates of childhood physical health problems over time are premature at best, especially concerning the magnitude of trends. Documenting real changes in the prevalence of specific diseases is a high-priority research topic. In contrast, the evidence is much stronger that childhood mental health problems are becoming worse.

The authors next present new evidence on the effects of early childhood physical and mental problems on health and economic status in adulthood. They find that both childhood physical and mental health problems contribute significantly to poorer adult health. However, they also find that childhood mental health problems have much larger impacts than do childhood physical health problems on four critical areas of socioeconomic status as an adult: education, weeks worked per year, individual earnings, and family income.

Finally, the authors examine evidence regarding the efficacy of early mental health treatment for children in terms of promoting good health later on. Existing studies suggest that a combination of cognitive behavioral therapy and medication appears to be effective in the treatment of both anxiety and depression in children. However, much more research is needed on the efficacy of these childhood interventions into adulthood. Clinical trials have been too short to evaluate the long-term impacts of various forms of treatment, and these impacts are definitively long term.

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Evidence indicates that childhood health has persistent effects through adulthood on health and socioeconomic status.¹ This paper examines the changing prevalence of childhood physical and mental health conditions, particularly in the United States; considers the estimated lifetime economic costs of childhood health problems; and reviews the literature on costs and consequences of childhood interventions.

Recent work has documented the shift in developed countries from focusing on early life health crises that often result in death to identifying and treating specific chronic childhood illnesses and providing a foundation for good child mental health. At a societal level, the growing importance of childhood mental health is emphasized in several recent papers.² We argue that poor treatment of childhood mental health problems carries significant long-term costs not only to individuals but to large populations.

How the approximately 75 million U.S. children through age 18 are provided with the best possible conditions for good mental and physical health will affect their well-being now and have implications for America's transition to an increasingly graying society. Americans spend proportionately more of their income on health care than residents of any other country in the world, and federal, state, and local health care agencies spend more than \$1 trillion each year. It is possible that the promotion of childhood health might reduce these costs in the long run.

We present evidence on the changing prevalence of physical and mental health problems for American children and raise issues about the reliability of this evidence. Then we examine the lifetime economic consequences

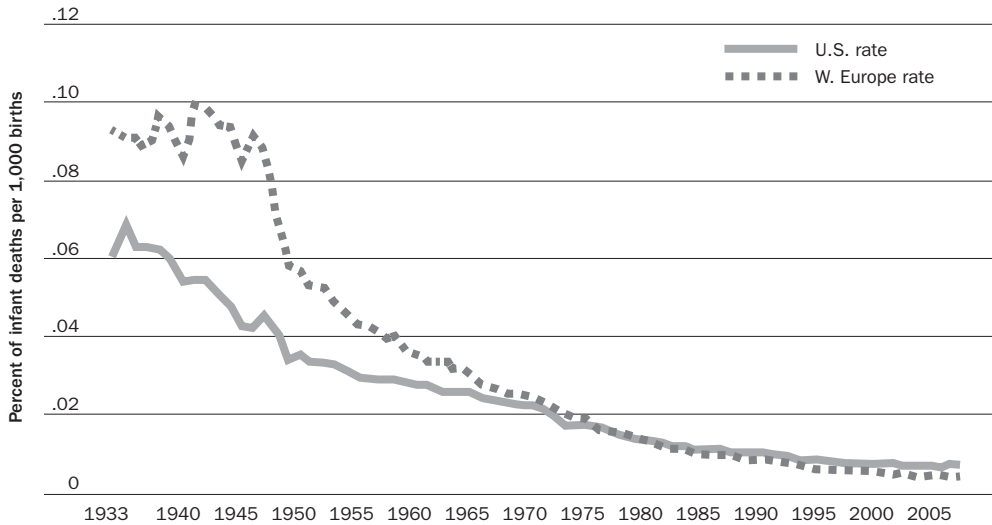
of poor health in childhood, with an emphasis on distinguishing between childhood physical and mental health. Finally, we discuss potential routes to improve outcomes for children with mental health disorders and offer suggestions for research and policy.

Global Trends in Childhood Health

Robert Fogel documents historical shifts in patterns of health through three periods: first, where infant mortality is high and life expectancy low, largely because of food shortages; second, where, although improved from the first stage, infant mortality remains high and life expectancy remains low because of infectious diseases; and third, where infant mortality falls and life expectancy increases significantly as major infectious diseases are suppressed by sanitation systems, vaccinations, improved nutrition, and other factors.³

Inadequate sanitation and nutrition are common in poor countries, where an estimated 7.8 percent of childhood deaths are caused by complications arising from below-normal birth weight, 6.6 percent of childhood deaths stem from unsafe sex (that is, sexual behaviors that increase the risk of contracting a sexually transmitted disease), and 6.1 percent arise from unsafe water.⁴ Globally, the main causes of death among children are pneumonia (17 percent), diarrhea (17 percent), other infections (12 percent), severe neonatal infections (11 percent), premature birth (11 percent), and malaria (7 percent). The main factors implicated in child deaths in developing countries include deficiencies of zinc, iron, and iodine; poor sanitation; suboptimal breast-feeding patterns; and poor nutrition. Worldwide, deaths of children younger than age five dropped from 11.9 million in 1990 to 7.7 million in 2010, with almost half of the percentage decline occurring in sub-Saharan

Figure 1. Infant Mortality Rate in the United States and Western Europe



Source: Berkeley World Mortality Tables.

Africa, a third in South Asia, and less than 1 percentage point in high-income countries.⁵

In the United States, recent work has demonstrated a shift in patterns of childhood illness away from acute health problems and toward chronic conditions. Several recent papers have argued that, contrary to the picture of improving child health suggested by mortality data discussed below, the extent of childhood chronic physical illnesses is increasing in the United States.⁶

Changing Patterns in the United States

As outlined by David Cutler and Ellen Meara, increasing life expectancy during the first half of the twentieth century was driven largely by substantial declines in infant mortality related to improved sanitation and nutrition, while other factors such as medical improvements contributed mainly to increased life expectancy during the second half of the century.⁷ Cutler, Angus Deaton, and Adriana Lleras-Muney also documented

that declining infant mortality was the most significant contributor to increased life expectancy during the first half of the 1900s.⁸ While medical advances occurred throughout the late twentieth century in treatments of illnesses affecting infants, infant mortality rates were already so low as a fraction of total mortality that the advances had only small effects on overall life expectancy.

Figure 1 shows trends in infant mortality since the mid-1930s in the United States and in a population-weighted average aggregate of Western European countries that have had comparable data and consistent geographical boundaries.⁹ In the United States, there was a rapid decline in infant mortality rates, with the 2008 rate falling below 1 percent. Based on variation in timing and location of scientific advances, Cutler and Grant Miller estimated that improved water purification accounted for almost half of the overall mortality reduction and three-quarters of the decline in infant mortality during the first

third of the twentieth century in America.¹⁰ Cutler and Meara attributed the continuing decline in infant mortality after the 1960s to improvements in neonatal medical care for low-birth-weight babies.¹¹

From the 1930s to 1945, infant mortality rates in Western Europe were higher than in America (see figure 1). During this period, the gap actually widened as the Western European rate stalled, most likely because of the Great Depression and World War II. After the war, Western European infant mortality rates fell rapidly, converged with U.S. rates by the mid-1970s, and then fell slightly below U.S. rates. Still, both U.S. and Western European infant mortality rates are low relative to historical levels and also relative to reported rates of childhood chronic conditions.

Childhood Chronic Conditions

Figure 1 documents a marked improvement in the health of U.S. children when infant mortality is the yardstick. However, as the infant mortality rate declined during the past half-century, public attention in developed countries shifted from acute fatal health problems toward chronic problems. While there is no doubt that chronic conditions are increasing in relative importance, it is often argued that chronic childhood illnesses are increasing in absolute importance as well.

Table 1 uses the childhood retrospective module that was placed into the 2007 wave of the Panel Study of Income Dynamics (PSID) by James P. Smith.¹² The PSID has been tracking incomes and working conditions of a representative sample of American families on a yearly basis since 1967. Given the quality of its economic information, the PSID is an ideal data source to track the impact of poor childhood health on adult health and

socioeconomic status. The major limitation of the PSID was the absence of information on childhood health, which was addressed by the retrospective module. This module enables us to combine childhood health data with excellent adult data on health and socioeconomic status. The information in the module focuses on the presence or absence of chronic conditions rather than on functional disabilities associated with those conditions.

Using calendar life-history methods, the initial set of questions asked respondents in the module whether—in the years up to and including age sixteen—they had any of a list of important childhood illnesses or conditions. This list included asthma, diabetes, respiratory disorders (such as bronchitis, wheezing, hay fever, shortness of breath, and sinus infection), speech impairment, allergic conditions, heart trouble, chronic ear problems or infections, epilepsy or seizures, severe headaches or migraines, stomach problems, high blood pressure, difficulty seeing with eyeglasses, mumps, measles, chicken pox, and three indicators of childhood mental health problems (depression, drug or alcohol problems, and other psychological problems). In the last category, there was no mention of the specific problem, such as attention-deficit/hyperactivity disorder (ADHD) or bipolarism.

Table 1 organizes reported prevalence rates of these childhood diseases by birth years of PSID respondents. Because the most recent group in the table was born in 1986, the data do not address rates of disability among younger groups of children who have not yet reached their adult years, which for our purpose we define as beginning at age twenty-five. These data offer a valuable and consistent picture of the consequences of poor childhood health in older individuals, where these pathways can be traced.

Table 1. Percentage of People in Each Birth Group with a Childhood Illness

		1986–77	1976–67	1966–57		1956–47	1946–37	<1936
Measles		7.6	15.5	49.8	Vaccine 1963 ↓	81.8	85.2	86.7
Mumps		4.3	12.7	43.4		68.1	67.3	68.6
Chicken pox	Vaccine 1995 ↓	83.0	79.1	75.9		83.0	79.6	72.3
Asthma		12.9	9.0	5.5		5.6	4.1	2.8
Respiratory illness		14.3	12.6	9.5		10.8	7.2	7.2
Speech impediment		3.3	2.4	2.7		2.6	1.6	1.0
Allergies		12.3	11.6	8.9		9.4	6.9	5.0
Heart trouble		1.8	1.7	1.6		1.3	2.8	1.0
Ear problem		8.6	7.8	5.4		6.2	7.9	7.2
Headaches or migraines		11.9	9.0	6.6		6.7	5.5	5.8
Stomach problem		5.5	4.0	3.7		3.4	2.8	2.6
Depression		7.3	4.6	3.1		3.0	1.2	1.0
Diabetes		0.8	0.5	0.1		0.2	0.2	0.2
Epilepsy or seizures		1.2	1.2	1.3		0.6	0.5	0.0
Hypertension		1.1	0.4	0.3		0.1	0.4	0.9
Number		1,813	1,531	1,715		1,375	553	557

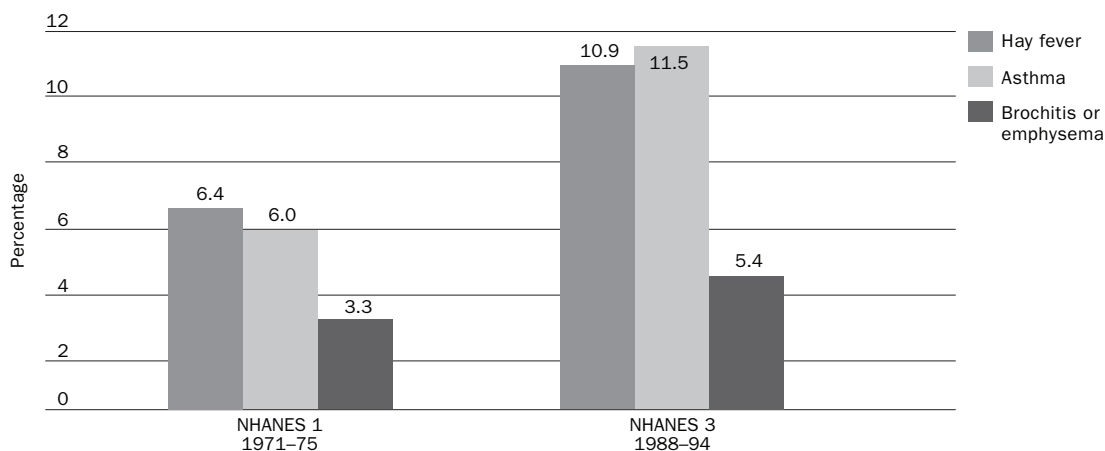
Source: James P. Smith, "Re-constructing Childhood Health Histories," *Demography* 46, no. 2 (2009): 387–403.

These data show several interesting patterns. First, when effective vaccines were developed, common childhood infectious diseases almost disappeared—first measles and mumps, and more recently chicken pox, for which a vaccine was developed in 1995.¹³ Second, it is difficult to read conclusive evidence on the direction of secular trends with regard to rarer childhood diseases—type 1 diabetes, hypertension, and epilepsy or seizures—although there may be an increase in the most recent birth years. Third, table 1 suggests that several common childhood diseases are becoming more prevalent. This is especially the case for respiratory diseases (asthma and respiratory illness), allergies, and depression.

There are reasons why the data in table 1 should not be taken at face value. Because the data are based on recall, memory biases may play a role. Memory typically declines with time, although salient events may suffer

less from this memory decay, and memories of childhood have been shown to be superior to memories of other times of life.¹⁴ A second problem is the difficulty of separating true prevalence and incidence from improved detection. For most childhood diseases, diagnosis and detection have improved over time. For some diseases, including mental illness, there may also be lower thresholds for diagnosis, reflecting both medical advances and changing social attitudes. Finally, at very old ages, mortality selection effects, whereby the least healthy die at earlier ages, may be operative because those with childhood diseases may have lower life expectancies. However, selective old age mortality is not likely to explain the increasing trends among children born in the most recent birth years. Declines in infant mortality could lead to an alternative form of selection bias if unhealthy infants become increasingly likely to survive over time.

Figure 2. Prevalence Rates of Selected Childhood Diseases among 12–17-Year-Olds



Source: James P. Smith, “Re-constructing Childhood Health Histories,” *Demography* 46, no. 2 (2009): 387–403.

How serious are these sources of bias? The second form of mortality selection—healthier babies surviving to older ages—cannot be playing much of a role in the rise in childhood chronic illness or childhood disability, given the low rates of infant mortality evidenced in figure 1 for people who are now less than sixty years old. For younger age groups, trends in childhood chronic disease still appear to be growing over time.

One way of assessing how important recall bias could be is to use contemporaneously reported data on childhood chronic conditions. Even then, one difficulty is that statistics on American health, unlike those related to the U.S. economy for instance, do not generally reflect consistent, comparable reporting over time. Data on health conditions over time come from two long-running U.S. health surveys, the National Health and Nutrition Examination Survey (NHANES) and the National Health Interview Survey (NHIS), and both periodically have changed definitions of what is included within a disease category.¹⁵ Using subsets of childhood diseases

that can be defined more or less consistently over time, figure 2 examines trends in reported rates of asthma, bronchitis, and hay fever. Similar to trends from recall data, all three childhood chronic diseases exhibit sharply rising secular trends. The similarity between the contemporaneous record and the PSID recall data indicates that recall bias is unlikely to be the primary driver of the secular trends in table 1.

Other studies using contemporaneously reported statistics also show increased rates of chronic illnesses among Americans. James Perrin and others documented substantial increases in childhood chronic illnesses such as obesity, asthma, and ADHD in the United States.¹⁶ Jeanne Van Cleve and others, using data from three National Longitudinal Survey of Youth groups aged two to eight, reported that the prevalence of any chronic health condition was 12.8 percent for a group in 1988 that was followed to 1994, 25.1 percent for a group in 1994 followed to 2000, and 26.6 percent for a group in 2000 followed to 2006.¹⁷ Using data from the Centers

for Disease Control and Prevention, Lara Akinbami and others showed an increase in the prevalence of childhood asthma from approximately 3.6 percent in 1980 to about 9.7 percent in 2007.¹⁸ Some 14 percent were reported as either currently having or having once been diagnosed with asthma during their lifetimes, based on the 2009 National Health Interview Survey.

Rising rates of chronic diseases among children present a puzzle in light of rapidly declining infant mortality rates. And because many indicators of adult health have been improving over this period, questions arise about the extent to which childhood health contributes to adult health, and more basically the extent to which chronic childhood conditions are actually increasing.

Some of the major factors thought to contribute to better childhood health have been improving rather than worsening. Table 2 focuses on some determinants of child health and shows that the proportion of children who grew up in a home where neither parent smoked has been rising and that the proportion of PSID respondents who thought that they grew up in a poor family, as they self-defined what poverty meant, has been

declining over time. While this may seem surprising in light of today's headlines about rising levels of child poverty, the period when these PSID adults were children was a time of significant declines in U.S. poverty, including among children. Although older mothers (those age thirty-five or older) are a risk factor for poor childhood health, once again we see declining trends in table 2. Many environmental problems (like air pollution) related to children's health are being corrected, although it is possible that new environmental toxins are being introduced.

While childhood obesity rates have risen rapidly in recent years, figure 3 demonstrates that most of that rise in childhood obesity affected the youngest age groups in table 1 and hence cannot be responsible for the table 1 trends. Figure 4 indicates that there has been only a small rise in low-birth-weight babies over time.

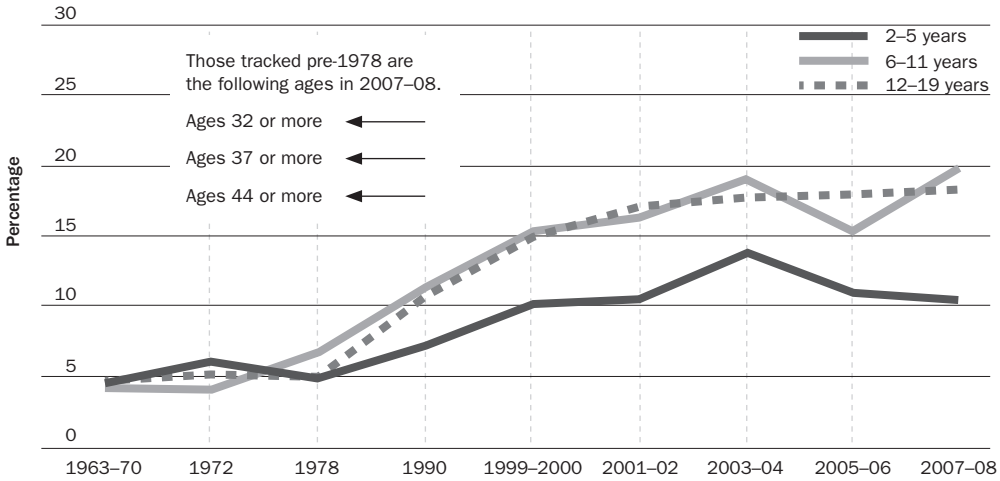
Although there is almost universal agreement that reported rates of childhood chronic conditions are rising, we believe that any conclusion about rapidly rising rates of childhood chronic physical health conditions over time are premature at best, especially concerning the magnitude of trends. More

Table 2. Percentage of People in Each Birth Group by Selected Childhood Family Characteristics

	Year of birth					
	1986-77	1976-67	1966-57	1956-47	1946-37	<1936
Percentage of people where neither parent smoked when respondent was <17	51.3	41.1	39.2	34.9	32.3	43.0
Percentage of people where parents were poor when child	26.9	31.4	34.8	41.7	49.9	55.9
Percentage of children raised in a home with both parents	59.5	66.2	70.4	76.4	79.7	75.4
Percentage of children born to a mother 35 years old or older	5.5	5.5	10.3	10.9	12.6	NA

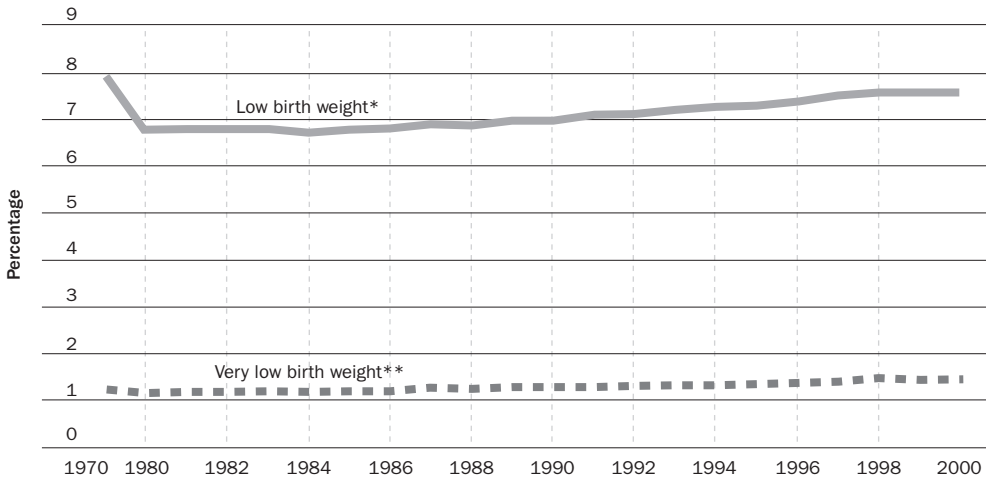
Sources: Data on children born to a mother age thirty-five or older are from NCHS-National Vital Statistics Reports. All other data from the Smith PSID module.

Figure 3. Trends in Obesity among Children and Adolescents: United States, 1963–2008



Source: Cynthia Ogden and Margaret Carroll, *Prevalence of Obesity among Children and Adolescents: United States, Trends 1963–1965 through 2007–08* (National Center for Health Statistics, June 2010) (www.cdc.gov/nchs/data/hestat/obesity_child_07_08/obesity_child_07_08.pdf).

Figure 4. Low-Birth-Weight and Very Low-Birth-Weight Rates by Year, United States, 1980–2000, All Races



Source: National Center for Health Statistics. Birth weight data based on birth certificate data.
 Note: Low birth weight is less than 2,500 grams. Very low birth weight is less than 1,500 grams.

work is needed to separate out the impacts of improved detection and diagnosis. The real trends in health may be nowhere near as dramatic as suggested by simple time-series of reported prevalence rates of childhood disease. Documenting real changes in

prevalence of specific diseases is a high-priority research topic.

One area of greater confidence about deteriorating trends over time concerns childhood mental health issues. As table 2 shows, one of

Table 3. Percentage of People in Each Birth Group by Childhood Illness and Family Income

	Year of birth			
	1986–77	1976–67	1966–57	1956–47
Measles	4.6 11.6	9.7 18.7	45.9 52.8	Vaccine 1963 ↓ 85.6 79.7
Mumps	2.2 8.1	7.4 15.5	42.9 48.2	Vaccine 1963 ↓ 76.9 66.2
Chicken pox	Vaccine 1995 ↓ 91.1 78.1	86.2 74.8	82.2 72.8	90.9 80.3
Asthma	10.8 14.5	7.8 10.4	6.0 5.7	4.5 6.4
Respiratory illness	16.4 11.5	14.2 11.4	11.6 7.7	12.4 11.5
Speech impediment	4.0 4.4	2.7 2.0	3.8 2.6	1.7 1.9
Allergies	15.1 9.7	14.9 10.2	10.9 7.7	9.6 7.1
Heart trouble	1.4 3.0	1.1 1.9	1.5 1.4	0.6 1.9
Ear problem	10.2 7.7	8.9 7.5	6.8 4.9	7.3 7.7
Headaches or migraines	10.8 12.1	8.9 8.7	5.5 7.3	6.8 9.0
Stomach problem	5.7 6.2	3.1 4.4	3.2 3.8	1.7 4.5
Depression	6.7 9.8	3.8 5.4	2.7 3.3	3.4 4.5
Diabetes	0.8 1.5	0.4 0.7	0.3 0.0	0.0 0.0
Epilepsy or seizures	1.1 1.2	0.6 2.4	0.9 1.4	0.6 1.2
Hypertension	0.3 1.8	0.2 0.9	0.5 0.2	0.0 0.0
Number	1,813	1,531	1,715	1,375

Source: Smith PSID module.

Note: The top number represents percentage with a childhood illness in each group above median family income; the bottom number (in bold) represents percentage below median family income.

the drivers of depression in childhood—being raised in the absence of both parents—has been worsening over time.¹⁹ Similarly, in a careful study, Marissa King and Peter Bearman showed that changing diagnosis alone does not explain the increasing rates of childhood autism, even though up to half of the reported increase might be due to changes in reporting and definitions.²⁰ The PSID childhood retrospective module can also display trends based on family income.

Table 3 documents trends for children who lived in households with family incomes above and below the median. Historically, the reported prevalence of the three childhood infectious diseases was greater among better-off American families, as was the effectiveness of vaccines for measles and mumps, reflecting the greater availability of vaccinations to the above-median income group. The pattern of rising prevalence of childhood disease is true both above and

below the median income, but with few exceptions (respiratory illnesses, allergies, ear problems) in the most recent birth groups, prevalence rates are higher for children who grew up in below-median income families. Increases in reported rates of diabetes and hypertension in the below-median income group are especially striking. Our findings are consistent with a large body of research showing that children from low-income families experience higher prevalence rates for the main childhood health problems.

Prevalence rates also vary by race. For example, Akinbami and others, using one measure of social-economic differences, racial differences in asthma prevalence, show Asian American children having lower prevalence than whites, black children having 1.6 times the prevalence rate of whites, and Puerto Rican children having 2.4 times the prevalence rate of whites.²¹ For more on socioeconomic disparities, see the article in this volume by Neal Halfon and others.²²

Long-Term Economic Consequences of Childhood Health Problems

Recent studies have examined the role of environmental shocks such as famines and toxins in affecting early childhood and gestational environments and subsequently influencing the path of development and adult health. A large body of work, reviewed by Tessa Roseboom and others,²³ examined the effects of growing up during the 1944 Dutch famine on later patterns of heart disease; Douglas Almond and others used a 1 percent sample of China's 2000 census and found a range of adverse economic effects on Chinese exposed to the famine of 1958–61.²⁴

The main advantage of these approaches, as argued by their proponents, is that they

provide an opportunity to isolate causal effects of early-life conditions. However, the extent to which the shocks that were examined can be seen as representative of other types of shocks to childhood health remains unknown (see Angus Deaton²⁵). It is important to examine the extent to which shocks generate unintended selection effects, such as differential fertility or mortality, that change the measured average health of surviving babies. However, given the rapid decline of infant mortality in America, and the currently low levels, selection effects due to unhealthy children dying in early childhood are less of an issue.

One common technique scientists use to disentangle cause and effect is to observe “natural experiments,” that is, specific changes taking place in nature, and then study the impact of these changes on other aspects of life. Recent natural experiments on the impacts of early-life conditions stem from Robert Barker's hypothesis that foundations for chronic illness in later life are laid in the uterus. Barker argued that stress to the fetus during pregnancy leads to the diversion of resources to protect the brain at the expense of other organs, weakening these organs and predisposing the fetus to later patterns of disease.²⁶ In line with this, several studies found that birth weight (often used as a proxy for the uterine environment) was a predictor of health in later life.²⁷

Caleb Finch and Eileen Crimmins argued in a 2004 article that much of the improvement in adult health over the centuries came about because of reduced exposure to early-life stresses.²⁸ They provided evidence that declining infant mortality in Sweden predicted mortality declines among adults in the same group. They suggested that lower risk of gastroenteritis among infants might lead to lower risk of inflammation in later life.

Population studies have also examined whether early physical health adversity affects economic circumstances later on. This research follows individuals from childhood to adulthood or supplements existing studies that do follow individuals over time with data that are missing from those studies. The two mainstays of this research are British studies following individuals from the week of their birth, and long-term American studies.

Using the data from the PSID, Smith found that childhood health bears on a range of adult economic variables including levels and trajectories of family income, household wealth, individual earnings, and volume of work that are robust to controlling for personal attributes that are observed in the data and those that are unobserved.²⁹

Anne Case, Darren Lubotsky, and Christina Paxson found that respondents to the United Kingdom National Child Development Study (NCDS) who had low birth weight and poor childhood health experienced later problems that included lower school and occupational attainment. In another paper, Case and Paxson indicated that childhood health (proxied by height) is associated with many positive life outcomes, only some of which are related to education.

One weakness in examining the effects of childhood illnesses on later health and economic status in America is the lack of data that track people from early life through adulthood. Individual life histories have become a useful tool in examining the effects of early conditions on adult health in panel studies, which follow the same respondents over time.³⁰ Life histories ask respondents to recall important information about their early lives, including general childhood health, health care utilization, and onset and duration of childhood illnesses. Visual and verbal

memory cues prompt respondents to remember this information.

Several major studies have employed life-reconstruction data, including the Health and Retirement Study (HRS), the English Longitudinal Study of Ageing, and the Survey of Health, Aging, and Retirement in Europe. (See the data appendix to this volume for additional information about these data sets.) This technique enables researchers to extract relevant information from recent large-scale panel studies that did not interview respondents as children. Using data from HRS and PSID, Smith found that patterns of recalled childhood illnesses closely matched information about illness during respondents' childhoods as measured in the contemporaneously collected American national health surveys, such as NHANES and NHIS.³¹ The recalled measures of childhood illness act as important predictors of later patterns of illness using these samples.³² On the physical health side, Katayoun Bahadori and others reviewed sixty-eight studies and found evidence pointing to associations between asthma, poorer schooling outcomes, and lower future earnings.³³

Lifetime Effects of Childhood Mental Illness

Given the increasing prevalence of mental health problems among young children, the role of childhood mental illness is increasingly important. Janet Currie and others found significant effects of childhood mental health problems.³⁴ They used data based on public health insurance records of 50,000 children born between 1979 and 1987 in Manitoba, Canada. Their design allowed them to compare siblings with noncongenital health problems. They reported that, although childhood *physical* health problems often lead to future health problems, childhood *mental*

Table 4. Estimated Effects of Childhood Health on Adult Health Reported as Excellent or Very Good (Percentage Point Change)

Variables	Across-individual model		Across-sibling model	
	1	2	3	4
Childhood diseases				
Mental health	-12.1***	-14.9***	-10.3***	-9.3**
Physical health	-2.1	X	-9.1***	X
Infectious		4.2***		0.7
Sight problems		-11.0***		-12.0**
Asthma		-6.5***		-8.1**
Diabetes + heart		-17.0***		-10.4
Respiratory + allergies		-2.5*		-1.2
+ ear + stomach		-2.4		-1.2
Speech problems		-0.7		-2.0
Epilepsy		-2.4		-1.3
Headaches		-6.0***		-8.7**
Hypertension		-27.6***		-25.3

Source: Authors' calculations.

Note: Mental health percentages in columns 1 and 3 control for physical health conditions generally; mental health percentages in columns 2 and 4 control for the specific physical health conditions listed in the table. Models also include age controls. Physical health does not include the common childhood infectious diseases.

***Statistically significant at 1 percent level; **statistically significant at 5 percent level; *statistically significant at 10 percent level.

health problems produce significant effects that are not dependent on future physical health problems.

James Smith and Gillian Smith used the retrospective PSID health data to uncover substantial effects of recalled childhood depression on future economic well-being.³⁵ Their estimations showed substantial reductions in income largely caused by a reduction in weeks worked per year. Respondents who reported childhood mental problems also had lower educational attainment, although this effect was small relative to the impact on income. The authors estimated that the family of each affected individual lost about \$300,000 over a lifetime, on a discounted net value basis. The corresponding cost to the current American population would be \$2.1 trillion. Note that this cost is larger than the annual costs calculated by Mark Stabile and

Sara Allin in this volume, in part because it reflects the present discounted value of costs that would be accrued over a lifetime.

Currie and Stabile used Canadian data to examine the long-term effects of ADHD, a common form of mental illness among young children. Controlling for confounding factors, they found that the effects of ADHD are much greater than those of physical health problems.³⁶ They reported reductions in future reading and mathematics test scores and increased probability of future grade repetition.

A New Look at the Effects of Childhood Health

Using the retrospective PSID childhood health module, we present new estimates of the impacts of being in excellent or very good health as a child on the economic and health

aspects of later life as an adult. Our analyses examine the association of both dimensions of childhood health—physical and mental—with salient aspects of adult life: health, education, work, and income.

In the first column of table 4, we summarize the impacts of having any one of the childhood physical health problems (with the exception of measles, mumps, and chicken pox) and the effect of having any childhood mental health problem on whether a person's self-reported adult health in 2007 was excellent or very good. In the second column of table 4, childhood physical health is separated into its component parts, although some subcomponents are aggregated either because of low prevalence or because of the commonality of the size of the effects of the childhood health problem on adult life. The asterisks in tables 4–6 indicate the likelihood that the effect is statistically different from zero (or no effect), with three asterisks indicating one in a hundred, two asterisks indicating one in twenty, and one asterisk indicating a one in ten chance that there is really no effect.

The two models on the left side of the table are estimated using ordinary least squares (OLS), the most widely used statistical way of showing the relationship of one variable to another, conditional on other variables. All the variation used in the OLS model to estimate an average effect represents variation *across people* who were originally children in the PSID. In contrast, the two models on the right side of table 4 focus on comparing siblings within the same families (often called sibling models). All of the variation used in sibling models represents differences *across siblings* in the same family. The sibling models are preferred because they account for all of the common

background characteristics shared by siblings (their family, neighborhoods, and schools) whether or not they can be measured in our models. All full age-range models include controls for being in age groups twenty-one through forty and forty-one through sixty; the over-sixty age group is excluded.

The models in table 4 show the association between childhood physical and mental health problems on the probability of being in either excellent or very good health as an adult. These indicate that childhood *mental* health problems have larger impacts on self-reported adult health than do childhood *physical* health problems, although the two sets of estimates are close in the sibling models. Using the sibling models, this implies that individuals who had a mental health problem as a child or those who had a physical health problem as a child are 10 percentage points less likely to be in excellent or very good health as an adult.

When the childhood physical health problems are separated into the specific childhood physical health problems, the negative effects on adult health are somewhat larger for hypertension, sight problems, asthma, epilepsy, and diabetes. For some childhood physical health problems, there are strong selection effects whereby children in better-off families are more likely to get a particular disease. A good illustration involves the common infectious diseases, where the across-person estimate is statistically significant and positive. In contrast, the across-sibling estimate is small and statistically insignificant. Table 3 suggests that children in better-off families are more susceptible to these common infectious diseases. This selection effect explains why the estimated effect of having these infectious diseases as a child is positively associated with better health

Table 5. Estimated Effects of Poor Childhood Health on Adult Socioeconomic Status (Percentage Point Change)

Socioeconomic indicator	Across-individual model	Across-sibling model
Number of years of adult education		
Mental health	-0.775***	-0.446***
Physical health	0.294***	0.108
Number of weeks worked in a year as an adult		
Mental health	-6.14***	-7.06***
Physical health	-2.25***	-2.20***
Percentage change in earnings†		
Mental health	-37.6***	-47.6***
Physical health	-1.8	-6.2
Percentage change in family income		
Mental health	-33.0***	-36.5***
Physical health	2.1	-12.6**

Source: Authors' calculations.

Note: Models also include age controls. Physical health does not include common childhood infectious diseases.

† Estimated over sample of workers only.

***Statistically significant at 1 percent level; **statistically significant at 5 percent level; *statistically significant at 10 percent level. Percentage changes are from log models and the coefficient is multiplied by 100.

as an adult in the across-person models. This example suggests that some caution is in order when interpreting across-person estimates in various studies in the literature.

Table 5 lists our estimates of the average effects of mental and physical childhood health problems (without the childhood infectious diseases) for adult socioeconomic status, including years of schooling, the number of weeks worked in a year, percentage change in earnings, and percentage change in family income. For the number of years of schooling—the most common adult socioeconomic factor examined in the literature—the across-person estimates suggest that the damage done on adult life is much larger for mental health problems (a loss of 0.8 of a year of schooling) than for physical health problems (where the estimated effect is actually positive). In the preferred across-sibling models, the impact of childhood mental health problems remains statistically

significant—a reduction of about a half-year in schooling—but the impact of childhood physical health problems is insignificant. Mental health problems as a child appear to be much more important than physical health problems during childhood on limiting educational opportunities.

For the number of weeks worked in a year, we find the same relationship: childhood mental health problems are much more important than childhood physical health problems. In fact, the impacts of childhood mental illness are about three times greater on the number of weeks worked than those for childhood physical illnesses. The preferred across-sibling model indicates almost seven fewer weeks worked yearly by those who had childhood mental health problems. When we examine the percentage change in adult labor market earnings, estimated impacts again are much larger and more statistically significant for childhood

Table 6. Estimated Effects of Childhood Health on Adult Outcomes by Age Group, Using Across-Sibling Models (Percentage Point Change)

Outcomes	Age 21–40	Age 41–60
Adult health is excellent or very good (percentage points)		
Mental health	-13.5***	-4.7
Physical health	-8.1***	-10.8***
Number of years of education as adult		
Mental health	-0.486***	-0.288
Physical health	0.127	0.043
Number of weeks worked in a year as an adult		
Mental health	-8.39***	-4.54
Physical health	-1.87*	-2.64**
Percentage change in earnings		
Mental health	-53.0***	-25.9
Physical health	-5.4	-8.6
Percentage change in family income		
Mental health	-39.8***	-25.7
Physical health	-10.4	-14.5*

Source: Authors' calculation.

***Statistically significant at 1 percent level; **statistically significant at 5 percent level; *statistically significant at 10 percent level. Percentage changes are from log models and the coefficient is multiplied by 100.

mental health problems than for childhood physical health problems.

Our preferred and most general economic outcome is the percentage change in family income. Using across-sibling models, the estimate for children's mental health problems suggests a 37 percent lower family income—a decline that is three times greater than the estimated impact for a childhood physical health problem.

All of these adult socioeconomic models point to the same conclusion: childhood mental health problems have much larger effects on later adult life than childhood physical health problems.

An important issue not addressed by table 5 concerns how these effects of childhood health problems vary by age. Using the preferred across-sibling models, table 6 provides

separate estimates for two age groups, twenty-one through forty and forty-one through sixty.

These estimates across age groups for a single calendar year (2007) could be interpreted either as effects associated with an individual becoming older (aging effects) or as effects associated with individuals being born in different calendar years (birth-cohort effects). There is no way to identify separate birth-cohort or aging effects with data in a single calendar year because an older person must necessarily have been born in an earlier calendar year. But physical improvements in workplace disability accommodations over time may have made physical health problems less limiting over time, especially for younger persons. The extent of accommodation may be much smaller for mental health problems. In fact, the impact of childhood mental health may have increased over time as the U.S. economy increasingly values

mental and academic skills over physical skills. Whichever interpretation is preferred, estimates for these socioeconomic outcomes indicate that the effects of childhood mental problems are somewhat smaller in the older age group for all such outcomes, while the childhood physical health outcomes become slightly larger in the older age adult group.³⁷

Effect of Interventions in Influencing Lifelong Health: A Focus on Mental Health

Given the prevalence and large long-run effects of childhood mental health conditions such as ADHD and childhood depression, the importance of remediation is readily apparent (see the article in this volume by Mark Stabile and Sara Allin for a more complete treatment of ADHD³⁸). Effective interventions could potentially offset not only the psychological and economic costs experienced by children and their families when children are young but also reduce high costs associated with lifelong psychological problems. Recent studies examining the lives of individuals who have experienced childhood psychological problems indicate lifetime costs in terms of earnings alone that could exceed \$500,000.³⁹ Such assessments underestimate total effects because they do not include many costs that spill over to family members, such as treatment costs and mental distress of the family. Many studies have examined the most effective pharmacological, behavioral, and psychological treatments for each of these problems.

Attention-Deficit/Hyperactivity Disorder, or ADHD

ADHD is the most common childhood mental health condition. Treatment for ADHD generally takes the form of pharmacological or behavioral interventions. Several studies have examined effects of stimulant and

nonstimulant medication either solely or in combination with other forms of treatment.⁴⁰ These studies have documented the efficacy of stimulant medications for treatment of ADHD.⁴¹ Studies continue to look into the optimal combination of pharmacological and behavioral interventions, and the effectiveness of different types of behavioral interventions and pharmacological treatments.

One of the largest recent examinations of the effectiveness of treatments for ADHD is the National Institute of Mental Health's multimodal study. Researchers studied four groups of children: those who were treated with intensive medication management alone, those who were treated with intensive behavioral treatment alone, those who received a combination of both, and a control group of children who received the care that was routinely available in the community. The fourteen-month follow-up of more than 600 children revealed that both medication and combined conditions were superior to community care.⁴² Effects, while diminished, were also apparent in a follow-up ten months later.⁴³

While the literature provides strong evidence that appropriately applied stimulant treatment, perhaps in combination with behavioral interventions, can alleviate at least some symptoms of ADHD, there is no way yet of knowing whether these treatments break the link between childhood ADHD onset and the potential adverse effects over the long term. This gap in our knowledge is due largely to the fact that most studies have not followed children treated for ADHD over long periods of time.

Childhood Depression

Childhood depression is another of the more common childhood mental health conditions. For childhood depression, studies

have evaluated the effectiveness of various pharmacological, behavioral, and psychological interventions. For the latter two, the use of cognitive behavioral therapy, or CBT (an approach that focuses on patients' understanding of their patterns of thoughts and beliefs and the behaviors that flow from those thoughts), has been widely studied. In general, this literature has suggested that CBT is effective in treating both anxiety and depression. A 2005 Cochrane Literature review, authored by John Cochrane, of CBT treatment for anxiety in children found a 50 percent success rate, higher than in control cases.⁴⁴ Several experiments and reviews found that CBT is effective in treating child and adolescent depression.⁴⁵

For pharmacological interventions, several studies examined the use of selective serotonin reuptake inhibitors (SSRIs, commonly prescribed antidepressants) to treat childhood depression. Uncertainty remains about the efficacy of SSRIs in treating childhood depression. Almost all reviews stress the incompleteness of the evidence in terms of drawing conclusions on efficacy. The Cochrane review by S. E. Hetrick and others reviewed twelve trials examining the use of SSRIs in children and concluded that there was little evidence for effectiveness.⁴⁶ However, several papers and reviews demonstrated the effectiveness of the SSRI fluoxetine for treatment of childhood depression.⁴⁷ Although fluoxetine, sold as Prozac and under other brand names, is currently FDA-approved for children, unlike some other SSRI medications, debate continues about the potential for increased risk of suicide attempts.⁴⁸

There is much still to learn about optimal combination of treatments in terms of promoting child mental health. Reviewers are almost unanimous in believing that the

existing body of evidence, based largely on short-term and small-scale trials, does not support efforts to draw substantive conclusions regarding overall efficacy. Given evidence on the lifelong effects of childhood psychological problems and the growing number of trials that have tested the efficacy of different treatments, longer-term follow-up studies are needed to examine the effectiveness of these treatments in breaking the link between childhood psychological problems and negative consequences in adulthood. Complex issues also surround how results from clinical trials might be scaled up to the broader population. While CBT has been demonstrated to be effective in treating childhood depression in many trials, the task of rolling out this and other effective treatments to wider and more heterogeneous populations is obviously more difficult than demonstrating effectiveness in single trials.

Conclusions

While the raw data show sharp increases in the prevalence of most childhood physical health problems over time, such data are also consistent with improved detection of childhood disease, especially since many causes of childhood disease have not become worse over time. Conclusions about rapidly rising rates of childhood physical health problems over time are premature at best, especially concerning the magnitude of trends. Documenting real changes in the prevalence of specific diseases is a high-priority research topic. In contrast, the evidence that childhood mental health problems are becoming worse over time is much stronger.

We find that both childhood physical and mental health problems result in poorer adult health. However, childhood mental health problems have much larger impacts than do childhood physical health problems on four

critical areas of socioeconomic status as an adult: education, weeks worked in a year, individual earnings, and family income. For example, mental health problems in childhood are associated with a 37 percent decline in family income, three times greater than the decline related to having physical health problems.

Finally, we examine evidence on the efficacy of early mental health treatment for children

in terms of promoting good health later on. Existing studies suggest that a combination of the use of cognitive behavioral therapy and medication appears to be effective in the treatment of both anxiety and depression in children. However, much more research is needed on the long-run efficacy of these childhood interventions. Clinical trials have been too short to evaluate the long-term impacts of medication, and the impacts are definitively long term.

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The Economic Costs of Childhood Disability

Mark Stabile and Sara Allin

Summary

Childhood disabilities entail a range of immediate and long-term economic costs that have important implications for the well-being of the child, the family, and society but that are difficult to measure. In an extensive research review, Mark Stabile and Sara Allin examine evidence about three kinds of costs—direct, out-of-pocket costs incurred as a result of the child’s disability; indirect costs 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.

Not surprisingly, the evidence points to high direct costs for families with children with disabilities, though estimates vary considerably within these families. Out-of-pocket expenditures, particularly those for medical costs, for example, are higher among families with children with a special health care need. An important indirect cost for these families involves decisions about employment. Stabile and Allin examine several studies that, taken together, show that having a child with disabilities increases the likelihood that the mother (and less often the father) will either curtail hours of work or stop working altogether. Researchers also find that having a child with disabilities can affect a mother’s own health and put substantial strains on the parents’ relationship. In the longer term, disabilities also compromise a child’s schooling and capacity to get and keep gainful employment as an adult, according to the studies Stabile and Allin review. Negative effects on future well-being appear to be much greater, on average, for children with mental health problems than for those with physical disabilities.

Stabile and Allin calculate that the direct costs to families, indirect costs through reduced family labor supply, direct costs to disabled children as they age into the labor force, and the costs of safety net programs for children with disabilities average \$30,500 a year per family with a disabled child. They note that the cost estimates on which they base their calculation vary widely depending on the methodology, jurisdiction, and data used. Because their calculations do not include all costs, notably medical costs covered through health insurance, they represent a lower bound. On that basis, Stabile and Allin argue that many expensive interventions to prevent and reduce childhood disability might well be justified by a cost-benefit calculation.

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Childhood disability entails economic costs that are to some extent measurable. This article focuses on children with disabilities from birth through childhood and adolescence and the associated direct and indirect costs of these disabilities on both the immediate family and the child. Where possible, it also considers the costs of childhood disability on publicly financed programs.

The economics literature provides a theoretical foundation for the structure and timing of these costs. Starting with the seminal work of Michael Grossman and Gary Becker, the theoretical literature in this area provides some testable implications for the economic costs of early childhood disability on family decision making, out-of-pocket costs, and the child's accumulation of human capital that will help shape future economic performance.¹ These testable implications guide this review of the empirical literature. Dividing this literature into two major streams, we first examine the relationship between childhood disability and contemporaneous direct and indirect costs to families. We then review the empirical literature on the relationship between childhood disability and future human capital and economic success. Finally, we attempt to aggregate the various economic costs, including the costs of disability on public programs in the United States, to present an overall cost of early childhood disability.

This literature is vast and has a long history. To narrow the focus, this review concentrates on the empirical contributions in economics, public health, and health policy that allow for causal inference on the major implications of the theory. Because others have examined much of this literature in the past, we look

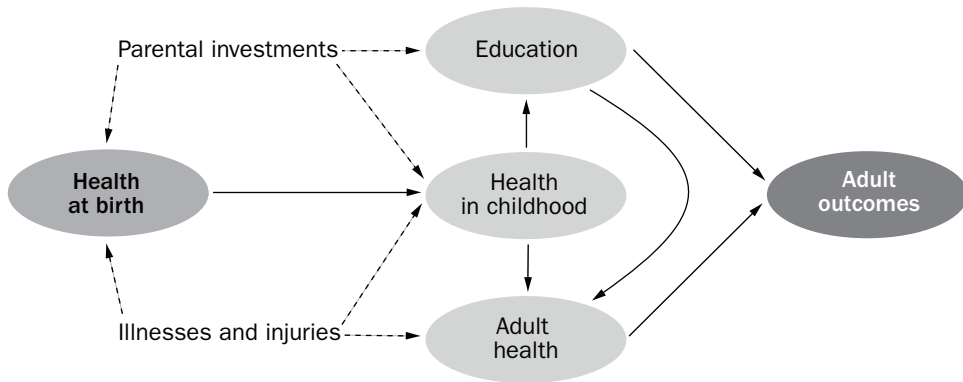
only at the most recent contributions.² We also discuss the benefits of various empirical approaches and remaining empirical challenges.

Modeling the Economic Costs of Childhood Disability

At least two areas of economic theory are particularly relevant to the study of the costs of childhood disability. One models the relationship between health status in childhood and longer-run economic outcomes. The main idea is that health is an input into the production of human capital, the development of the competencies and knowledge that increase one's ability to work and to be productive. The "health stock" itself is a function of current and past investments.³ This idea can provide an organizing framework for the literature on the longer-term economic consequences of early childhood disability. One such model, presented by Michael Baker and Mark Stabile, assumes that children are born with a stock of health that can be eroded by chronic conditions (both mental and physical), diseases, and injuries.⁴ A child's health stock can also be augmented with parental investments, including investments of time and money, so that the health stock in the next period is a function of the health stock in the previous period, investments made to health, and any realized insults to the child's health. This theoretical relationship is expressed in figure 1.

At the most basic level, a child must be well enough to go to school. Beyond that, however, changes in the child's stock of physical and mental health affect the ability to learn and participate at school. Health is therefore one determinant of human capital. Human capital, in turn, influences future economic outcomes such as labor market earnings (as illustrated in figure 1). This simple economic

Figure 1. Pathways for Child Health to Affect Adult Outcomes



framework produces several testable implications that are explored in the empirical literature. First, children from families with more resources would be expected to have, on average, a higher level of health. Insults to health may also depend in part on the child's environment (housing stock, neighborhood, and the like), so children from families with fewer resources not only may have poorer health but also may receive more shocks to their health. Families with more resources may also be able to mitigate the effects of child health shocks more than families with fewer resources (for example, through better information or better medical treatment). Children who have poor health are likely to have lower levels of human capital and therefore poorer labor market outcomes.

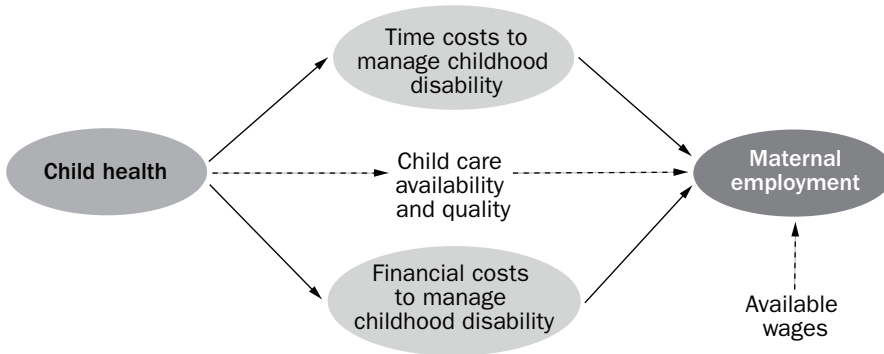
James Heckman describes the notion of “dynamic complementarity” in the case of human capital accumulation as arising when “stocks of capabilities acquired in the previous period make investment in the [current] period more productive. Such complementarity explains why returns to educational investments are higher at later stages of the child's life cycle for more able, more healthy, and more motivated children.”⁵ In this representation, health stocks in previous periods

contribute to the current health stock, which then contributes to current human capital accumulation.⁶

In addition to the theoretical literature on the production of health and the long-term economic consequences, a second strain of the economics literature examines the labor force and consumption decisions of families and the implications for these decisions of having a child with poor health. Jacob Mincer and Gary Becker explored models of labor supply where the costs of time and household responsibilities were explicitly introduced into the labor allocation decision.⁷ Others have expanded this literature considerably to consider the specific issue of female labor supply and the effects of child care on a family's labor supply decisions,⁸ as well as on its consumption decisions.

On the consumption side, the idea is that the child's well-being contributes to the overall well-being, or utility, of the family. Parents make decisions about what to purchase, and how much time to spend on caring for their children, to increase the family's overall well-being. For example, families with disabled children have to buy some things (such as wheelchairs) that other families do not have

Figure 2. Pathways for Childhood Disability to Affect Maternal Labor Market Activity



to buy, and these purchases have implications for other consumption decisions.

On the labor supply side, mothers (much of the literature is focused on maternal labor supply) make decisions on whether and how much to work based on the broad needs of the family, both financial and uncompensated home needs. Mothers make decisions about how much to work based on the wage they can earn, how much time they would like to spend on leisure activities, and how much time they need to spend with their child. The choice that a mother makes about whether to work will then depend on the perceived benefit of working another hour versus the benefit of staying home (or consuming leisure) conditional on the other variables in play, including, importantly, the quality of child care that is available and its cost.⁹ The empirical literature explores whether having a child with a disability increases the mother’s labor supply, because the child’s poor health places greater financial pressures on the family, or decreases it, because of the increased time required to care for the child. Figure 2 illustrates the theoretical pathway between childhood disability and maternal employment.

Another strand of the theoretical literature on the economics of the family hypothesizes that children may affect the stability of the marriage. The desire to have children should positively influence the probability that individuals wish to marry.¹⁰ By extension, a negative shock to the well-being that parents derive from children may lead to lower marriage rates or higher divorce rates.¹¹

While providing mostly intuitive results, these models serve as a starting point to identify the channels through which childhood disability can affect the economic well-being of both the child and family. The remainder of this article explores the empirical literature that stems from these intuitive theoretical implications. We examine four specific areas: the longer-term economic costs to a child with a disability measured by human capital attainment and labor market outcomes; the effect of childhood disability on the financial decisions and well-being of the family; the effects of childhood disability on the labor market decisions of the family, and in particular the mother’s labor supply; and the effects of childhood disability on family structure. This literature faces a number of empirical challenges that are described later. One key challenge relates to

the unavailability of data; few studies that include information on economic costs also have good measures of disability. (The difficulties associated with measuring disability in addition to the evolving definition of disability are discussed in greater depth in the article in this volume by Neal Halfon and others.)¹²

Childhood Disability and Direct and Indirect Costs to Families

An extensive literature documents the direct and indirect costs to families associated with childhood disabilities. Direct monetary costs include expenditures on health care, therapeutic, behavioral, or educational services; transportation; caregivers; and other special needs services. Indirect costs consist primarily of reductions in parents' ability to sustain paid employment. This loss of productivity could relate to additional time that is required to care for a child with a disability combined with high costs or unavailability of adequate child care.

Direct Costs to Families

Estimates of the costs to families directly associated with childhood disability not only vary with the type and severity of disabilities being investigated but are very context specific: the monetary costs incurred by families depend on the availability of health and social care benefits, which change over time and across jurisdictions. A comparison of estimates reported in different studies is difficult because of differences in the definitions of disability; the components of costs that are calculated (for example, some studies include only the costs of medical care¹³ while others capture a broader range of costs related to the disability); and the sample characteristics (for instance, some studies estimate the out-of-pocket costs associated with childhood disability only among families

receiving benefits, for whom the prevalence of childhood disability is high compared with the general population¹⁴). Some studies also estimate the costs of caring for children with particular diseases.¹⁵ Consistent with other reviews, cost estimates reported here are in U.S. dollars in the year the data were collected in the different studies. In the final section that summarizes costs, all cost figures are inflated to 2011 dollars.

A review of seventeen studies from 1989 to 2005 that estimated the annual direct (consumption) costs associated with severe physical childhood disabilities (such as cerebral palsy and spina bifida) shows a range from \$108 to \$8,742.¹⁶ The upper estimate was reported in a study of only sixteen families, so it may not be generalizable; the next highest estimate was \$6,036 from the United Kingdom for additional costs annually for a severely disabled child compared with a healthy child.¹⁷ An earlier review of six studies reported average annual expenditures in the 1980s ranging from \$334 for families with children with cystic fibrosis to \$4,012 for families of children with cancer.¹⁸

Other studies have estimated the direct costs of caring for children with a broad range of disabilities, including children with a special health care need. On average, these estimates are much lower than those cited above because they include less severe disabilities than the studies discussed above. Using the 2001 National Survey of Children with Special Health Care Needs (NS-CSHCN), one study reported an average annual cost of medical care (excluding insurance premiums and reimbursable costs) of \$752 (or \$620 if the 17.5 percent of families with no expenditures are factored into the estimate).¹⁹ More recent estimates from the 2005–06 wave of this survey were similar, at approximately

\$832.²⁰ Among low-income families in this same survey, the estimated annual expenditure on medical care was lower, at about \$283 on average.²¹ Another study used this survey to relate health insurance adequacy with reported financial problems: those with inadequate insurance were three times more likely to experience financial problems.²²

Another study used the 2000–02 NS-CSHCN to compare the direct costs of childhood mental health problems with those of physical problems.²³ Caring for children with mental health needs was associated with a greater financial burden than caring for children with other special needs. Although precise estimates are not available, among those with private insurance, about 40 percent of families with children with mental health conditions reported spending more than \$500 out of pocket in the past year compared with about 30 percent of families with children with physical health problems (there were no differences among families with public insurance). These estimates used matching methods to adjust for differences in the samples in demographics, condition severity, and family structure. The authors suggest that less generous insurance coverage for mental health care may be one reason why mental health problems may be associated with a greater direct financial burden on families than physical problems.

Susan Parish and her colleagues used a sample from the 1999 National Survey of America's Families that included only low-income families to estimate child care use and costs.²⁴ They found that children with disabilities living with single parents spent significantly more hours in child care than did children with disabilities living with two parents and children without disabilities in single- and two-parent households. However,

children with disabilities in single-parent households had the lowest monthly child care costs, suggesting that single parents were compelled to use cheaper (and perhaps lower-quality) child care. Estimated monthly child care costs averaged \$179 for single-parent families with children with disabilities, \$250 for single-parent families with children without disabilities, and \$271 for two-parent families with a child with disabilities compared with \$225 for two-parent families with healthy children. Using the 2002 wave of this survey, Parish and her coauthors examined indicators of material hardship and found that having a child with a disability was associated with twice the odds of experiencing hardship after controlling for family income, maternal education, family structure, and race.²⁵

Overall, the literature that estimates the direct costs to families associated with childhood disability presents a very wide range.

Another study used the 1994–95 National Health Interview Survey to estimate the average out-of-pocket spending on rehabilitative and mental health services.²⁶ Annual spending on rehabilitation for those who used it (30 percent of the sample) averaged \$1,096; for the 15 percent who had at least one visit to a mental health care provider, costs averaged \$1,129 in one year. Using the 1992–94 National Health Interview Survey, Paul Newacheck and Neal Halfon estimated the costs of childhood disability on the child's activities, on the education system (as

measured by days lost from school, estimated at 27 million), and on the health system.²⁷ Children with disabilities reported three times the rate of physician visits of children without disabilities (8.8 physician contacts compared with 2.9 contacts) and had significantly higher rates of hospitalization (11.4 percent compared with 2.8 percent) and days spent in a hospital in a year. Translated to the national level, these estimates amount to an additional 26 million physician contacts and 5 million hospital days annually attributable to childhood disability. Another study estimated total medical costs for children with and without attention-deficit/hyperactivity disorder (ADHD) by drawing on administrative data of medical and disability claims for beneficiaries. The study reported that employees with a child diagnosed with ADHD had annual average medical expenditures of \$1,574, significantly higher than the average \$541 in medical expenditures incurred by other employees.²⁸

Newacheck, Moira Inkelas, and Sue Kim estimated the patterns of health care utilization and expenditure for children with disabilities using data from the 1999 and 2000 editions of the Medical Expenditure Panel Survey (MEPS).²⁹ Families with disabled children, who accounted for 7.3 percent of the sample, paid an annual average of \$297 out of pocket for health care, substantially more than the \$189 yearly average paid by families with healthy children. However, the proportion of out-of-pocket spending to total health care costs was lower for children with disabilities, at 11 percent, than for those without, at 28 percent. The researchers also found that the distribution of total and out-of-pocket expenditures was highly concentrated among a small proportion of disabled children. Analyses of data from the 2001 and 2002 MEPS reported similar

findings.³⁰ Using a broader definition of disability, Newacheck and Kim found that out-of-pocket expenditures on health care were twice as high among the 15 percent of children with a special health care need than among otherwise healthy children (\$352 versus \$174), and that expenditures were highly skewed toward a small share of the disabled children.³¹

Overall, the literature that estimates the direct costs to families associated with childhood disability presents a very wide range. These estimates depend on the measure of disability that is used, the types of costs that are included in the estimate, and the population that is sampled. The studies all point to higher direct costs for families with children with disabilities than for other families. Not only do the estimates of direct costs vary by disability status, they also vary considerably within families with disabled children; studies consistently point to a significantly skewed distribution of expenditures, in particular in medical costs, among families with children with a special health care need. The direct monetary costs may be the smallest component of costs to families, however, given a range of indirect costs that are associated with children with disabilities.

Indirect Costs

Several studies provide evidence about the correlation between childhood disability and maternal employment in a sample of families at a point in time. The majority of these studies focus on the probability that a mother is employed as a function of predicted wages, regional economic measures, availability of other sources of income (such as husband's income), receipt of benefits (such as social assistance, or benefits for the disabled child), mother's health, child's health and age, and other socioeconomic factors such as maternal

education. Some studies also look at hours of work, and others also control for whether and how much the mother worked before the birth of her child.

These studies consistently find negative associations between child disability and mother's work activity.³² Mothers of children with disabilities are 3 to 11 percentage points less likely to work, and the effect is larger (13 to 15 percentage points) if the child is severely disabled. The negative effects of child disability on maternal employment are not always statistically significant among single mothers.³³ Some studies estimate the labor market effects on mothers of children with specific diseases such as spina bifida, Down syndrome, asthma, and ADHD.³⁴

One study that used the 1997 Survey of Income and Program Participation found that child disability reduced employment significantly among both married and single mothers, but only among mothers of children in certain age groups (ages zero to five for married mothers and ages six to fourteen for single mothers). The magnitude of the effect was smaller than that for the mother's own disability status, however.³⁵ Using earlier data from this survey (1986–88), another study found a negative but insignificant effect of childhood disability on the likelihood of a mother being employed.³⁶

Among welfare recipients, having a child with a severe disability was estimated to reduce the probability of a mother being employed by 15 percentage points. Being in poor health herself had a similar effect, while having any child under six years old reduced her employment by 11 percentage points.³⁷ Moreover, in this same study, among mothers who worked, having a severely disabled child in the household was associated with an average

reduction of fifteen hours a month in time worked (equivalent to \$77 a month in forgone income at the minimum wage at the time of the study, or \$81 after accounting for the reduced probability of employment).

As the theory of labor market decisions would suggest, employment effects appear to differ depending on the child's medical expenses and the caregiving time required. When the child's illness is associated with high medical costs, married mothers are 25 percent, and single mothers 5 percent, more likely to be employed than mothers whose child costs more in terms of time. In this situation, married mothers work 19 percent more hours, whereas single mothers work 5 percent more hours. Having a child with a time-intensive condition significantly reduces the likelihood of employment by 41 percent and the number of hours worked by 38 percent among single mothers, but the effects are not significant for married mothers.³⁸ These findings point to the challenge of measuring child disability in a way that disentangles the potentially opposing effects of monetary costs and time costs of disability on employment.

Challenges in Measuring Indirect Costs

Several important methodological challenges make it difficult to measure with certainty the indirect costs associated with child disability. The first challenge relates to the difficulty of establishing causation. Poorer families are more likely to have a disabled child; therefore, it is difficult to distinguish between the effect of having a child with a disability and the effects of other correlated measures of socioeconomic status and human capital (such as maternal education and family income) on maternal employment.³⁹ For instance, if mothers with disabled children are less likely to work than other mothers,

this difference could be related to lower maternal education or other obstacles to employment that are unrelated to the presence of a child with a disability.⁴⁰ Moreover, the mother, or family, may have characteristics that are unobserved and that affect both her work activity and the likelihood of having a child with a disability. For example, there may be genetic or environmental causes of child health that also affect the mother's health and subsequently her probability of being employed. Another potential problem is that some mothers who would not have worked in any case might use the health of their child to justify not working. All of these problems might cause an analyst to overestimate the effect of child disability on maternal employment.

There are additional methodological challenges that receive varying degrees of attention in the literature. One relates to the difficulty of accounting for the dynamics of child rearing and employment: as children age, the caregiving burden falls for parents of healthy children relative to parents of disabled children.⁴¹ Another challenge results from small sample sizes given the low incidence of many forms of childhood disability. Several studies have used some promising strategies to address these challenges.

Panel Data Methods. One way to disentangle the effect of having a child with a disability from the effects of other correlated factors is to follow families over time, that is, to use "panel data." We have identified several studies that make use of panel data to assess the relationship between childhood disability and maternal employment.⁴² Another study uses panel data to examine the effect of having a disabled child on mothers' and fathers' health, where reduced health could be one causal pathway between children's disability

and maternal employment.⁴³ Finally, one study draws on the Fragile Families and Child Wellbeing Study to estimate the effects of poor child health on paternal, as opposed to maternal, labor supply, an indirect cost that has received very little attention in the literature.⁴⁴

Karen Norberg uses the National Longitudinal Survey of Youth (NLSY) to estimate the timing of mother's employment after a child's birth as a function of child disability risk factors at the time of birth (children were considered "high risk" for disability based on prematurity, intrauterine growth defects, congenital defects, and length of child's hospitalization at birth); maternal reports of early childhood development; and maternal and family background characteristics assessed before the child's birth.⁴⁵ The mother's past work history was the strongest predictor of her employment after the child's birth, but child health also influenced the decision to work: mothers of high-risk infants were 13 percent less likely than other mothers to begin working at any interval, and 55 percent less likely to work at all in the first five years.

To better account for the correlation between socioeconomic status and childhood disability, and to control for unobserved maternal characteristics that might simultaneously affect a mother's labor market activity and the health of her children, Norberg compared siblings to each other (using a fixed-effects model).⁴⁶ The results showed that mothers were about half as likely to have returned to work within five years after the birth of a high-risk infant than after the birth of a healthy sibling.

Peihong Feng and Patricia Reagan use random-effects models and the NLSY to estimate the contemporaneous effects of child

disability on maternal employment.⁴⁷ While they are able to control for some aspects of unobserved maternal characteristics that are constant over time and that may affect both childhood health and maternal employment, the authors do not exploit the panel nature of the data to consider the timing of the effects. They found greater labor market disruption among mothers with an asthmatic child than among mothers with a child with another type of disability, perhaps because of the episodic nature of asthma. Mothers of children with asthma were more than twice as likely as mothers of children with other disabilities to be unemployed.

Elizabeth Powers found that the estimated effect of childhood disability on maternal employment was smaller when she used panel data than when she used data for a single point in time.⁴⁸ Using two years of data, Powers tested whether relative work effort was reduced over time by the addition of a childhood disability among families with a stable family structure. She found that work reductions were statistically significant for single mothers (a reduction of 16 to 20 percentage points in the likelihood that a nonworking mother would start working, and a reduction of between three and five hours worked if she was working), but not for wives.

Nazli Baydar and her colleagues used the MEPS to analyze the effects of childhood asthma on maternal employment.⁴⁹ They reported that having a child with asthma reduced the odds of full-time employment by 30 percent and part-time employment by 26 percent. A married mother who had a child with severe asthma had a 16 percentage point reduction in the likelihood of being employed (a child was deemed to have severe asthma if the mother reported that the child suffered “less than good” health and had more than

three bed days in the past month). A single mother with a child with severe asthma had a 10 percentage point reduction in employment compared with mothers of healthy children. Using the panel nature of the data to estimate the effects of asthma on transitions out of full-time employment, the researchers found that a single mother who had a child with asthma was twice as likely to leave full-time employment over a two-year period than a similar mother whose child did not have asthma. They found no differences among married women.

Another study modeled the likelihood of a father being employed one year after a child’s birth as a function of the child’s health, controlling for the father’s employment status at the time of the child’s birth as well as for characteristics of the father, the mother, and the family.⁵⁰ They found that fathers of children in poor health (using a definition meant to capture severe health shocks at the time of birth) were 4 percentage points less likely to be employed one year later. Fathers were less likely than mothers to change their work status after the birth of a child in poor health.

Raising a disabled child may have a direct influence on maternal employment, such as reducing the time available for work, but child disability also may have an indirect influence on maternal employment through effects on maternal health. Peter Burton and his coauthors drew on the Canadian National Longitudinal Study of Children and Youth from 1994 to 2000 to estimate the long-term effects of having a child with a disability (defined by an activity limitation) on maternal and paternal health in 2000, after controlling for previous health status and other family and sociodemographic characteristics.⁵¹ They found that having a disabled child in the household increased the

Raising a disabled child may have a direct influence on maternal employment, such as reducing the time available for work, but child disability also may have an indirect influence through effects on maternal health.

likelihood that a mother reported her own health as poor, and that mothers experienced a relative decline in health compared with fathers. The authors found no effect on the health of fathers. Similar effects of childhood disability on parental health were reported in a study using the 1996–2001 MEPS.⁵² These findings were consistent with studies that have examined the stress associated with caring for children with disability. One study, for example, found significantly worse sleep quality among parents of children with developmental disabilities than among parents with healthy children, a finding that was mostly explained by parenting stress.⁵³ Other studies confirmed that caring for children with disabilities heightens stress and other measures of psychological distress.⁵⁴ In contrast, one study, which used the GHQ-12, a common diagnostic tool, as a measure of mental health, found that mothers of children with intellectual disabilities had slightly reduced odds of poor mental health.⁵⁵

Overall, the findings of studies using panel data are largely consistent with the rest of the literature: child disability has a negative influence on parental, and especially maternal,

employment and hours worked. The smaller effects using panel data indicate, however, that families with disabled children may, on average, have other characteristics that are associated with lower maternal employment.

Direct Questioning of Parents. An alternative strategy for eliciting the effects of childhood disability on parents is to ask parents directly.⁵⁶ This approach offers a validity check on panel data studies. Qualitative studies also provide insight into the causal pathways and mechanisms underlying the relationship between childhood disability and maternal employment.⁵⁷

The Aid to Families with Dependent Children (AFDC) Household Survey asks mothers whether caring for their disabled children caused them to reduce their employment, and whether they expected their caregiving to reduce employment over the next twelve months. Anna Lukemeyer and her coauthors found that almost 40 percent of mothers with a severely disabled child reported that the child's condition reduced the number of hours they worked, and about one-third reported that the child's condition prevented work entirely.⁵⁸ Other authors using these data found that the number of children with disabilities, and the severity of the disability, increased the reported impact on employment.⁵⁹

The NS-CSHCN includes the following questions: "In the past 12 months, have you or other family members stopped working because of child's health conditions?" and "In the past 12 months, have you or other family members cut down on the hours you work because of child's health conditions?" Reporting the results from the 2001 survey, one study found that 28 percent of the sample had to cut work hours and 13 percent

had to stop working. The odds of either reduction increased with the severity of the condition and with the number of episodes in which the child was affected by the condition, and decreased with the child's age.⁶⁰ Using the 2005–06 data from this survey, another study found differences among two- and single-parent households. Among married couples, 15 percent had reduced work hours, and in 13 percent one of the two parents had stopped working to care for a child. Among single-parent families, 20 percent had reduced work hours and 16 percent had stopped working.⁶¹ Both employment effects were more likely the more severe the child's condition. Other factors associated with a reduction or stoppage of work included having a preschool-age child, holding public versus private insurance, receiving Supplemental Security Income (SSI) benefits, and reporting unmet mental health needs for another family member.⁶² The authors also found that coordinating appointments or treatment allowed parents to work or to work longer hours.

Drawing on this same NS-CSHCN survey, Susan Busch and Colleen Barry compared the reported labor market effects of having a child with a mental health condition with those of having a child with a physical health condition.⁶³ After using matching techniques to adjust for demographics, severity of the health condition, and family structure, about 35 percent of families reported that they cut work hours to care for a child with a mental health problem compared with slightly more than 25 percent of families with children with a physical health problem. Similarly, about 15 percent of families reported that they stopped working because of their child's mental health problem compared with about 10 percent who stopped work because of their child's physical condition.

Overall, the studies reviewed here suggest that the labor market effects of having a child with a disability are greater for single mothers than for married mothers.

A survey of families with children with special needs was conducted as part of the Family Partners Project in 1998 and 1999, a collaboration between the Heller Institute at Brandeis University and a national advocacy organization, Family Voices. The survey includes questions about how caring for a special needs child affects parents' work.⁶⁴ More than half of the sample of working mothers reported that they had cut the number of hours they worked to care for their child. They were more likely to have done so in families with younger children and with children who had more severe and more unstable health conditions. Among those mothers who were not working, more than half reported that they had stopped working because of their child's health condition.⁶⁵

The 1994 and 1995 waves of the National Health Interview Surveys also included questions about the employment effects of having a child with a disability. Among families with a disabled child, 20 percent reported that they did not take a job because of the child's health, quit work other than for normal maternity leaves, turned down a better job or promotion, or worked fewer hours.⁶⁶ The more severe the functional limitations and medical conditions, the more likely the family was to report that employment was affected.

A Canadian study that used 2001 data from the Participation and Activity Limitation Survey found that 68 percent of mothers caring for a disabled child reported experiencing at least one labor market problem as a result of their child's condition (not taking a job, quitting work, changing work hours, turning down a promotion, or working fewer hours).⁶⁷ Similar to other studies, the odds of reporting one or more of these problems increased with the severity of the child's condition.

Overall, the reported reduction in work activity is consistent across the studies. The proportion of mothers with a disabled child who report that they have stopped work entirely ranges from 10 to 30 percent, while 15 to 68 percent report reduced work hours. Mothers of children with more severe disabilities, and studies with broad definitions of employment effects, report the higher estimates.

Instrumental Variables. Panel data methods allow the researcher to control for unobserved characteristics of the mother that may simultaneously affect both her work effort and the likelihood of her child being disabled or of her reporting her child to be disabled. Researchers also use instrumental variables to control for omitted variables that might affect both disability and maternal work effort. The challenge with this approach is to identify a suitable instrument, that is, a variable that is correlated with child health but uncorrelated with the omitted variables.⁶⁸

One such study involved a two-part model of labor force participation and child health and used two instruments for child health: the number of adoption agencies per 10,000 women in the city where the child was born, and the presence of a level-three neonatal intensive care unit in the hospital where the baby was born.⁶⁹ (The authors report

considerable variation in the number of adoption agencies, with a range from two to thirty-five across cities.) Using this instrumental variable approach, the authors found that poor child health reduced the probability of maternal employment by 8 percentage points, with an average reduction of three hours a week among those who were working.⁷⁰

In contrast, Elizabeth Powers used specific impairments as instruments for maternally reported child disability.⁷¹ Specific impairments are arguably less subjective than general questions about child health and disability and therefore are less likely to be reported with error. Powers found that, compared to a model of employment that measures childhood disability using maternal reports of general child health, a model that uses specific impairments as the measure of childhood disability yields reduced estimated effects of disability on employment for both single mothers and wives (for whom the effect becomes statistically insignificant).

Overall, the studies reviewed here that employ panel data methods, instrumental variables, or direct questioning of parents suggest that the labor market effects of having a child with a disability are greater for single mothers than for married mothers. In addition, parental reports of employment effects associated with their child's disability are larger than those detected in the statistical studies. This discrepancy could arise because parents report more subtle employment effects, such as turning down a promotion, along with reductions in work hours or stopping work altogether. The differences could also reflect an overestimation by parents of the extent to which having a disabled child has affected their employment decisions.

Effects on Family Structure

The presence of a child with a disability in the household may lead to marital stress and separation. The studies reviewed in the previous sections take family structure as a given and, for example, often divide mothers into those who are married and those who are single. Implicitly, the authors are assuming that having a disabled child does not affect marital status. However, a separate literature directly addresses this question.

Three studies of National Health Interview Survey data from 1981 and 1988 found significant but relatively modest effects of having a child with a severe health problem on the likelihood that parents who were married at the time of the child's birth were separated or divorced at follow-up.⁷² Analyses of the 1988 National Maternal and Infant Health Survey found that married parents of children with very low birth weight (a proxy for future disability) were significantly less likely to be married two years later; the predicted probability of being married was 95 percent among parents of healthy children and 90 percent for parents of very low birth weight children.⁷³ In addition, some disease-specific studies found associations between caring for a child with epilepsy and marital problems.⁷⁴

A more recent longitudinal study of the Fragile Families and Child Wellbeing Study (1998–2000), a survey of mostly unmarried parents, found that having a child with a severe disability decreased by 10 percentage points the probability that parents who were living together at the time of the child's birth were still together twelve to eighteen months later.⁷⁵ Overall, studies consistently report negative effects of having a child with disabilities on family structure.

Childhood Disability, Future Human Capital, and Economic Success

The second strain of the literature we review seeks to determine whether and how childhood disability affects the accumulation of education, skills, and other human capital and consequently economic well-being in adulthood. We look first at disability at birth and then at childhood disability.

Disability at Birth

An extensive literature examines the future economic cost of being born prematurely or with low birth weight or low Apgar scores (standardized evaluations of a newborn's health condition). While these conditions are not measures of disability themselves, they are associated with higher rates of disability and thus can be regarded as marker conditions. The goal of this literature is to determine whether children born with one of these conditions suffer adverse health and economic consequences later in life.

A key empirical challenge for these studies is the strong correlation between being born with one of these markers and other disadvantages such as low socioeconomic status. Therefore, separating the causal effect of being born with a marker condition from the effect of being born, say, into a family in poverty, has been a focus of the more recent work in this area. We focus here on the relationship between markers of poor health at birth, future disability, and future economic outcomes.

The most recent social science literature in this area has used a combination of large administrative data sets and samples of twins and siblings to examine the longer-term effects of health at birth on both education and labor market success. As noted, the most

common measures found in the literature are birth weight, Apgar scores, and length of gestation. In general these measures are considered more objective than survey measures of infant health. Weight at birth is considered low if it is below 2,500 grams, and very low if it is below 1,500 grams. Gestational periods are considered premature if they are below thirty-seven weeks. Apgar scores are based on five items and scored on a scale of ten. Scores below seven are considered poor.⁷⁶

Jere Behrman and Mark Rosenzweig used data on twins from the Minnesota Twins Registry to examine the effects of low birth weight on the educational attainment and adult health of women.⁷⁷ They found that increasing birth weight by one pound (454 grams) increased schooling attainment by about one-third of a year and that the difference in schooling attainment was larger between twins with different birth weights than across families with children of different birth weights. Using the Panel Study of Income Dynamics (PSID), Dalton Conley and Neil Bennett found that low birth weight had a more pronounced influence on timely high school graduation among siblings with different birth weights than between families.⁷⁸ These findings suggest that differences in birth weight between siblings account for much of the observed relationship between birth weight and educational attainment. Differences in birth weight between families account for less of this relationship.

Many of the findings in the United States can be extended by using evidence from other nations where the data are much richer and permit more robust studies of the long-term effects of disability at birth and in childhood. One study showed that, conditional on many measures of family background and circumstances, low-birth-weight children from

the 1958 British birth cohort (the National Child Development Study, or NCDS) had lower test scores, educational attainments, wages, and probabilities of being employed at age thirty-three than those with healthy birth weights.⁷⁹ Another study of a sample of Norwegian twins found that low birth weight was associated with lower height, IQ, educational attainment, and earnings.⁸⁰ A third study used administrative data from the Canadian province of Manitoba and found both low birth weight and low Apgar scores to be strong predictors of lower rates of high school completion and greater use of welfare for longer periods of time.⁸¹

The evidence over the past few years strongly indicates that even when other factors associated with health at birth are accounted for, children born with less than optimal health suffer from lower educational outcomes and poorer labor market outcomes on average.

Disability in Early Childhood

The development of physical or mental disabilities in early childhood can have both immediate and longer-term consequences for human capital accumulation and economic well-being. Most research in this area tends to focus on general measures of physical disability in early childhood, measures of childhood mental health, or specific physical conditions such as asthma (a recent exception is a study by Janet Currie and others, which examined all three of these groupings using administrative data⁸²). The literature has explored a range of health measures from subjective self-assessments of health to reported chronic conditions to administrative records of health problems. While the ideal set of health measures is open to some debate, the findings across these measures are mainly consistent with one another. We review the main findings in each of these areas.

According to the U.S. surgeon general's report in 1999, approximately one in five children and adolescents in the United States exhibits signs or symptoms of mental or behavioral disorders.

Measures of Physical Disability. The literature on chronic physical disability finds a consistent relationship between early childhood health and longer-term outcomes. Anne Case and her colleagues used data from the 1958 British birth cohort study, which allowed them to track children from childhood into middle age.⁸³ They examined childhood chronic conditions reported at ages seven and sixteen and found that children with such conditions had lower educational attainment, wages, and employment probabilities at age thirty-three than other children. Using the 1958 study as well as one other British survey (the Whitehall II study of British civil servants), and two American surveys (the PSID and the Health and Retirement Study), Anne Case and Christina Paxson found that childhood health, measured using height as a proxy, was associated with a number of later life outcomes: taller children tended to attain more schooling, employment, earnings, and health.⁸⁴ Case and Paxson also drew on the British Whitehall II study to show the long-term effects of early health on occupational attainment, with health proxied by a report of hospitalization for more than four weeks before age sixteen.⁸⁵ They found that adults who had better childhood health were more likely to start at

higher grades within the civil service and were more likely to be promoted once they entered the civil service.

Another study that examined the long-term effects of child health used a retrospective health measure with data from the PSID.⁸⁶ In 1999 PSID respondents aged twenty-five to forty-seven were asked whether their health when they were less than sixteen was excellent, very good, good, fair, or poor. In models with sibling comparisons, the adults who had suffered poorer health in childhood not only started at a lower level of earnings but experienced slower earnings growth over time than their healthier siblings.

Janet Currie and her colleagues used administrative data from Canada to track physical and mental health of children at various points in childhood (ages zero to three through ages fourteen to eighteen).⁸⁷ Using sibling comparisons (family fixed-effects models), they examined the relationship between health at different points in childhood and various outcomes including educational attainment and welfare take-up. They found that both poor health at birth and early mental health disabilities were associated with poorer long-term outcomes, even when one accounts for the health status of the child later in life. Physical disabilities in early childhood were also associated with poorer outcomes, consistent with the findings in other studies, but apparently because they predict future disabilities rather than leading directly to the poorer outcomes. Unless they persisted over time, physical disabilities in childhood had little effect on future educational outcomes and welfare take-up.

Mental Health Disabilities. According to the U.S. surgeon general's report in 1999, approximately one in five children and

adolescents in the United States exhibits signs or symptoms of mental or behavioral disorders.⁸⁸ This high prevalence of mental health problems among children and the potential for these problems to hinder the accumulation of human capital are worrisome. While the body of literature examining the effects of mental health disabilities is considerably smaller than that examining physical health, an increasing number of studies have explored the effects of common mental health conditions such as ADHD.

Studies seeking to examine the effects of mental health disabilities on child outcomes encounter several challenges. To begin with, definitive tests that allow for a conclusive diagnosis do not exist for most mental health disorders. Diagnoses are often made through a series of questions that are asked of parents and teachers, combined with observation of the child. The “threshold” for having a mental health disability is thus not entirely clear. Second, society’s acknowledgment of mental health problems as health disorders rather than poor behavior on the part of children has changed over time and continues to differ across cultures. Third, treatment for mental health problems, particularly for ADHD, has increased fairly rapidly, making it difficult to assess the effect of these problems with and without treatment.⁸⁹ Finally, as with other measures of health, there are large differences in mental health by socioeconomic status: one study, for example, reports that the prevalence rate of ADHD is almost twice as high for families in the United States with incomes below \$20,000 as for those with higher incomes. Observed differences in outcomes across children with and without a mental health problem may therefore partially reflect these other observable and unobservable differences across children.

Three strands of literature have attempted to address these empirical challenges. First, several studies focus on particular “externalizing” mental health conditions (for example, ADHD, conduct disorder, and oppositional-defiant disorder). Salvatore Mannuzza and Rachel Klein reviewed three studies of the long-term outcomes of children with ADHD.⁹⁰ In one study, ADHD children were matched to controls from the same school who had never exhibited any behavior problems and had never failed a grade; in a second study, controls were recruited at the nine-year follow-up from nonpsychiatric patients in the same medical center who had never had behavior problems; and in a third study, ADHD children sampled from a range of San Francisco schools were compared to non-ADHD children from the same group of schools. These comparisons consistently show that the ADHD children had worse outcomes in adolescence and young adulthood than control children. For example, they had completed less schooling and were more likely to have continuing mental health problems. By excluding children with any behavior problems from the control groups, however, the studies may have overstated the effects of ADHD.

A second set of studies looked at the longer-term consequences of behavior problems in relatively large samples. One examined adolescents who met diagnostic criteria for four types of disorders: anxiety, depression, hyperactivity, and conduct disorders when they were evaluated at age fifteen and who were followed up to age twenty.⁹¹ Those in the sample with hyperactivity and conduct disorders completed fewer grades, while anxiety and depression had little effect on schooling levels. Another study used the NLSY data to show that children who had behavior problems at ages six to eight were less likely

to graduate from high school or to attend college, even after accounting for differences among the mothers of these children.⁹² Like the first study, these researchers found that externalizing behavior problems were significant predictors of future outcomes, whereas internalizing problems were not. One limitation of this study is its focus on a relatively small number of children, who, given the design of the NLSY, were born primarily to young mothers. Several slightly older studies have found similar results. For example, children with early onset psychiatric problems were less likely to have graduated from high school or attended college.⁹³

Elizabeth Farmer used data from the 1958 British birth cohort study to examine the consequences of childhood externalizing behavioral problems on men's outcomes at age twenty-three. She found that boys who fell into the top decile of an aggregate behavior problems score at ages seven, eleven, or sixteen had lower educational attainment, earnings, and probabilities of employment at age twenty-three.⁹⁴ A separate study that used the NCDS data found that behavioral problems at age seven were related to poorer educational attainment at age sixteen, which in turn was associated with poor labor market outcomes at ages twenty-three and thirty-three.⁹⁵ A study of a cohort of all children born between 1971 and 1973 in Dunedin, New Zealand, found that those with behavior problems at age seven to nine were more likely to be unemployed at age fifteen to twenty-one than those without such problems.⁹⁶

Taken together, this research consistently shows that the children with ADHD and other behavior problems have worse outcomes in adolescence and young adulthood than control children, but the studies do

not address the possibility that the negative outcomes might be caused by other factors related to a diagnosis of ADHD, such as poverty, the presence of other learning disabilities, or the fact that many people diagnosed with ADHD end up in special education.

To address some of these concerns around selection into diagnosis and biases from omitted variables, Janet Currie and Mark Stabile used data from the NLSY and the Canadian National Longitudinal Survey of Children and Youth to examine the experience of children with symptoms of mental health problems as reported by parents and teachers. They compared affected children to their own siblings (within a sibling fixed-effects context similar to the models used to examine low birth weight reviewed earlier).⁹⁷ An advantage of using survey data is that questions about symptoms of mental health problems were asked of all children, whereas only children who are brought in for treatment receive a diagnosis. The survey questions are similar to those that would be used as part of a medical diagnosis, and because all of the children surveyed are asked the same questions, a "mental health score" can be constructed for all children in the sample, including those with potentially mild disabilities that would not result in a diagnosis. This feature allows researchers to examine the effect of both high and low levels of mental health disability on outcomes. Finally, because children are compared with their own siblings, the estimates control for both observed and unobserved family characteristics that are shared by siblings.

Currie and Stabile found that in both data sets children with symptoms of ADHD had a higher probability of future grade repetition and lower test scores in math and reading. These probabilities were large relative to

those of physical health problems in these same samples of children and appear even among children with symptoms of ADHD that would generally be considered too low to warrant a diagnosis. For example, the results suggest that the effect of moving from the mean to the lowest hyperactivity score in the United States on the probability of repeating a grade is similar to the effect of an additional \$50,000 in family income. The results are strikingly similar across children in the United States and Canada despite the significant differences in the health insurance systems across the two countries. The authors also found that socioeconomic status made surprisingly little difference; outcomes for poorer siblings were about the same as those for better-off siblings. Boys with higher levels of ADHD symptoms do worse than girls with the same levels of symptoms, however, particularly in the United States. The U.S. results were replicated and extended by Jason Fletcher and Barbara Wolfe, who found similar short-term effects but also found that these effects dissipated over time, meaning that there was little difference in educational outcomes between children with and without ADHD.⁹⁸ Fletcher and Wolfe also showed that having a sibling with ADHD was detrimental to educational outcomes for the non-ADHD sibling over the longer run. This finding may lead to the smaller estimated effects in models that rely on sibling comparisons over time, because the sibling without ADHD is also negatively affected.

In a related paper, Currie and Stabile examined a variety of mental health problems, including depression and conduct disorders, as well as ADHD and a general index of behavioral problems.⁹⁹ While ADHD remained the mental health disorder most strongly associated with poor educational outcomes in the future, conduct disorders and

depression had some effect on grade repetition. Consistent with other studies, the effects of early mental health disorders persist into the future even when Currie and Stabile controlled for contemporaneous mental health problems, suggesting that the effects of these problems may be cumulative and costly.

James Smith and Gillian Smith used retrospective health questions in the 2007 PSID wave to show that depression, substance abuse, and other psychological problems experienced in childhood significantly reduced the number of weeks worked a year and the level of earnings in adulthood, even after they adjusted for fourteen childhood physical illnesses and controlled for within-sibling differences.¹⁰⁰ Like Currie and Stabile, they suggest that the effects of mental health problems are much greater than those of most physical health problems (see the article by Delaney and Smith in this volume for further discussion of this point).¹⁰¹

Reviewing the literature on a wide variety of individual physical health problems and their effects on children is too broad a task for this article, but we do examine the literature on the relationship between childhood asthma and future outcomes given the large numbers of children who suffer from asthma. Estimates in the United States suggest that one in ten children has asthma and that the prevalence of asthma among children has doubled over the past twenty-five years.¹⁰² Asthma also tends to be more prevalent in lower-income households than in better-off ones. As with the other disabilities examined here, understanding the longer-term consequences of asthma in childhood is complicated by this correlation with socioeconomic status, treatment effects, and other omitted variables that may be correlated with all of these.

Table 1. Estimates of the Aggregate Costs of Having a Child with a Disability

Source of cost	Estimated average annual cost per family with children with disabilities (in 2011 \$)	Lower-end estimate	Higher-end estimate
Costs to family			
Direct monetary cost	1,000	100	8,000
Decline in hours worked	2,000	500	5,000
Reduced labor force participation	3,150	1,050	7,000
Reduced future earnings	4,680	1,560	5,460
Family health and well-being*	?		
<i>Subtotal</i>	10,830	3,210	25,460
Social program costs			
Increased Medicaid	4,408	4,408	4,408
Increased SSI	1,185	1,185	1,692
Increased TANF	283	113	453
Special education	13,826	13,826	33,498
Early intervention and prevention	?		
Other public (tax-funded) program costs	?		
Other private program costs	?		
<i>Subtotal</i>	19,702	19,532	40,051
Total (family and social)	30,532	22,742	65,511

Source: Authors.

Note: Costs are averaged across all families with a child with disabilities. See text for explanation of the estimates.

SSI = Supplemental Security Income; TANF = Temporary Assistance for Needy Families.

*These costs can include maternal mental health, costs to siblings, and the like.

Point-in-time comparisons support a correlation between asthma in childhood and poor future health.¹⁰³ A study that used sibling comparisons from the Study of Adolescent Health found that having childhood asthma increased the number of missing school or work days in young adults by 10 percentage points—a considerable loss in human capital and productivity.¹⁰⁴

Aggregating the Costs of Childhood Disability

Although this review has focused on the costs of childhood disabilities to disabled individuals and their families, a number of broader societal costs are also associated with childhood disability. The majority of studies we reviewed do not consider these costs, but some estimate health insurance costs,¹⁰⁵ and

some studies estimate societal costs for particular diseases such as autism and ADHD. One study, for example, estimated the cost to society of caring for children with autism, in 2005 in Sweden, to be 50,000 euros annually per child, or about \$70,000 (in 2005 dollars). The estimate included costs of services, cost of informal care, and the cost of lost productivity.¹⁰⁶ A study of the costs associated with ADHD in the United States estimated annual costs within the range of \$12,005 to \$17,458 (also in 2005 dollars) based on a review of studies that mainly considered health care costs but not lost productivity or long-term effects lasting into adulthood.¹⁰⁷

Recognizing that any aggregation requires a number of assumptions and generalizations, we have attempted to quantify and aggregate

the effects of childhood disability across three areas: direct costs to families, indirect costs through reduced family labor supply, and direct costs to disabled children as they age into the labor force themselves. The results are shown in table 1.

Direct costs to families are a function of insurance systems in different jurisdictions; therefore, our estimates for these costs must be interpreted with some caution. We then add some estimates of the direct costs on social programs in the United States. Where the estimates drawn from the empirical literature vary considerably, we present a range of estimates. Although these figures represent many of the major components of the cost of childhood disability, we do not claim to have captured all the costs. In particular, we have not attempted to measure either the costs of the medical care that is paid for by private insurance companies or the cost in decreased well-being of families. Table 1 uses a question mark to indicate areas where cost data are missing. Because we do not include all of the costs, we regard our estimates as a lower bound on the true costs of childhood disability.

Estimates of direct costs to families with a child with disabilities vary considerably depending on the severity of the disability and the estimation strategy. Estimates reported in this article range from \$100 to more than \$8,000 a year. We use an average of \$1,000 per child with a disability in 2011 dollars, which we take from the ADHD literature, given that ADHD is one of the most prevalent conditions among children. Estimates suggest that having a child with a disability results in a decline in mothers' labor force participation of 3 to 20 percentage points, with an average estimated decline of approximately 9 percentage points. The

Bureau of Labor Statistics estimates a participation rate for women of 61 percent, which suggests a participation rate of closer to 52 percent for women with a disabled child. Assuming a decline in employment of 9 percentage points for mothers with a disabled child relative to all mothers, we estimate an annual loss in earnings from absence from the labor force of approximately \$3,150, with a large range depending on the estimates used.¹⁰⁸ In addition, mothers who continue to work are estimated to reduce time worked by around two hours a week, with a range of between half an hour and five hours a week. Using the median women's wage in 2011 reported by the Bureau of Labor Statistics of \$679 a week or \$19.40 an hour, estimated lost income totals roughly \$2,000 a year.¹⁰⁹ The combined average annual cost for a disabled child is therefore roughly \$3,000 a year (\$2,000 in lost income plus \$1,000 in direct costs).

The second major category of personal cost is the future cost to the child through lost labor market activity. Lost labor market activity is, in part, a function of reduced accumulation of human capital. To avoid assumptions on the exact relationship between human capital accumulation and labor market activity, we restrict ourselves to estimates of the direct effects of childhood disability on future earnings. A 10 percent increase in birth weight has been estimated to increase earnings by 1.0 to 3.5 percent. Therefore, a child who weighs 3,500 grams at birth is likely to earn 4 to 14 percent more than a child weighing 2,500 grams at birth (a difference of approximately two pounds). A child who is in excellent health has 12 percent higher future earnings than one in poor or fair health. Based on the median earnings for 2011 of approximately \$39,000,¹¹⁰ a worker who had low birth weight or poor health as a child is

likely to earn \$1,500 to \$5,500 less in 2011 than a similarly situated worker in excellent health.

Finally the literature provides some estimates of the costs to social safety net programs. Two categories stand out in our review: contemporary costs to the health care system, and future costs to safety net programs. Two of these safety net programs are SSI, which provides benefits to help aged, blind, and disabled people, and the federal Temporary Assistance for Needy Families program (TANF), which provides cash assistance to indigent American families with dependent children. In 2009 the average SSI benefit per child receiving the benefit was \$7,116.¹¹¹ The average cost of TANF per family in 2004 was \$4,764.¹¹² Nancy Reichman and her colleagues report that mothers with children in poor health are between 2 and 8 percentage points more likely than mothers without a child in poor health to rely on TANF (24 percent of all mothers report receiving some TANF support over the past twelve months). They report 3 percent of all mothers receive SSI overall and between 14 and 20 percent of mothers receive SSI if the family has a child in poor health.¹¹³ Our estimate of 2.8 million mothers with a disabled child suggests that approximately 800,000 mothers with a disabled child were TANF recipients and that the *excess* cost per family with a disabled child (the cost over the rate of TANF receipt in the general population) was approximately \$238 in 2004 (or \$283 in 2011). Approximately 845,000 families received SSI for disabled children in 2009.¹¹⁴ The per-family cost (averaged over all families with a disabled child, not just those that receive benefits) of SSI based on the amounts reported above and the estimates in Reichman and others are approximately \$1,184 in 2011 dollars.

Medicaid expenditures are significantly higher for children with chronic conditions than for children without: in 1993 average payments for all Medicaid-enrolled children in the state of Washington (note that Medicaid eligibility and benefits vary by state) averaged \$955, compared with \$3,800 (\$4,407 in 2011 dollars) for the group of children with one of eight conditions (payments totaled \$69 million for these children).¹¹⁵ Even among children with one of the eight conditions, the costs are significantly skewed: 10 percent of the children accounted for about 70 percent of the total costs. Although these estimates are now more than a decade old, they are, to our knowledge, the best evidence available.

Finally, the article by Laudan Aron and Pamela Loprest in this volume outlines the significant costs of special education for children with disabilities. These costs depend significantly on the type of disability and the required special education. The majority of these children have a specific disability or speech impairment. The annual per-pupil special education costs for these children are estimated at \$10,558 in 1999–2000 or \$10,830 in 2011. However, for children whose disability requires that they receive education in a specialized institution, the costs can be more than \$30,000 a year, although these are generally private costs.¹¹⁶

Altogether, these estimates suggest that total average social costs associated with a child with disabilities range from \$20,000 to \$40,000 a year. The estimates available in the literature do not allow us to break costs down by important indicators such as race and ethnicity; such breakdowns are an important area for future research.

In summary, the theoretical and empirical literature suggests substantial costs, both

direct and indirect, of having a child with a disability. These costs are both contemporaneous (family expenditures, earnings, stability, and program spending) and lifelong (lost human capital and earnings for the disabled child). Estimates vary considerably depending on the methodology, jurisdiction, and data used, but the economic costs are indeed significant, by our estimates between \$20,000 and \$60,000, with an annual average of \$30,500 per family with a disabled child. These estimates may appear to be high, but we believe that they represent a lower bound because we are not able to capture all of the

costs associated with childhood disability. Given the magnitude of the costs, many expensive interventions to prevent and reduce childhood disability might well be justified by a cost-benefit calculation. Indeed previous research¹¹⁷ and other articles in this issue of the *Future of Children* (see, in particular, the article by Stephen Rauch and Bruce Lanphear) suggest that investments to create a comprehensive safety net for children and significantly reduce the risk of childhood disability would not be overly costly, especially in light of the evidence presented here.

Endnotes

For tables summarizing the specific studies of this article, please go to www.futureofchildren.org/futureofchildren/publications/journals. Then click on volume 22, number 1 (2012), and look for Appendix 3.

1. Michael Grossman, "On the Concept of Health Capital and the Demand for Health," *Journal of Political Economy* 80, no. 2 (1972): 223–55; Gary Becker, "A Theory of the Allocation of Time," *Economic Journal* 75, no. 4 (1965): 493–517.
2. Donna Anderson and others, "The Personal Costs of Caring for a Child with a Disability: A Review of the Literature," *Public Health Reports* 122, no. 1 (2007): 3–16. An update of this literature search using the same search terms yielded fifty-two new studies of the cost of child disabilities to families from 2000 to 2010, only seventeen of which estimated the direct or indirect costs associated with children with disabilities. Of these, nine were focused on a specific disability. Therefore we include the results of eight of these studies in our review.
3. Grossman, "On the Concept of Health Capital and the Demand for Health" (see note 1).
4. Michael Baker and Mark Stabile, "Determinants of Health in Childhood," in *Handbook of Health Economics*, edited by P. Smith and S. Clieid (Oxford University Press, 2011), pp. 164–88.
5. James J. Heckman, "The Economics, Technology, and Neuroscience of Human Capability Formation," *Proceedings of the National Academy of Sciences* 104, no. 33 (2007): 13253.
6. In Heckman's representation, health is one of these early capabilities, as would be cognitive and noncognitive abilities. Baker and Stabile, "Determinants of Health in Childhood" (see note 4).
7. Jacob Mincer, "Labor Force Participation of Married Women," in *Aspects of Labor Economics*, edited by H. Gregg Lewis (Princeton University Press, 1962), pp. 63–97; Becker, "A Theory of the Allocation of Time" (see note 1).
8. See, for example, Martin Browning, "Children and Household Economic Behavior," *Journal of Economic Literature* 30, no. 3 (1992): 1434–75; Rachel Connelly, "The Effect of Child Care Costs on Married Women's Labor Force Participation," *Review of Economics and Statistics* 74 (1992): 83–92; and Robert A. Pollak, "A Transaction Cost Approach to Families and Households," *Journal of Economic Literature* 23 (1985): 581–608.
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13. Paul W. Newacheck, Moira Inkelas, and Sue E. Kim, "Health Services Use and Health Care Expenditures for Children with Disabilities," *Pediatrics* 114, no. 1 (2004): 79–85; Paul T. Shattuck and Susan L. Parish,

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14. Anna Lukemeyer, Marcia K. Meyers, and Timothy Smeeding, “Expensive Children in Poor Families: Out-of-Pocket Expenditures for the Care of Disabled and Chronically Ill Children in Welfare Families,” *Journal of Marriage and Family* 62, no. 2 (2000): 399–415; Marcia K. Meyers, Anna Lukemeyer, and Timothy Smeeding, “The Cost of Caring: Childhood Disability and Poor Families,” *Social Service Review* (June 1998): 209–33.
 15. Andrine R. Swensen and others, “Attention-Deficit/Hyperactivity Disorder: Increased Costs for Patients and Their Families,” *Journal of American Academy of Child and Adolescent Psychiatry* 42, no. 12 (2003): 1415–23; Nathan L. Kleinman and others, “Incremental Employee Health Benefit Costs, Absence Days, and Turnover among Employees with ADHD and among Employees with Children with ADHD,” *Journal of Occupational and Environmental Medicine* 51, no. 11 (2009): 1247–55.
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Disability and the Education System

Laudan Aron and Pamela Loprest

Summary

Education is important for all children, but even more so for children with disabilities, whose social and economic opportunities may be limited. In this article, Laudan Aron and Pamela Loprest assess how well the nation's education system is serving students with disabilities.

Aron and Loprest trace the evolution of the special education system in the United States from its origins in the civil rights movement of the mid-twentieth century. They note the dual character of federal legislation, which both guarantees eligible children with disabilities the right to a "free, appropriate public education in the least restrictive setting" and establishes a federal funding program to help meet this goal. They then review the types of services and accommodations these children receive from infancy through young adulthood.

The special education system has given children with disabilities much greater access to public education, established an infrastructure for educating them, helped with the earlier identification of disabilities, and promoted greater inclusion of these children alongside their nondisabled peers. Despite these advances, many problems remain, including the over- and underidentification of certain subgroups of students, delays in identifying and serving students, and bureaucratic, regulatory, and financial barriers that complicate the program for everyone involved.

More important, the authors show that 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. Only limited evidence is available on the effectiveness of specific special education services or on how to improve student achievement for this important subgroup of students.

Improving the system will require better ways of understanding and measuring both ends of the special education continuum, namely, what services special education children need and receive, and what academic outcomes these students achieve. Without stronger evidence linking these two aspects of the system, Aron and Loprest argue, researchers will be unable to gauge the efficacy of the services now being delivered or to formulate effective reforms to the system as a whole.

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It is difficult to overstate the importance of the nation's education system for children with disabilities and their families. Education is important for all children, of course, but for those with disabilities or special needs it can mean the difference between a socially fulfilling, intellectually stimulating, and economically productive life and a future with few of these qualities. Education also has the potential to affect children's health by influencing their ability to advocate for themselves, manage chronic health conditions, and navigate complex medical, insurance, and social service systems during childhood and later in life.

An early childhood or preschool program or a child's elementary school is often the first regular contact a family has with a professional child-serving system. While children with obvious congenital, physical, or sensory disabilities are likely to have been identified and served within the health care system before starting school, many disabilities (particularly learning disabilities and behavioral disorders) and developmental delays are not identified or may not emerge before a child begins school. Many disabilities, moreover, are actually manifestations of physical or mental limitations within specific social or environmental contexts, and of the behavioral or performance expectations of socially defined roles within those contexts. In these cases, school represents a new and changing context within the life of a child, so new approaches and accommodations may be needed even for children whose conditions and limitations have been long known.

In this article, we offer a brief history of the legal underpinnings of the nation's special education system, explaining how and why the existing system has evolved as it has. We

highlight the dual nature of the law, which both defines civil rights for a class of protected persons and establishes a funding stream for programs and services to support these persons.

We then present basic information profiling special education students in the United States and the types of services and accommodations they receive. These services in principle are wide ranging, from providing early intervention to coordinating care to helping students transition from high school to postsecondary education or employment and training. The critical importance of early identification and prevention of childhood disabilities is now widely established. Intervening early and effectively can redirect the health and educational trajectory of many children with disabilities, especially those with specific learning disabilities, and can also prevent the onset of secondary disabilities. In addition to offering regular educational activities and any special educational services and interventions a child with a disability may need, schools are settings where a variety of other child- and family-centered services can be delivered and coordinated.¹ These services can be critical for children with disabilities and their families, especially for those who are poor, have limited English skills, or are precariously housed. Schools also have a particularly important role to play in helping students (and teens who leave school) transition successfully to postsecondary education and job training, employment, and independent living in adulthood. These transition points in the lives of children are important and can be especially challenging for young people with disabilities and their families.²

The discussion then turns to a review of the costs of special education (and related funding issues) and the educational outcomes

that children with disabilities are achieving. These two aspects of the system often raise the greatest concerns: not only is the system expensive and growing more so over time, but a substantial gap in educational outcomes remains between children with disabilities and other children. A final section discusses some implications for practice and policy.

History and Legal Context

The nation's current approach to educating children with disabilities is the product of dramatic shifts in disability law and public policy over the past four decades. Before the 1970s no major federal laws specifically protected the civil or constitutional rights of Americans with disabilities. Public policies were generally directed at veterans with disabilities returning home from two world wars. The civil rights movement of the 1960s led to a major shift in the "disability rights movement" from one primarily focused on social and therapeutic services to one focused on political and civil rights.³

A critical turning point came with the passage of the Rehabilitation Act of 1973—especially Section 504 of the act, which banned recipients of federal funds from discriminating against people with disabilities. For the first time, a federal law stated that excluding or segregating an individual with a disability constituted discrimination. It also challenged the assumption that disadvantages faced by people with disabilities, such as low educational attainment or unemployment, were the inevitable result of limitations stemming from the disability itself rather than from societal barriers or prejudices. Because almost all public schools receive federal funds, Section 504 also applied to them. The law entitles children to a public education comparable to that provided to children who do not have

disabilities, with disability broadly defined to include any person who has a physical or mental impairment that substantially limits one or more major life activities, has a record of such impairment, or is regarded as having such an impairment.⁴

While Section 504 helped establish greater access to an education by removing intentional and unintentional barriers, a more proactive law protecting the educational rights of children with disabilities came two years later with the passage in 1975 of the Individuals with Disabilities Education Act (IDEA).⁵ IDEA established the right of children with disabilities to attend public schools, to receive services designed to meet their needs free of charge, and, to the greatest extent possible, to receive instruction in regular education classrooms alongside nondisabled children. These core substantive rights at the heart of IDEA are embodied in the phrase "a free, appropriate, public education in the least restrictive environment." Part B of IDEA authorizes federal grants to states to cover some of the costs of special education services for pre-school and school-aged children aged three to twenty-one.

Unlike Section 504, IDEA does not cover all children with disabilities. The law has a two-pronged eligibility standard—children must have at least one of a list of specific impairments, and they must need special education and related services *by reason of such impairments* (note that this definition is primarily a medical or diagnostic one, with some functional criteria added). The specific impairments and disabilities listed in the law are mental retardation (also known as intellectual disabilities); hearing impairments, including deafness; speech or language impairments; visual impairments, including blindness; serious emotional disturbance; orthopedic

impairments; autism; traumatic brain injury; other health impairments; specific learning disabilities; deaf-blindness; and multiple disabilities requiring special education and related services. Children aged three through nine who experience “developmental delays” in their physical, cognitive, communication, social or emotional, or adaptive development are also eligible for special education and related services.

In 1986 Part C of IDEA was established as a federal grant program focused on younger children (birth through age two) with disabilities. Its goals are to enhance the development of infants and toddlers with disabilities; reduce educational costs by minimizing the future need for special education; maximize the likelihood of independent living in adulthood; and enhance families’ capacity to meet their children’s needs. Part C provides states with federal grants to develop and administer a comprehensive statewide system of early-intervention services for any child under age three who has a disability or significant delay in development.

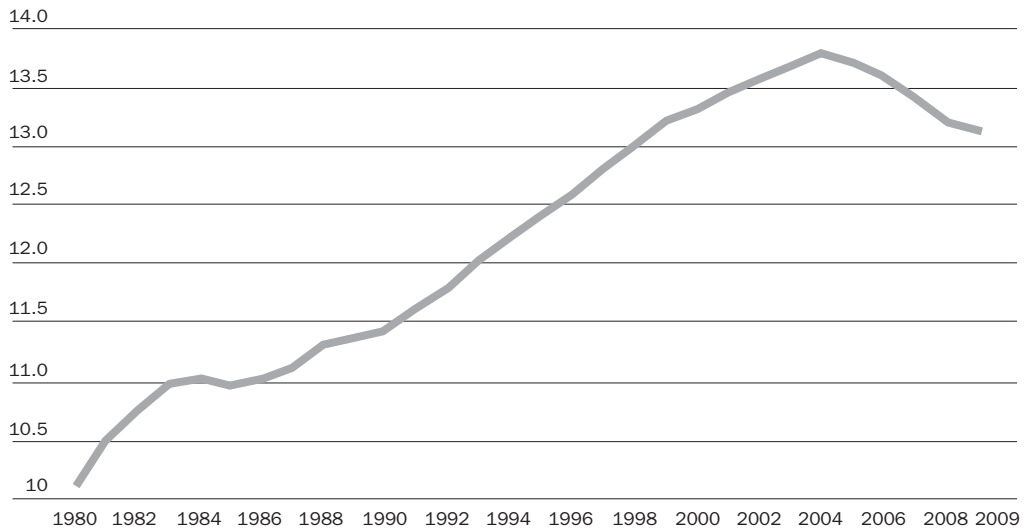
As a relatively young program, IDEA continues to evolve. Amendments to the law in 1997 focused on improving students’ access to the general education classroom and curriculum, developing more accurate and appropriate assessments of academic achievement, implementing better disciplinary procedures and alternative placement options, and bolstering transition services and supports for students aging out of special education. The most recent amendments, enacted in 2004, were designed to promote better accountability for results, enhance parent involvement, encourage the use of proven practices and materials, and reduce administrative burdens for teachers, states, and local school districts.

The development of the nation’s special education system has come in the midst of major and ongoing attempts to reform the general public education system. Significant influences include the standards-based reform movement, which led to and was then accelerated by the federal No Child Left Behind law of 2002; the school choice and public charter school movement; and the growing need for “alternative” schools and programs for students who for a variety of reasons are not succeeding in regular public schools.⁶

Special Education Students

IDEA has thrown open the doors of public education to children with disabilities. Before its passage in 1975, only one in five children with identified disabilities attended public school, and many states explicitly excluded children with certain types of disabilities from school; these included children who were blind or deaf, and children labeled “emotionally disturbed” or “mentally retarded.” More than 1 million children with disabilities had no access to the public school system and often lived in state institutions with limited or no educational or rehabilitation services. Many of the 3.5 million children with disabilities who did attend school were warehoused in segregated facilities with little or no effective instruction. By the 2004–05 school year, thirty years after IDEA was first enacted, more than 6.7 million children (13.8 percent of all students nationally) were receiving special education services through the law. Another 295,000 infants and toddlers and their families were served under Part C.⁷ Since peaking in the middle of the decade, the number of special education students has been gradually declining, and as of the 2009–10 school year, stood at 6.5 million, or 13.1 percent, of all students (figure 1).

Figure 1. Proportion of the National Student Population in Special Education, 1980–81 to 2009–10



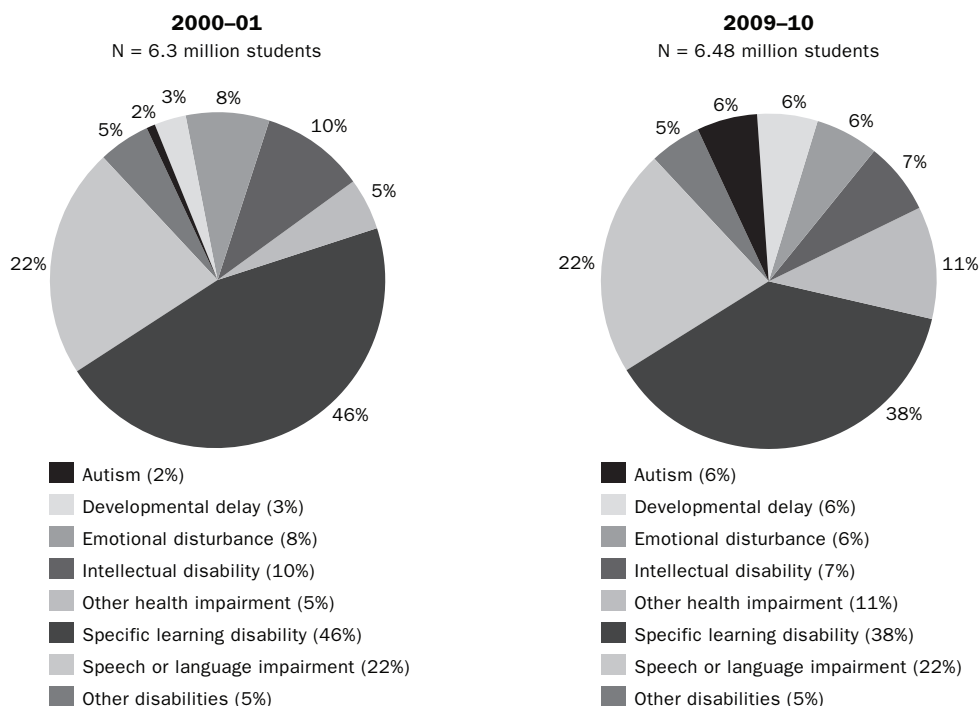
Source: National Center for Education Statistics, *Digest of Education Statistics* (Washington, D.C.: Institute of Education Sciences, U.S. Department of Education, various years).

Learning disabilities are the most common disability among special education students today. For many years, almost half of special education students were classified as having a specific learning disability as their primary disability. The share of special education students with learning disabilities fell from 46 percent in 2000–01 to 38 percent in 2009–10, but these students still remained the single largest disability group (figure 2).

Like many other childhood conditions that are on the rise (see the article in this volume by Halfon and others⁸), it is unclear how much of the growth in learning disabilities is a true increase in prevalence or a reflection of our new understanding and ability to identify the problem. When IDEA was passed, learning disabilities were neither well-known nor understood. Today, the causes of learning disabilities are still unclear, but an explosion of research and program and policy attention has focused on this class of disorders.

Definitions—both diagnostic and programmatic—have evolved over time. IDEA regulations define a specific learning disability as a disorder in one or more of the basic psychological processes involved in understanding or using spoken or written language that may manifest itself in an imperfect ability to listen, think, speak, read, write, spell, or do mathematical calculations. Contributing conditions include perceptual disabilities, brain injury, minimal brain dysfunction, dyslexia, and developmental aphasia. Specific learning disabilities can also affect executive function skills, such as impulse control, flexibility, planning, and organizing, as well as social and emotional skills. The regulations make clear, however, that learning problems resulting primarily from visual, hearing, or motor disabilities; mental retardation; emotional disturbance; or environmental, cultural, or economic disadvantage are not specific learning disabilities under the law. Specific learning disabilities

Figure 2. Special Education Population by Disability



Source: Janie Scull and Amber Winkler, "Shifting Trends in Special Education" (Washington, D.C.: Thomas B. Fordham Institute, 2011), figure 2.

are an important group of disorders for the special education population, both because so many students have them and because by definition they affect learning.

The next most common type of disability, affecting 22 percent of all special education students in 2009–10, is speech or language impairment. "Other health impairments," a catchall category for students whose health conditions reduce their abilities to perform in the educational setting, account for 11 percent of special education students.⁹ Mental retardation accounts for 7 percent of special education students, and autism, developmental delay, and emotional disturbance each account for 6 percent. Like specific learning disabilities, the shares of students classified as having mental retardation and emotional

disturbance has declined since 2000, but other disabilities have increased. The share of students with autism rose from 2 percent to 6 percent of all special education students over the past decade, and the share of those with "other health impairments" more than doubled.

Some of these trends in the share of special education students with certain disabilities, such as autism, are mirroring changes documented in national population-based surveys of children's health and, like these sources, may be reflecting both true changes in prevalence as well as improvements in awareness, identification, and diagnosis. Some observers have speculated that students who would have been classified as having a learning disability in the past are now classified as

having autism or “other health impairment.” Most of the information on special education students comes from administrative data, however, and is therefore influenced by many factors in addition to students’ disabling conditions. These factors include how students are referred, evaluated, and identified for special education services. Given the very real, and often perverse, financial incentive structures within the special education system, state and local policies and practices designed to influence if and how students are identified and served are another important factor. Large state-by-state variation in overall (and disability-specific) identification rates suggest that many considerations other than underlying prevalence of disability are at play.

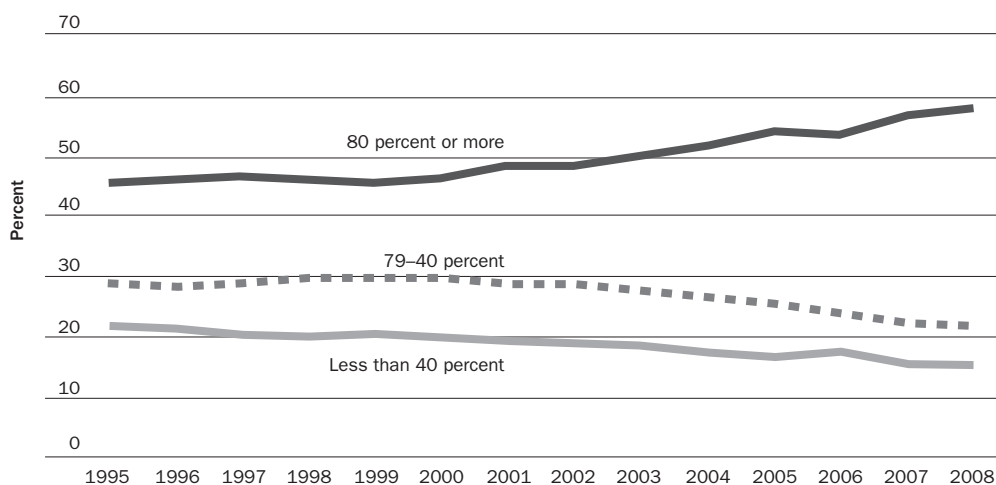
Disability profiles also vary with students’ age—speech or language impairments and developmental delays are common among preschoolers, while elementary school students are most commonly diagnosed with speech or language impairments and specific learning disabilities. Students aged twelve and older are most often diagnosed with learning disabilities, and they are less likely than their younger counterparts to be diagnosed with speech and language impairments and more likely to have mental retardation or an emotional disturbance.¹⁰

The limitations and service needs of children vary greatly depending on the types of disabilities involved. Combining special education students into small groups defined by disability types with similarities in service needs eases discussion of program outcomes, policies, and practices. In 2001 Wade Horn and Douglas Tynan proposed segmenting the special education student population into three distinct subgroups: children with significant developmental disabilities and sensory and physical impairments; children

with milder forms of neurological conditions, such as learning disabilities and attention-deficit/hyperactivity disorder; and those with conduct or behavioral problems (the groups can and do overlap with one another).¹¹ The first group includes children who were the primary target of the original IDEA legislation—a relatively small share of special education students today. Each of these groups requires a distinct set of services and disability-related accommodations, such as medical services, learning-related interventions, or behavioral supports. Alternate groupings have been used by several long-term special education studies—such as the Special Education Elementary Longitudinal Study and the National Longitudinal Transition Study—and recommended by the President’s Commission on Excellence in Special Education. These organizational schemes differ somewhat from one another, but all are efforts to simplify differences in service needs among special education students.

While the disability profile of special education students is largely similar for students from different racial or ethnic groups (the most common category for all groups, for example, is specific learning disabilities), overall rates of identification do vary by race and ethnicity. In 2005, for example, the share of students aged six through twenty-one identified for services under IDEA ranged from 6.3 percent of Asian school-age children to 14.1 percent of white children and 16.7 percent of African American children. For American Indian and Hispanic school-age children, the shares were 15.8 and 11.8 percent, respectively. Serious concerns have been raised for many years about the overrepresentation of African American students in special education. For example, non-Hispanic African American students are almost three times as likely as other students to be

Figure 3. Percentage Distribution of Students Aged 6 to 21 Served under IDEA, Part B, Placed in a Regular School Environment, by Time Spent in General Classes



Source: S. Aud and others, "The Condition of Education 2011," NCES 2011-033 (Washington, D.C.: U.S. Department of Education, National Center for Education Statistics, 2011), figure 7-2.

identified as needing special education services for mental retardation and nearly two and a half times more likely to be identified as needing services for emotional disturbance.¹²

Disproportionate representation has also been documented along dimensions such as family income, native language, and gender (boys are more likely to be identified as needing special education than girls), but much of the policy and research focus has centered on the overrepresentation of African American students.¹³ The 2004 amendments to the law required states to establish policies to prevent inappropriate overidentification by race or ethnicity and to track (dis)proportionality on the basis of race and ethnicity over time. Many factors are thought to contribute to this problem, including poverty, institutional racism, biased standardized testing, and low numbers of teachers and other school professionals from diverse backgrounds. States typically respond to criticism regarding the overrepresentation of African American students by providing more

teacher awareness training, examining the way students are identified and placed, and improving the way students at risk for reading problems are monitored and served. There has been little systematic analysis of the causes and consequences of overrepresentation or of the effectiveness of attempted solutions.

A related challenge has been the identification of learning disabilities among English language learner students. Many of these students have been incorrectly identified as having learning disabilities, while others with true learning disabilities have gone unidentified. The needs of students who are both learning English and learning disabled represent an important and evolving area of attention within the educational research and practice communities.

A critical and closely monitored aspect of special education has to do with where students are served. In addition to providing them with "a free and appropriate

education,” IDEA requires schools to serve students in “the least restrictive environment,” meaning that to the greatest extent possible, special education students should be kept in “regular” classrooms alongside their nondisabled peers. While almost all (about 95 percent) special education students are enrolled in regular schools, many spend a portion of their school day outside this classroom.¹⁴ Gradually, an increasing number of these children have been spending most of their school day in general education classes. In 2008–09, for example, 58 percent of them spent 80 percent or more of their day in a regular classroom, up from 46 percent in 1995–96 (figure 3).

The educational environments of students also vary by their age and type of disability. Regular classrooms are the most common setting for special education students in all age groups, but older students are more likely than their younger counterparts to spend portions of their school day away from their regular classrooms, often going to separate classrooms for specialized instruction. Similarly, students with speech or language impairments, developmental delays, visual impairments, and specific learning disabilities are much more likely to spend large shares of their day in a regular classroom compared with students with mental retardation, multiple disabilities, or deaf-blindness.¹⁵

Education Services for Children with Disabilities

Once a child is deemed eligible for special education services, a team that includes the child’s parents and representatives of the public education system is charged with developing an individualized education program that outlines academic goals and incorporates all the services and supports necessary to meet the child’s unique needs.

Services and supports can include transportation; speech-language pathology and audiology services; psychological services; physical and occupational therapy; therapeutic recreation; counseling services including rehabilitation counseling, orientation, and mobility services; medical services for diagnostic or evaluation purposes; school health services; social work services in school; and parent counseling and training.

Within schools and classrooms, special education students can benefit from a variety of approaches and supports, including curriculum modification, small-group or individual instruction, and teachers who are especially skilled in motivating students, adapting instructional materials, teaching reading skills and language arts, and managing student behaviors. Specific accommodations might include tutors or aides, more time for students to take tests, alternative tests or assessments, modified grading standards, slower-paced instruction, shorter or different assignments, more frequent feedback, a reader or interpreter, a peer tutor, or special behavior management approaches and programs.

IDEA requires states to identify, locate, and evaluate all children from birth to age twenty-one who are in need of early intervention or special education services. In practice, children enter the program in many different ways, and they are also often assessed, identified, and then served quite differently. Two groups of students who have received more systematic attention by researchers and program planners are those who struggle with reading and those with behavioral problems. We describe recent innovative approaches for intervening successfully with these students. Because the importance of children’s experiences before they reach school age

(whether or not they have a disability) is also well established, we also discuss the types of services preschool-age children can receive through the Part C special education system before they start their formal schooling.

Response to Intervention

The reauthorization of IDEA in 2004 changed the law about how children with specific learning disabilities could be identified by allowing an approach known as response to intervention (RTI). Rather than identify learning disabilities by documenting a discrepancy between a student's ability (usually measured by IQ) and his or her academic achievement (usually measured by grades and standardized test results), RTI calls for a tiered process of instruction in which schools identify struggling students early and then deliver a variety of appropriate instructional interventions.¹⁶ In theory, RTI should benefit all students (including those who previously did not qualify for special education services) because it requires that all essential components of reading instruction be delivered as part of the core curriculum.¹⁷ Schools using RTI must deliver scientific, research-based reading instruction to all students in the general education classroom; screen all children early to determine if they are at risk for learning disabilities; monitor the progress of all at-risk children to determine if they are benefiting from instruction; and use programs or curricula correctly and as intended.

Like many aspects of the special education system, RTI is still being developed and refined, and its effectiveness in reducing the number of students with specific learning disabilities remains unproven. At best, it may be an effective driver of schoolwide instructional improvement, one that also prevents the misidentification of learning disabilities

(poor instruction sometimes leads to children being identified as having a disability) and that allows schools to intervene early with students with true learning disabilities. But some observers are concerned that school districts can use RTI to delay and limit access to full-blown special education services. Because RTI often takes place over a number of years, with new teachers and approaches each year, it has the potential to serve as a bureaucratic means for delaying a full evaluation and identification of a learning disability. Districts' desires to contain high special education costs lend credibility to this viewpoint (more on this point later). These tensions reflect a more general discussion within education circles about the need to improve teaching by differentiating instruction for *all* students and to limit special education services to a smaller number of students with more disabling conditions.¹⁸

Positive Behavioral Interventions and Supports

Can and should students with behavioral problems and other disabilities be disciplined? This question has been a major focus of special education law and regulations, in part because schools are struggling with how to manage disciplinary problems, which appear to be increasing among students with disabilities, and in part because these students are most likely to be negatively affected by zero-tolerance discipline policies and other high-stakes testing and accountability measures. IDEA requires that disabilities be taken into account when students are disciplined. Schools must also conduct functional behavioral assessments and use positive behavioral supports with students who are at risk for expulsion, alternative school placement, or suspension of more than ten days. *Positive behavioral support* is a general term that refers to the application of behavioral analysis

to achieve functional behavior changes; positive behavioral interventions and supports are often based on functional behavioral assessments and involve long-term strategies designed to reduce inappropriate behavior, teach more appropriate behavior, and provide supports necessary for successful outcomes.¹⁹

Originally an alternative to traditional behavioral approaches for students with severe disabilities who engaged in extreme forms of self-injury and aggression, positive behavioral interventions and supports are now used both schoolwide and for individual students with and without disabilities.²⁰ Schoolwide interventions can include evaluating the school environment—classrooms, hallways, cafeteria—to determine where and when problems are likely to occur; creating strategies to prevent the identified problems; teaching all students rules and routines to encourage desirable behavior; responding to inappropriate student behavior with correction and reteaching procedures; establishing behavior support teams to monitor effectiveness of prevention strategies; and using data collection (direct behavioral observation, office discipline referrals, interviews with staff and family members) and analysis to identify students who are at risk for school failure. More intensive, individualized interventions include drawing on functional behavioral assessments to monitor and modify behavior plans as necessary (the responsibility of behavior support teams); ensuring that all adults in the school understand what skills these students are learning so that all settings in the school environment can be arranged in ways that reduce problem behavior and encourage appropriate behavior; and delivering effective instructional strategies, aggression replacement training, counseling, and classroom supports. Students with chronic or intense behavioral problems might also

receive “wraparound” services that coordinate services and input from home, community, and school.

Early Intervention and Transition to Schooling

Early intervention is based on the now widely accepted idea that identifying children’s needs and providing services early in their lives can avoid or alleviate future service needs by lessening the effects of a disabling condition and in some cases actually reducing the occurrence of additional disabling conditions. Early intervention services include screening, assessment, referral, and treatment and tend to be less specialized, intrusive, and costly than “higher order” services.

Early intervention services are provided to children with disabilities through several public programs. In addition to Part C of IDEA, states offer early intervention services under Title V of the Maternal and Child Health program and the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) component of Medicaid. Part B of IDEA also provides services to children aged three to five. The group of children receiving early intervention services through Part C includes infants and toddlers with diagnosed medical conditions (many of whom had low birth weight) that put them at risk for developmental delay and toddlers who are showing developmental delay, meaning a gap between their actual development and age-appropriate expectations.²¹ In 2005 about 2.4 percent of the population under age three and their families were receiving services through Part C. It is unclear what fraction of the eligible population this represents, since each state has different criteria and to date no study has estimated the numbers of eligible children.

Other programs that provide educational services to low-income preschool children with disabilities include Head Start (three- and four-year-olds) and Early Head Start (under age three). About 12 percent of Head Start students have disabilities, half of which are identified during the program year and half before joining the program. Almost all of these children receive special education and related services.²² A similar percentage of children in Early Head Start has disabilities.

Despite the widespread recognition of the value of early intervention, the programs face several challenges to their effectiveness: reaching eligible children is difficult (often the neediest children are hardest to reach), resources are limited, needed services are not always available for eligible children, and transitioning from programs serving young children to those serving preschool and school children can be complicated and uneven. Evidence shows that high-quality early intervention at young ages can provide long-term cost savings.²³ However, because these savings accrue over time and across public programs (such as education, health, or criminal justice), the full impact of long-term savings may not be taken into account in individual program decisions.

Eligibility, services, program structures, and access to early intervention programs vary greatly from state to state. Under Part C, for example, states must serve all eligible children and families but have a great deal of latitude in setting eligibility criteria. State choices in developing their eligibility criteria are influenced by concerns over numbers of eligible children and costs. For example, states are allowed to serve children who are *at risk* of a developmental delay, but only four states have opted to do so, in part because of funding concerns.²⁴

Identification and access to screening services constitute another challenge. Each state is responsible for implementing a Child Find program that locates, identifies, and refers all children in need of early intervention or special education services. Each Child Find program is required to include procedures for screening child health and development. Screening is also mandated under Medicaid's EPSDT Program and is required of pediatric health care providers who deliver routine health supervision services such as preventive care and well-child visits. For low-income children with disabilities, screening through EPSDT is a potentially powerful tool because it mandates coverage for certain medically necessary health care services identified through the screening. But many families do not have access to these screening services. A recent report found that, in nine states, four of ten Medicaid-enrolled children eligible for EPSDT did not receive any of the required screenings and that the screenings were incomplete for nearly 60 percent of those who did receive them. This record comes despite requirements that all eligible Medicaid recipients be notified within sixty days of enrollment about available EPSDT services and amid multiple other forms of state outreach activities and provider incentives. According to the states, barriers to completing screenings include cultural or family beliefs that screenings are not necessary, the unwillingness or inability of families to take time off work to take their child to the screening, limited access to providers, and incorrect contact information for beneficiaries.²⁵

Finally, transitions for young children from early childhood programs to preschool to school are not always smooth.²⁶ When a child receiving Part C services reaches age two and a half, IDEA requires a meeting between the Part C service agency, parents, and the

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local education agency to determine continuing eligibility for special education services and to ensure a smooth effective transition to preschool. Disconnects can and do occur, however, because of the number of agencies involved in determining eligibility for preschool special services, the number of agencies in the community (private, nonprofit, for profit, and Early Head Start programs) involved in providing these services, and the variety of ways and settings in which young children receive early intervention services.²⁷ Similar challenges occur when children with disabilities transition from the preschool setting into the school system or move from one state or school district into another.

Funding

Special education programs are funded by a combination of federal, state, and local government programs. The most recent comprehensive estimates of total public expenditures on special education come from a special study for the 1999–2000 school year.²⁸ Special study is required to gather this information because states are not obligated to give detailed state and local breakdowns of special education spending to the federal government. In the 1999–2000 school year, the United States spent an estimated \$50 billion on special education services and an

additional \$27.3 billion in general education funds for those special education students who spent part of their time in general education classroom settings, for a total \$77.3 billion.

This total represents about 21 percent of total U.S. spending on elementary and secondary education that year—a substantial increase from 1977–78, when total spending on students with disabilities was about 17 percent of total education spending. Most of this increase is attributable to an increase in the number of children in special education rather than to an increase in per-pupil costs.

Federal funding has always been a relatively small share of total expenditures on special education. In 2010 federal funding on special education through IDEA was \$12.5 billion, most of it in the form of grants to help states pay the additional costs of providing early intervention, special education, and related services to children from birth through age twenty-one. The federal government also makes discretionary grants to states for personnel development and training, technology and technical assistance, and parent information centers.²⁹ Federal funding levels for special education have been relatively flat since 2004, with the exception of a significant infusion of special funds under the American Recovery and Reinvestment Act of 2009.³⁰

When IDEA was enacted, its intention was to help states provide special education by funding a portion of the additional, or “excess,” cost of special education over general education. The original legislation set the maximum federal contribution at 40 percent of the estimated excess cost of educating children with disabilities, but federal funding has never come close to this “full funding” cap. In 2010, federal grants to the states under

IDEA, Part B, covered about 17 percent of the excess cost for special education students. In the 1999–2000 school year, schools spent 90 percent more on the average school-age special education student (including general and special education funding) than on the average general education student.³¹

As total special education spending has increased and federal spending has remained flat, state funding for special education has declined, leaving local school districts to cover the difference. In the 1987–88 school year, states funded 56 percent of special education expenditures, local school districts 36 percent, and the federal government 8 percent. In 1999–2000, the distribution was 45 percent from states, 46 percent from local school districts, and 9 percent from the federal government.³²

Financing structures can provide incentives that influence the way children are identified for special education services, the services they receive, and the settings in which they receive them. For example, financing structures that provide additional state funding per special education student can encourage identification at the local level on the margin. Studies show that in states that switched from distributing their special education funding based on the number of children enrolled in special education, resources used, or past actual spending to a distribution based largely on the total number of children in the school, the number of students identified as having a disability and being eligible for special education fell.³³ On the federal level as well, the formula for distributing state grant funds has been tweaked in an effort to limit overidentification of special needs children; a portion of the grant funds is now based on each state's share of school-age children and children in poverty.

At the same time, financing incentives also exist to underidentify students eligible for special education. The “excess” cost of education for a child in special education coupled with legal protections that mandate services (that might be provided for the rest of a student's education) and an increasing share of funding coming from local school districts provides incentives for school districts to limit identification of children for special education services. Which incentive effect predominates is unclear and likely differs by school district or state given different sets of incentives.

Variation in Spending across Disability Type

The range of educational needs among students served by the special education program leads to significant differences in expenditures. Children with specific learning disabilities and speech or language impairment made up the majority of children in special education and had the lowest per-pupil expenditures, \$10,558 and \$10,958, respectively, in 1999–2000.³⁴ The highest expenditures were on children with multiple disabilities (\$20,095) and on those who were placed in private settings after the public school has been found unable to provide an appropriate education (\$25,580). These “high-cost” children are the focus of some efforts to reduce special education spending. The 2004 reauthorization of IDEA allowed states to put up to 10 percent of their federal grants into state risk pools to aid local districts with high-need, high-cost students. The growth in total special education expenditures is not caused by growth in the number of high-cost children, however, but primarily by the increase in numbers of children across all categories of disability.

Variation in Spending across States

Studies of special education spending across several states have uncovered dramatic

differences in spending. Nationally, as noted, average spending on special education students is 90 percent higher than spending on general education students. But it is 57 percent higher in Alabama, for example, and 155 percent higher in Maryland.³⁵ These ratios also reflect differences in general education spending: states that spend more on general education also tend to spend more on special education.

Special Education and Outcomes

IDEA and Section 504 are widely credited with improving access to education for young people with disabilities and establishing an infrastructure for educating them, as shown in figure 1. The next important question is the extent to which special education has been successful in meeting the educational needs of students with disabilities and improving their educational achievement.

To answer this question, one must first ask whether special education programs are serving the right students, and whether these students are being identified in a timely manner and given the most appropriate and effective services. As suggested by the overrepresentation of African Americans, some children may be inappropriately placed in special education, while others may go unidentified or not receive the services they require. Clearly, many needy students who eventually receive special education did not receive the early intervention services to which they were entitled.

Accurate measures of outcomes for special education students are also needed, including appropriate measures of academic achievement, attendance, grade promotion, and engagement in school activities. Assessing these outcomes is challenging because of the heterogeneity of the students' capacities and

school experiences and a paucity of data on in-school outcomes for these students. The lack of good data even on the interventions and inputs—the types and amounts of services special education children receive—further compromises the ability to measure the effectiveness of interventions. In addition, there is no agreement on whether the right measure of academic achievement should be appropriate standardized testing or some alternative assessment. Even the benchmarks for outcomes are not clearly agreed upon and may vary across students with disabilities. IDEA's requirement that each student have an individualized education program and goals reflects this difficulty in measuring progress.

Perhaps an even greater challenge to assessing student outcomes lies in separating the effects attributable to specific educational practices from other intervening and coexisting factors such as socioeconomic circumstances and need for supportive services. For this and other reasons, relatively little research has been conducted on the effectiveness of specific special education practices or programs. Of course, these difficulties mirror similar problems in measuring and improving outcomes for general education. In addition, the impact of special education for most students with disabilities is intertwined with their general education experiences and opportunities, including whether they have access to the full range of general education options. Finally, studies have found that the limited expectations of teachers and parents for many students with disabilities can lessen the effectiveness of an educational program.³⁶

That said, we report on a set of measures that are available on educational and postsecondary outcomes for students in special education. These measures clearly suggest that

there is room for improvement. We look specifically at assessments of educational progress, school completion rates, postsecondary outcomes, and the transition to adulthood.

Educational Assessments

One measure of the academic progress of students in special education is performance on standardized achievement tests. Since passage of No Child Left Behind, students with disabilities must be included in state testing and assessed against the same standard of proficiency as other students to determine whether schools are making the required “adequate yearly progress” toward goals for academic proficiency.³⁷ The intention is to hold schools accountable for the performance and progress of all students, including those with disabilities. Results indicate continuing problems. For example, in 2003–04, among schools nationwide with subgroups of students with disabilities large enough to be counted separately, students in 36 percent of them did not make the required progress.³⁸

Debate continues on the appropriateness of using the same tests and standards for assessing students with and without disabilities and on the use of accommodations in test taking. Some argue that many students with disabilities have inherent learning difficulties and start with lower test scores and so should be held to different standards while still maintaining progress toward goals.³⁹ In the late 1990s, the U.S. Department of Education began to allow states to make testing accommodations for students with disabilities who need them, and in the early 2000s states were allowed to use alternative assessments and modified standards for a small percentage of students with disabilities, particularly those with cognitive disabilities.⁴⁰ However, states report continuing challenges in developing and validating alternate

assessments (such as portfolios of work), including costs related to development. This area would be a useful place for federal assistance and coordination.

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Because of differences in the way states identify the students who take assessment tests, the tests and standards that are used, and the testing accommodations they may provide, clear comparisons and interpretations of the results of state assessments are difficult to make. Comparing results over time, even for the same state, is complicated by changes in the composition of special education students and in policies, such as test accommodations, that can directly influence who participates in standard assessments as well as the results.

Given these caveats, results from the National Assessment of Educational Progress (NAEP) standardized test, which is conducted in the same way in all states and which changes only slowly over time, provide useful information on the achievement and progress of students with disabilities.

These results suggest some progress but also point to substantial gaps between students with disabilities and their nondisabled peers. Academic achievement trends from 2003 through 2007 measured by the NAEP showed significant increases in average reading and math scores for children in fourth grade who received IDEA services. But in each of these years, students in special education had significantly lower scores than other students.⁴¹ In the 2009 reading assessment for twelfth graders, 64 percent of students with disabilities but 24 percent of other students tested below basic proficiency; in math 76 percent of students with disabilities and 34 percent of other students fell below basic proficiency.⁴² Other grade-level assessments show similar gaps. Several reasons account for the lower scores among students with disabilities. The factors cited by one study were type of disability, cognitive ability, race, income, parental expectations, school absenteeism, and disciplinary problems. Grades, school mobility, and repeating a grade level were not significantly related to test scores.⁴³

Graduation Rates

Another important educational outcome is the rate at which students with disabilities either graduate from or drop out of high school. Measurement of graduation rates can be complicated. Results from national studies that track secondary school students with disabilities found that 70 percent of the teenagers with disabilities who were out of school in 2003 had received a regular graduation diploma or certificate of completion, up from 54 percent in 1987⁴⁴ and not far below the 74 percent graduation rate for all public school students in 2002–03.⁴⁵ However, far fewer special education students receive regular diplomas than do those in general education. In 2005, 46 percent of youth receiving IDEA services graduated with a regular diploma,

compared with 75 percent for all students.⁴⁶ High school completion rates also differ substantially across disability type. For example, students with sensory disabilities have much higher graduation rates than students with emotional disturbance.

Evidence is limited on how best to improve graduation rates for students with disabilities. One recent study in Chicago found that ninth grade course performance is a strong predictor of graduation rates for these students. This study also found that high absence rates are an important factor explaining why students with disabilities have poorer course performance than students without identified disabilities.⁴⁷

Postsecondary Outcomes and the Transition to Adulthood

Many studies have found that students with disabilities have poorer outcomes in the years after high school than their peers without disabilities, including lower rates of postsecondary schooling and employment, greater involvement with the criminal justice system, and lower likelihood of living independently.⁴⁸ Other dimensions to consider for these students (but less often measured) are quality of life, satisfaction, and social and civic engagement. Relatively little is known about the relationship of the school program to these life outcomes for those with disabilities.

Recognizing the difficulties some youth face as they transition to adulthood from schooling, IDEA requires that transition planning be provided to all special education students starting no later than age sixteen. One obvious problem is that students who drop out of school at age sixteen may never receive these services. Transition services may include coordination of services (such as vocational

training, case management, and benefit counseling) in and outside of schools, assessments of students' interests and aptitudes, help with gathering information on and choosing among relevant opportunities, and planning for necessary supports including assistive technology. The 2004 amendments to IDEA require that transition planning be based on students' "strengths," not just their preferences and interests, and that the process be "results-oriented." In 2001 almost 90 percent of special education high school students were receiving transition planning, with two-thirds of parents satisfied with these services.⁴⁹ Nonetheless, the extent to which current planning services are improving outcomes for students with disabilities has not been clearly demonstrated, although research has shown the potential for positive impact.⁵⁰

Given the importance of higher education for future economic well-being, one area of concern for students with disabilities is their relatively low participation in postsecondary schooling. One study found that in 2005, 46 percent of students with disabilities were enrolled in postsecondary education within four years of leaving high school, mostly in community colleges or vocational, technical, or business schools.⁵¹ This rate represents a good deal of progress since 1990 when only 27 percent of these youth were enrolled in postsecondary education. But it is still substantially below the enrollment rate of 63 percent in the general population. Other studies find that adults with disabilities have significantly lower levels of postsecondary school completion than those without disabilities, even among the subgroup who had a disability during their school years.⁵²

Another concern is whether youth are being appropriately prepared for employment, given the low rate of employment among

adults with disabilities. Employment rates among youth with disabilities just out of high school were similar to those of other youth without disabilities in 2005—roughly 60 percent. However, employment rates at this age reflect schooling choices as well as employment choices—unemployed youth attending school are of less concern than those who are neither working nor in school. In 2003, 30 percent of students with disabilities were not participating in schooling, employment, or job training in the years immediately after high school. This lack of engagement varied considerably by disability status. For example, more than half of students with mental retardation had not engaged in any of these activities compared with 17 percent of students with learning disabilities.⁵³

Opportunities for vocational or career training opportunities and vocational assessments of interest and aptitude are part of students' transition planning that can improve employment outcomes. Coordinating job training, both while students are still in school and after they leave, with available workforce options from other public programs such as those funded through the Workforce Investment Act and Vocational Rehabilitation is also important. Even as the focus on transition planning in IDEA has been strengthened, many challenges remain in preparing and supporting special education students for the transition to adulthood. Enhancing the ability of secondary school students to advocate for their needs in various settings, improving access to supports and services after high school, and coordinating services across postsecondary education, health, mental health, and human services are all areas of intervention that need to be improved.⁵⁴

Additional transition issues concern children with disabilities in the juvenile justice system,

alternative education systems, and the foster care system. Special education children are disproportionately represented in all three systems, and their transition to adulthood is particularly complicated and difficult.⁵⁵ Challenges to receiving appropriate educational services in these settings are compounded by the particular difficulties that lead children to be in these systems and the specific challenges these systems face. The need for coordination between the public education system and these other systems goes well beyond transition planning to extend throughout the educational experience.

Implications for Practice and Policy

The nation's special education system, like the legal and regulatory framework that underpins it, has evolved considerably since IDEA was first passed in 1975. Along with the efforts of parents and educators and greater societal awareness about disability issues, IDEA has clearly led to better access to public education for students with disabilities, an established infrastructure for educating children with disabilities, earlier identification of disabilities in children, and greater inclusion of these children in classrooms with their nondisabled peers. Despite these advances, 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. Nor is there much evidence regarding the basic effectiveness of many services that special education students receive (at considerable expense and bureaucratic complexity) or whether these services improve student achievement.

Over the years many studies have documented fundamental problems with IDEA. In 2002 a President's Commission on Excellence in Special Education determined the system to be "in need of fundamental re-thinking, a shift in priorities, and a new commitment to individual needs."⁵⁶ Among the problems they identified were financial incentives to define an increasing share of school-age children as having a disability, adversarial procedures between parents and schools that contributed to unnecessary litigation, and a major redirection of financial resources from regular education to special education. Other studies have demonstrated states' noncompliance with the many administrative and procedural requirements of the program, as well as the federal government's lack of funding and ineffectiveness in enforcing the law.⁵⁷

Despite widespread agreement that the special education system is not working as it should or could, opinions differ over how it should be fixed. Policy makers, advocates for children with disabilities, and researchers increasingly have called for financing reforms and for more accountability measures similar to those introduced in the No Child Left Behind Act.⁵⁸ Many of the 1997 and 2004 amendments to the law were designed to increase accountability and flexibility regarding financing; these amendments addressed but did not fully resolve perverse state incentives to increase identification of special education students. Families of children with disabilities, disability rights groups, and other advocates and supporters of IDEA have sharply opposed calls for fundamental changes to the special education system.⁵⁹ They believe the program is well conceived and properly structured but has been poorly funded, implemented, and enforced.

These tensions around reform reflect the law itself. IDEA constitutes a blend of civil rights law and state grant programs. The dual nature and purpose of the law has contributed to the creation of different stakeholders, with different goals, at the grassroots level. The major stakeholders in civil rights laws tend to be the individuals who are protected by the law—in this case, children and youth with disabilities and their families and supporters. The major stakeholders in grant programs are the recipients of the grants, in this case state and local educational agencies, school boards, their staffs, and other professionals who are supported financially by the grants. In addition, the natural course of reform for government programs with limited resources is to debate priorities and make trade-offs among them. But the civil rights requirements of IDEA limit the ability to make trade-offs because states are required to provide all services necessary for a “free and appropriate education.” Part of the ongoing challenge for program financing is how to divide these costs across the three levels of government, given the already increasing share borne by local districts and tight budgets at all levels.

Another challenge for the special education system is the adversarial nature of the program. The many legal conflicts that arise between parents and schools can be counterproductive for children and their educational success and costly for school systems. To some extent, these conflicts arise because parents play an integral role—one that is required by law—in the team that develops their child’s individualized service plan. The incentives for parents to obtain the most help for their child may differ from those for school systems that are trying to balance educational needs and budgets. In some cases, parents feel that school systems are

trying to avoid mandated responsibilities and need to be held accountable legally. In any case, the role of parents in education generally as well as in special education is essential. Children without parents who can advocate for them are often the least well served, in general and special education, and these are often children from families who are already socially and economically disadvantaged. Forming a less adversarial system that can serve the broader community of children needing special services is an important challenge.

Reforming special education cannot be done in isolation; it requires integration with reforms being made in general education. The large amount of time that many special education students spend in general education settings is one argument for this integration. Another is the absence of a bright line between many of the needs of special education students and those of other students. Efforts such as response to intervention and positive behavioral interventions and supports demonstrate this fact by creating school environments that are more conducive to positive behaviors and to learning for everyone. These efforts, when implemented as designed, break down a legal and programmatic firewall that has existed between the general and special education systems. They may serve as models for other aspects of the special education system and point the way for better serving not only children with disabilities but all students.

Despite calls for increased funding and the need for reform, little evidence exists to suggest that additional federal funding or better enforcement will improve student outcomes or solve many of the problems experienced by schools and families alike. More evidence on the impacts of special education services

on achievement and student outcomes is necessary to gauge the efficacy of the money being spent. Pinpointing the causes of the gap between special education and other students' outcomes and determining how to reduce this gap effectively requires ongoing research. That in turn requires better data on outcomes as well as services provided across special education students of all ages. In addition, greater efforts are needed to develop and standardize appropriate assessments of academic achievement for students with disabilities. Finally, given the vast differences in service needs and outcomes across students of different disability types, attention needs to focus on understanding how all these issues affect different subgroups of special education students.

The direction special education might take in the next few decades is uncertain. Clearly, providing children with disabilities equal access to public education and protecting this important civil right should not be undone. But aspects of the current program appear to be both unsustainable and unwise—unsustainable because of the cost and unwise given evidence of the continuing gap between outcomes for students in special education and their nondisabled peers. Together those responsible for the general and special education systems must craft solutions that make education special for all students while not leaving children with disabilities behind.

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Health Insurance and Children with Disabilities

Peter G. Szilagyi

Summary

Few people would disagree that children with disabilities need adequate health insurance. But what kind of health insurance coverage would be optimal for these children? Peter Szilagyi surveys the current state of insurance coverage for children with special health care needs and examines critical aspects of coverage with an eye to helping policy makers and clinicians improve systems of care for them. He also reviews the extent to which insurance enhances their access to and use of health care, the quality of care received, and their health outcomes.

Szilagyi begins by noting that nearly 9 percent of children with disabilities are uninsured for all or part of a year and that coverage even for many such children with insurance is inadequate—either not meeting their needs or not adequately covering the costs of care. By one estimate, nearly two of every five special needs children are either uninsured or inadequately insured.

The author finds strong evidence that health insurance improves access to health care. Children with disabilities who are insured are more likely than those who are uninsured 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 needs for medical and oral health care and receive care more quickly. The bulk of the evidence shows that insurance improves quality of care for children in general and for children with disabilities. Parents of insured children with chronic conditions are more satisfied with their children's primary care, medications, specialty care, and overall health care than are parents of their uninsured peers. A handful of studies of specific diseases have found insurance to be related to improvements in quality measures, such as more doctor visits and greater continuity of care.

In conclusion, Szilagyi stresses the need to provide adequate health insurance to all children with disabilities and to develop a set of best practices in health insurance to cover important services needed by this population. To that end, implementation of the federal health care reform act, including the mandate for insurance coverage, is important. He also urges support for medical home and other quality initiatives and better ways to monitor quality and health outcomes to ensure that children with disabilities receive cost-effective and equitable care.

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Nearly everyone agrees that children with disabilities need adequate health insurance. Recent debates surrounding the reauthorization of the State Children's Health Insurance Program in 2009 and the passage of the Patient Protection and Affordable Care Act in 2010, with its new provisions to protect individuals with preexisting conditions, brought to national attention the central role of health insurance for Americans, including those with disabilities.¹ A substantial body of research has highlighted the large number of children who have disabilities, their many unmet health care needs, the suboptimal health care many of these children receive, and their poor outcomes. To the extent that it can attenuate some of these problems and facilitate access to needed health care, adequate health insurance is particularly critical for children with disabilities. But while most people agree with the importance of health insurance, there is little consensus on what an optimal health insurance policy might look like for children with disabilities.

In this article, I review evidence about critical aspects of health insurance for children with disabilities to help policy makers, clinicians, and other leaders improve systems of care. After surveying overall health insurance coverage for children and adolescents with disabilities, including the extent of underinsurance and lack of insurance, I examine coverage for different types of disabilities and the role played by key government programs. Next I review research regarding the impact of health insurance for children and adolescents with disabilities on their access to and use of health care, the quality of care they receive, and their health outcomes. Finally, I make recommendations on the future of health insurance for children and adolescents

with disabilities, in the context of health care reform, medical home initiatives, and the need for accountability and metrics.

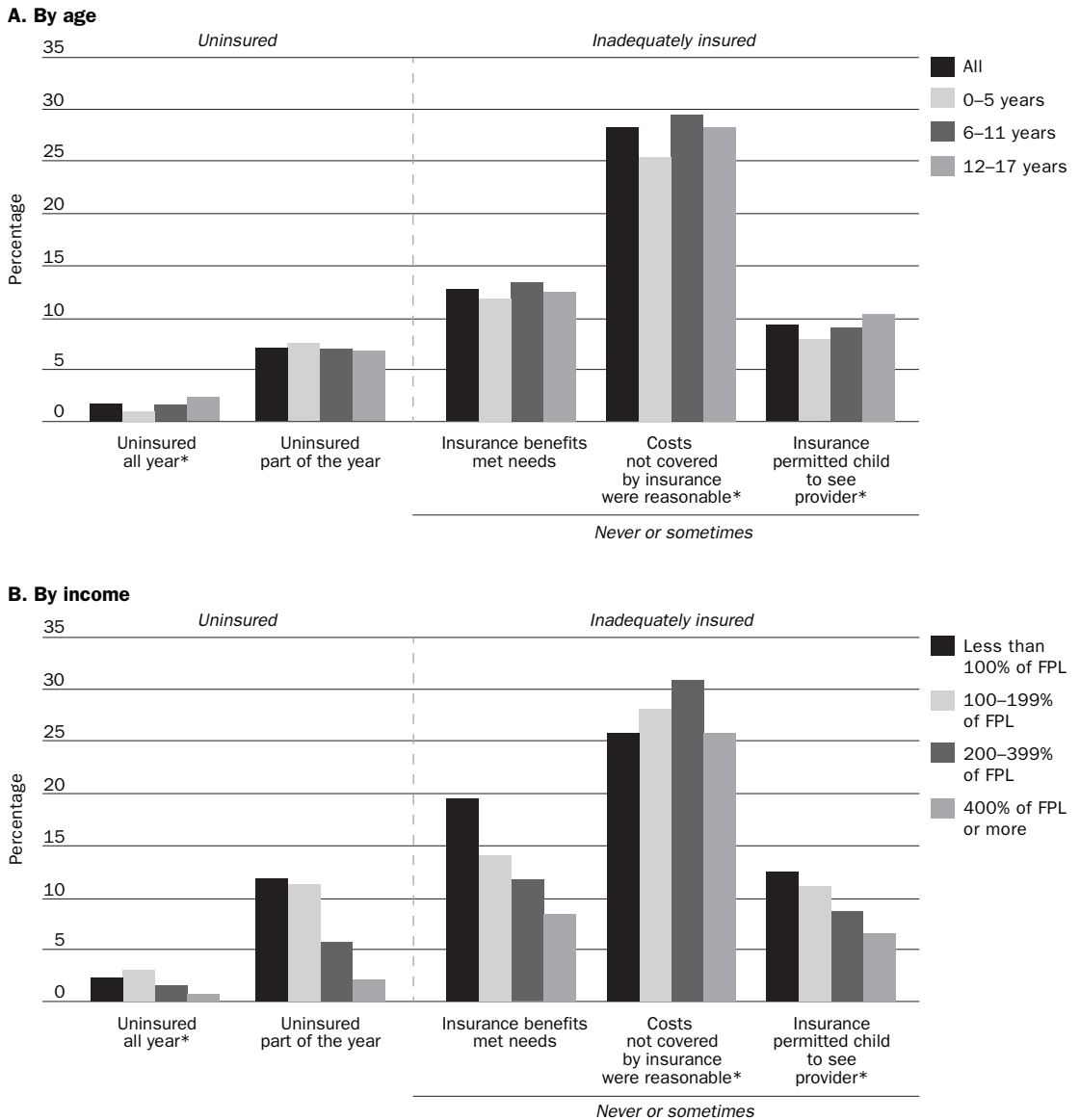
Current Patterns and Recent Trends in Health Insurance

The federal Maternal and Child Health Bureau defines children with special health care needs (CSHCNs) as “those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.”² That definition is incorporated into the CSHCN Screener, a tool created by a national public-private collaboration for identifying such children. The screener is used in several surveys, including three—the Medical Expenditure Panel Survey, the National Survey of Children's Health, and the National Survey of Children with Special Health Care Needs (NS-CSHCN)—that provide nationally representative data on the extent of health insurance, lack of insurance, and underinsurance among American's children.³ Under the Maternal and Child Health Bureau definition, 13 percent of U.S. children have a special health care need; by an alternative, “activity limitations” definition, that figure is 7.7 percent (see the article by Neal Halfon and others in this volume for further discussion of definitional issues).⁴

Adequacy of Health Insurance Coverage

In 2005–06, the most recent year for which data from the NS-CSHCN are available, children with special needs were less likely than other children to be uninsured for the full year, but large shares of both groups were uninsured for all or part of the year. Figure 1A displays the share of children with special health care needs by age who were uninsured or inadequately insured. Among all children

Figure 1. Insurance Status among Children with Special Health Care Needs



Source: Author's calculations based on data from the 2005-06 National Survey of Children with Special Health Care Needs.

FPL = federal poverty level.

*Differences are statistically significant ($p < .01$).

with special health care needs, 1.8 percent were uninsured all year; another 7.0 percent, for part of the year. In sum, a total of 8.8 percent, or about 900,000, of these children were uninsured at least some time during the year. In comparison, 4.3 percent of all other

children were uninsured all year and 6.7 percent were uninsured for part of the year, for a total of 11.0 percent.

Insurance status varies by race and ethnicity among children with special health care

needs, with black and Hispanic children more likely than white children to be inadequately insured. According to the 2005–06 NS-CSHCN, the share of children with special needs uninsured all year was 1.5 percent for whites, 1.3 percent for blacks, 4.5 percent for Hispanics, and 1.6 percent for “other” race or ethnicity. The share uninsured for part of the year varied as well—5.6 percent of whites, 9.8 percent of blacks, 10.6 percent of Hispanics, and 7.5 percent of other racial and ethnic groups.

Large shares of children with special health care needs also had insurance coverage that their parents considered inadequate because it did not meet the child’s needs (13 percent), did not cover costs adequately (28 percent), or did not permit the child to see needed providers (9 percent). Based on these data, Paul Newacheck and several colleagues concluded that 3.8 million (38 percent) U.S. children with special health care needs were either uninsured or inadequately insured.⁵

Adequacy of insurance differed by age, with older children with disabilities somewhat more likely to be uninsured or to have insurance that did not cover costs or allow them to see a needed provider. Adequacy also differed by race and ethnicity; insurance for black and Hispanic children with disabilities was more likely to fall short of their needs, fail to cover costs adequately, or not permit them to see a provider.

Adequacy of insurance also varies by income (figure 1B). Children with special health care needs whose families have incomes at 100–199 percent of the federal poverty level are most likely to be uninsured, even though they are eligible for Medicaid or the State Children’s Health Insurance Program (SCHIP), thus demonstrating that many who are eligible for these public programs are not enrolled.⁶

Children with families in lower income brackets are also more likely than those in upper income brackets to be inadequately insured even when they do have health insurance. These findings highlight the need for enhanced outreach to enroll all eligible children into public health insurance programs.

In sum, very large numbers of children with disabilities are uninsured or inadequately insured, with greater shares of older and lower-income children and minority children being uninsured or inadequately insured than others.

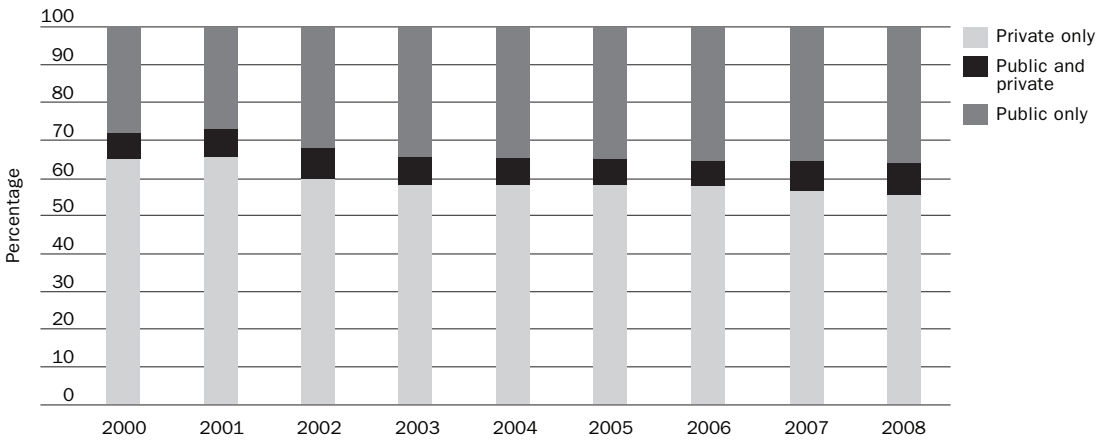
Recent Trends in Types of Coverage

Over the past decade, employer-based private health insurance has declined, with a commensurate increase in public health insurance.⁷ Between 2000 and 2008, among insured children with disabilities, the share with private insurance coverage declined from 65 percent to 55 percent, and the share with public coverage increased (figure 2A). Private insurance coverage fell for children in all income brackets below 300 percent of the federal poverty level, largely because of the rising cost of health insurance. Public coverage expanded because of the extension of Medicaid to higher income brackets, the creation and expansions of SCHIP, the decline in private coverage, and economic and employment disruptions that made private coverage unaffordable or inaccessible for many families. For these reasons, over the past decade children with special health care needs have increasingly been covered by public insurance.⁸

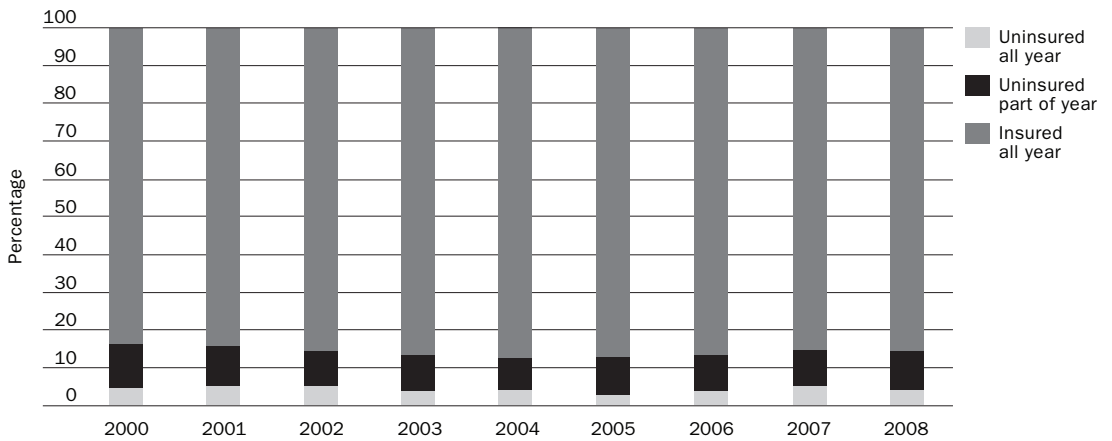
The result has been an overall decline in uninsured rates among children in general and a slight decline among children with disabilities. The Medical Expenditure Panel Survey for each year since 2000, the first year

Figure 2. Trends in Health Insurance Coverage among Children with Special Health Care Needs

A. Type of coverage among those covered



B. Levels of insurance coverage throughout the year



Source: 2000–08 Medical Expenditure Panel Survey.

in which it used the CSHCN Screener, finds that the share of children with special health care needs who were uninsured all or part of the year declined slightly from 16.4 percent in 2000 to 14.6 percent in 2008 (figure 2B). The decline was small, notably so at a time when SCHIP and Medicaid were expanding. Estimates of the number of children who were uninsured vary between the NS-CSHCN and the Medical Expenditure Panel Survey because of methodological differences even though both use the CSHCN Screener.⁹

Health insurance coverage for children with disabilities saw two other changes over the past several decades: a rise in managed care and a decline in indemnity coverage.¹⁰ Today the vast majority of privately insured children, including those with special needs, are in managed care plans. Recently the rising costs of health care have also led to the development of high-deductible health plans in which parents pay lower premiums but have higher deductibles.¹¹

Box 1. Publicly Funded Health Insurance Programs for Children with Disabilities

Medicaid: Medicaid is the largest public funding source for health care services for children in general as well as for those with disabilities. Children with disabilities are eligible if they meet the same eligibility criteria that apply to children in general (family income below certain state-specific cutoffs or foster care); if they are eligible for Supplemental Security Income (SSI, see below); if they qualify for medically needy provisions (optional for states) for children with significant needs who live in families above Medicaid income cutoffs, or if they are severely disabled and living at home but would meet Medicaid eligibility if they were institutionalized or hospitalized (includes Katie Beckett waivers, described below).

Medicaid offers the most comprehensive benefit package for children with disabilities, including dental, mental health, durable equipment, and ancillary services. It requires states to cover a set of federally mandated services and allows states to include additional optional services. The vast majority of states offer a comprehensive set of optional services for children such as prescribed drug and dental, mental health, speech, and many wraparound services. Medicaid requires states to offer early and periodic screening, diagnosis, and treatment health services that cover medically necessary diagnostic and treatment services for chronic conditions. This includes comprehensive screening and treatments necessary for conditions identified by screening. Medicaid funds a variety of other programs including school-based health services and mental health agencies.

SCHIP or CHIP: The State Children's Health Insurance Program (SCHIP) was enacted as Title XXI of the Balanced Budget Act of 1997. It was reauthorized in 2009 as the Children's Health Insurance Program (CHIP). States generally use one of two models for CHIP—Medicaid expansion programs, in which Medicaid operates the CHIP program, or separate CHIP programs in which CHIP is administered by insurance plans separate from Medicaid. Most states do not have separate eligibility rules for children with disabilities. Benefits vary by type of program; in general, separate CHIP programs offer a more limited benefit package than do Medicaid-CHIP programs.

Some states with separate programs also offer supplementary coverage (wraparound approaches), while others have service carve-out programs or specialized systems of care

that enroll some children into special programs designed to serve children with disabilities. Relatively few children with disabilities across the United States are served by these supplementary programs.

Supplemental Security Income (SSI): This program provides cash assistance to help families meet some expenses related to disabilities, qualifies children for Medicaid, and ensures that children receiving SSI are referred into the state's Title V Social Security Act programs. Children must demonstrate both disability and financial need. Welfare reform legislation of 1996 tightened the definition of disability, particularly for children with behavioral problems. To qualify for SSI, children must have "a medically determinable physical or mental impairment, which results in marked and severe functional limitations, and which can be expected to result in death, or which has lasted or can be expected to last for a continuous period of not less than twelve months." Thus low-income children on SSI are among the most disabled. A recent national survey found that 70 percent of SSI recipients lived in families above the poverty level, and about half received special education.

Katie Beckett Waivers: Since 1982 states have been able to apply to the Department of Health and Human Services for state-specific Medicaid waivers (called "Katie Beckett waivers" or "1115 waivers") allowing them to use federal and state funds to cover people with special health care needs who would otherwise be institutionalized or forgo needed care. The waivers vary by state, often involve demonstration projects, and usually include wraparound services.

Title V of the Social Security Act (through the Maternal and Child Health Services block grant): This program provides money to states to develop community-based programs for mothers and children to improve the care of children with disabilities. Federal funding is relatively low compared with other publicly funded programs, and states provide substantial matching funding. Consequently states have great flexibility in administering this program and serve varying populations and provide a variety of different services. Recently the federal Maternal and Child Health Bureau consolidated its system outcomes into six core outcomes, which are also part of Healthy People 2010. Title V programs are focused on achieving these system outcomes.

Sources: L. Aron and P.J. Loprest, *Meeting the Needs of Children with Disabilities* (Washington: Urban Institute Press, 2007); Henry J. Kaiser Family Foundation, *Medicaid Resource Book* (Washington: 2002) (www.kff.org/medicaid/2236-index.cfm); American Academy of Pediatrics, "Policy Statements: Supplemental Security Income (SSI) for Children and Youth with Disabilities," *Pediatrics* 124, no. 6 (2009): 1702–08.

Coverage for Specific Services

The availability and comprehensiveness of health insurance coverage for children with disabilities varies widely depending on the type of medical disability (physical, behavioral, mental, oral, or disease-specific) and type of service offered (preventive care;

acute or emergency care; hospital, specialty, wraparound, or coordination services).

Researchers have highlighted several overall patterns. First, coverage tends to be more comprehensive for physical disabilities than for behavioral and mental health or oral health services.¹² Second, coverage

for different types of services varies greatly. Although coverage for acute or emergency and hospital services tends to be comprehensive under most plans, coverage for preventive services varies somewhat, and coverage for wraparound services, such as speech therapy, physical therapy, and early intervention, varies a great deal.¹³ Few programs other than Medicaid cover coordination of care, and even Medicaid coverage is limited. Third, benefit packages for public health insurance tend to be more comprehensive than those for private plans, with Medicaid offering the most comprehensive package.¹⁴ Fourth, many private plans have recently reduced benefit coverage.¹⁵ Fifth, many children with severe disabilities receive certain coverage, such as home-based services, transportation, or ancillary services from special programs described below.¹⁶ Finally, no standard exists for benefit coverage for children with disabilities. This enormous variability in insurance coverage has led many experts to describe the U.S. health insurance system as a patchwork of programs for all children and particularly for children with disabilities.

Special Public Programs for Children with Disabilities

Five public programs are critical to the financing and delivery of services for children with disabilities. The two main health insurance programs are Medicaid and SCHIP (known since 2009 as the Children's Health Insurance Program, or CHIP). Nearly half of children with special health care needs who have insurance are covered by one of these two programs; 90 percent are enrolled in Medicaid, the other 10 percent in CHIP.

Three additional programs also provide health services for children with disabilities: the Supplemental Security Income (SSI) program, Katie Beckett waivers, and the

Maternal and Child Health Services block grant program (Title V of Social Security) (box 1).¹⁷

Medicaid is the largest public funding source for health care for children with disabilities. Every state Medicaid program, including CHIP programs that were implemented by expanding Medicaid, includes an Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) Program, which covers medically necessary diagnostic and treatment services for chronic conditions.¹⁸ The program requires states to cover a general health screening and specific vision, hearing, and dental screenings for Medicaid beneficiaries under age twenty-one, as well as services necessary to treat physical or mental conditions identified by these screenings even if states do not normally cover these services. Benefits include wraparound, or ancillary, services such as dental care, physical and occupational therapy, prescription drugs, eyeglasses, rehabilitation, social work, and home nursing. States interpret these "medically necessary" standards in varying ways and specify coverage and service delivery in their managed care contracts.¹⁹ Because the EPSDT program is complicated and implementation across states varies, many eligible families do not use its services.²⁰

SCHIP was enacted in 1997 as Title XXI of the Social Security Act and reauthorized in 2009 as the Children's Health Insurance Program. Most state CHIP programs do not have separate eligibility rules for children with disabilities. In states in which CHIP is administered separately from Medicaid, it generally offers a more limited benefit package and often does not include wrap-around services.²¹ The 2009 reauthorization finances CHIP through September 30, 2015, although states can enroll children in

Table 1. Provisions of the 2010 Affordable Care Act with Relevance to Children with Disabilities

Provision	Year provision begins
Young adults under age 26 years remain on parents' health plans	September 2010
Required coverage of recommended preventive care and immunizations, without cost-sharing	September 2010
National strategy to improve health care quality	January 2011
Children's Health Insurance Program Reauthorization	September 2010–15
Individual requirement to have health insurance	January 2014
Expansion of Medicaid program	Phases in starting in 2010
Prohibition on preexisting condition exclusions for children	September 2010
New rules for insurers that prohibit restriction of coverage, basing premiums on health status, or setting unreasonable annual limits	Phases in starting in 2010
Investments in demonstrations or projects on medical homes or care coordination projects	2011

Source: Commonwealth Fund, "Major Provisions of the Affordable Care Act" (2010) (www.commonwealthfund.org/Health-Reform/Health-Reform-Resource.aspx).

comparable insurance exchanges before this date.²³ Congress will need to act again on the program to extend it further.

The Supplemental Security Income program provides cash assistance to families with children meeting the eligibility requirements.²³ Children in SSI tend to be severely disabled, particularly because eligibility for benefits has been tightened over the past decade. Children who are covered by SSI are automatically eligible for Medicaid.

Under the 1982 Tax Equity and Fiscal Responsibility Act, states can offer home and community-based services options known as Katie Beckett waivers, which allow them to cover children with disabilities who would otherwise be institutionalized or forgo needed care. These children often require substantial wraparound services. Relatively few children with disabilities are covered by these waivers.²⁴

Finally, the Maternal and Child Health Services block grant, Title V of the Social

Security Act, is a partnership between the federal government and state Maternal and Child Health and Children with Special Health Care Needs programs to serve children with disabilities. States provide a substantial funding match and have great flexibility in administering the program with the goal of coordinating the care of children with disabilities and meeting outcomes listed in the National Agenda for Children with Special Health Care Needs.²⁵

Health Care Reform 2010 and State Programs

Several provisions of the Patient Protection and Affordable Care Act of 2010 may improve health insurance for children with disabilities (table 1).²⁶ Allowing parents to claim their adult children as dependents until age twenty-six and requiring Americans to purchase insurance coverage by 2014 may improve access for all children, including those with disabilities. Particularly relevant for children with disabilities, the new law forbids insurers from excluding children with preexisting conditions (as of September 2010) and from restricting

coverage, basing premiums on health status, or setting unreasonable annual limits on benefits. The legislation also outlines essential services to be covered by plans in the newly established insurance exchanges that will affect, and should maintain, services to the disabled.

Many states are experimenting, within their budget constraints, with models to improve the effectiveness of public health insurance. For example, one analysis published in July 2011 noted that seventeen states had aligned standards for patient-centered medical homes with state-level Medicaid incentive payments to primary care practitioners to attempt to improve the effectiveness of primary care management of Medicaid beneficiaries. A medical home is not a specific site but rather a comprehensive approach to providing optimal health care in partnership with children and their parents. Health care providers at the medical home assist children and families in obtaining comprehensive health and other educational and community-based services. Although the medical home model is not specifically focused on children with disabilities, it should improve care for this population. States are using several innovative payment strategies to promote medical home models—including enhanced fee-for-service payments for providers who meet National Committee for Quality Assurance or other medical home criteria; monthly care management fees to supplement fee-for-service payments; up-front funding for specific programs that serve a population of children with disabilities; additional payment for community-based health networks that provide comprehensive, integrated services; and supplemental payments based on specific performance criteria.²⁷

In summary, most children with disabilities have some form of health insurance coverage, although 9 percent are uninsured at

some time during the year, and well more than one-third of those with health insurance have coverage that their parents perceive as inadequate to cover their needs. Before federal health care reform was enacted in 2010, the uninsured rate had remained stubbornly steady despite expansions in Medicaid and SCHIP. Three major trends in health insurance have been the emerging dominance of managed care (since the 1980s), a steady decline in private coverage with a commensurate increase in public coverage, and a recent emergence of high-deductible plans or plans with increasing family co-payments. The health insurance system for children with disabilities represents a conglomeration of public and private programs with excellent coverage and benefits for many children but inadequate coverage for many others.

Impact of Health Insurance on Children with Disabilities

Determining the impact of health insurance is challenging both conceptually and methodologically. A key conceptual challenge is that neither health insurance nor “disability” is a standardized construct. Comparisons are difficult to make across studies that evaluate the impact of different types of health insurance products with widely divergent benefit structures. Likewise, it is challenging to compare findings for the general group of children with disabilities (which includes a wide variety of chronic conditions with different levels of disability) with findings for a specific disorder such as asthma or autism. In addition, health insurance is often a family issue, and the link between parent insurance and child insurance is strong.²⁸ It is sometimes difficult to distinguish the impact of child health insurance alone.

The major methodological challenge is to isolate the effect of health insurance.

Because of the lack of randomized clinical trials of health insurance for children with disabilities, researchers must rely on other study designs. The most common are cross-sectional point-in-time studies that compare outcomes among children with and without insurance. Such studies must be interpreted with care because they cannot completely take into account confounding factors that influence both the selection of health insurance and the health metrics that are being assessed. A more promising study design involves prospective cohort studies that assess the experience of children with disabilities before and after a change in insurance, such as enrollment in CHIP or Medicaid. These studies, however, often lack an adequate control group, and they too are unable to control perfectly for confounders or selection effects. Studies of children who became insured as a result of SCHIP coverage or expansions of Medicaid are an example of these “pre-post” study designs. Studies using these designs have tended to demonstrate greater effects of insurance than have studies using cross-sectional designs.

Another methodological challenge is that few studies have been able to investigate medium- or long-term health outcomes but instead have focused on short-term metrics. Presumably, by increasing the level of care children with disabilities receive and the degree of functioning they achieve, health insurance could have later effects on outcomes in adulthood.²⁹ But studies have been unable to evaluate these long-term effects.

Despite these conceptual and methodological challenges, in this section I assess the preponderance of evidence regarding the impact of health insurance on children with disabilities, considering both the strength of the studies and the consistency of findings across studies.

Health Insurance and Access to Appropriate Health Services

Many experts have described the concept of “access to care,” which tends to include dimensions of accessibility (such as ease of obtaining desired care); the ability to obtain services across the spectrum of primary care, acute, specialty, and ancillary services; and the ability to meet the needs of the child.³⁰

The bulk of the evidence strongly suggests that health insurance improves many measures of access to care for children with disabilities, including having a primary care provider, reducing unmet medical and oral health care needs, receiving care more quickly (or not delaying care), being able to reach a specialist, and having access to ancillary services.³¹ Regardless of insurance status, the vast majority of children with disabilities do have a usual source of care; this measure, however, has been found to be important but not sufficient for high-quality primary care. More detailed metrics are needed.

As one example, a pre-post study of the impact of SCHIP on children with special health care needs throughout New York State (which included a comparison group enrolling one year later) found that SCHIP was associated with an increase in having a usual source of care (among children with physical conditions), a reduction in unmet needs for prescriptions (among children with both physical and behavioral conditions), and a reduction in unmet needs for specialty care (among children with behavioral conditions).³² An analogous study focusing on children with asthma found marked improvements in having a usual source of care and substantial reductions in problems getting to the primary care office for both asthma tune-up visits and asthma attacks and obtaining asthma medications.³³

Several cross-sectional studies have noted that among children with special health care needs, those who have inadequate health insurance or no insurance have more unmet health care needs than those with adequate health insurance, more delays in receiving care, more financial problems in getting care, and more problems accessing community-based services.³⁴ Most but not all studies of dental care found that lack of dental insurance was associated with unmet needs among children with disabilities.³⁵ The extent to which provision of health insurance for dental care improves access is still unclear, however, and experts agree that interventions beyond dental insurance are required.³⁶ Numerous studies suggest that uninsured children have worse access to specialty care than do insured children.³⁷ Few of these studies have distinguished children with disabilities from other children, but presumably many of the children needing specialty care have chronic conditions. In sum, the bulk of the evidence supports the prediction that provision of health insurance improves access to health care among children with disabilities.

Health Insurance and Use of Care

Economic theory predicts that provision of health insurance will increase preventive care and specialty visits by removing financial barriers; might increase acute care visits through the same mechanism; but might either increase or decrease emergency department visits and hospitalizations depending on the extent to which enhanced primary care prevents these more extensive urgent care visits.

The research evidence has largely supported these predictions, at least for the impact of health insurance on the use of primary care. The bulk of the evidence suggests that health insurance for special needs children increases preventive visits, receipt of preventive

services, and primary care visits in general.³⁸ The two SCHIP studies mentioned earlier noted these findings. The study of asthma noted increased asthma tune-up visits and reduced visits to primary care for asthma attacks.³⁹

The evidence for the impact of health insurance on emergency department visits or hospitalizations is mixed. The study of SCHIP for children with asthma noted reduced emergency visits and fewer asthma-related hospitalizations following enrollment in SCHIP (controlling for confounders). Other studies of SCHIP have noted no effect on emergency visits or hospitalizations among children with chronic conditions.⁴⁰ Studies have consistently demonstrated high rates of emergency visits and hospitalizations among Medicaid enrollees, but evidence is lacking about the impact of Medicaid on use of these services among children with disabilities (after controlling for confounders).

Nor is the evidence clear about the impact of having or not having health insurance on overall health care expenditures for children with disabilities. Paul Newacheck and his colleagues analyzed the Medical Expenditure Panel Survey and found no difference in total health care expenditures between uninsured and insured children with disabilities.⁴¹ The most consistent finding was that the provision of health insurance for children with disabilities reduced parental out-of-pocket expenditures.⁴²

Overall, research has tended to support the prediction that health insurance increases the use of preventive and primary care visits among children with disabilities and reduces out-of-pocket expenses but is inconclusive about the effect of insurance on emergency department use or hospitalizations. This

pattern is similar to that seen for children in general. Because primary care and preventive visits may be viewed as more discretionary than other visits, increases in the use of these services signifies a beneficial effect of health insurance.

Health Insurance and Quality of Care among Children with Disabilities

A number of different metrics could be used to assess the role of health insurance on quality of care for children with disabilities. This section reviews three: medical home criteria, parent satisfaction, and disease-specific quality measures.

Medical Home Criteria. Over the past decade, the concept of a medical home has emerged as a guiding framework to assess and improve the quality of health care not only for children with disabilities but for all children and adults.⁴³ Table 2 shows the seven core elements of the medical home: accessibility, family-centered care, and care that is continuous, comprehensive, coordinated, compassionate, and culturally effective. A recent review of the literature found that attributes of the medical home appear to improve health outcomes for children, including those with special needs.⁴⁴ Thus, health insurance that improves these elements of the medical home for children with disabilities can be considered good evidence that health insurance leads to better quality of care.

As noted, several studies have shown that health insurance improves *accessibility* to primary and specialty care and medications among children with disabilities. A recent analysis of the National Survey of Children's Health that focused on children with asthma examined factors associated with all medical home components except compassionate care. This study found that uninsured

children with asthma had three times the odds of poor accessibility compared with insured children with asthma; they were three times less likely than insured children with the illness to have access to a medical home.⁴⁵

While some evidence suggests that *family-centered care* is related to better overall quality,⁴⁶ there is little evidence for whether insurance improves family-centered care; other measures such as provider-related factors have a greater impact. For example, the study of medical home criteria among children with asthma did not find a relationship between health insurance and family-centered care.⁴⁷

Studies evaluating SCHIP have noted greater levels of primary care *continuity* following acquisition of health insurance as measured by the proportion of visits with the primary care practice before and after coverage.⁴⁸ The study of asthma and the medical home also found a relationship between insurance and improved continuity.⁴⁹ Other studies have noted relatively poor levels of continuity even among insured populations. Lengthy waiting periods between enrolling in SCHIP and being able to see a primary care physician could also lead to discontinuity.⁵⁰

Overall, the bulk of evidence suggests that while *care coordination*, even among privately or publicly insured populations, is generally poor, enrollment in health insurance or SSI appears to improve it.⁵¹ Of note, not all studies have found this association—for example the study of asthma and SCHIP did not find that acquisition of health insurance improved care coordination.⁵²

Several studies have noted that children with special needs are more likely to receive

Table 2. Seven Core Components of a Medical Home for Children with Disabilities

Component	Characteristic
Accessible	Care is provided in the child's community and is available 24 hours a day, 7 days a week. All insurance, including Medicaid, is accepted, and changes are accommodated.
Family-centered	The family is recognized as the principal caregiver and the center of strength and support for children. Unbiased and complete information is shared on an ongoing basis.
Continuous	The same primary pediatric health care professionals are available from infancy through adolescence. Assistance with transitions (to school, home, and adult services) is provided.
Comprehensive	Preventive, primary, and tertiary care needs are addressed.
Coordinated	Families are linked to support, educational, and community-based services.
Compassionate	Concern for the well-being of the child and family is expressed and demonstrated.
Culturally effective	The family's cultural background is recognized, valued, and respected.

Sources: "The Medical Home," *Pediatrics* 110, no. 1, pt. 1 (2002): 184–86; C. Stille and others, "The Family-Centered Medical Home: Specific Considerations for Child Health Research and Policy," *Academic Pediatrics* 10, no. 4 (2010): 211–17.

preventive services if they have health insurance.⁵³ No studies specifically address *comprehensiveness* of specialty care. Evidence also is insufficient to assess the role of health insurance in improving the *compassionate and culturally sensitive aspects* of the medical home for either the general population of children or for children with disabilities.

Parent Satisfaction. Several studies have found an association between health insurance for children with chronic conditions and higher parental satisfaction with primary care, medications, specialty care, and overall health care.⁵⁴ Many studies have used satisfaction measures from the Consumer Assessment of Healthcare Providers and Systems and have noted improvements in four measures—provider listens carefully, explains things in an understandable way, respects what parents have to say, and spends enough time with parents.⁵⁵ Further, studies of SCHIP have noted improved parent rating of the overall quality of care of their child with chronic conditions following enrollment compared with the period before enrollment.⁵⁶ The predominant mechanism for these improvements appears to be that health

insurance enhances the use of primary care, rather than that health insurance changes the actual doctor-patient relationship per se or causes families to switch to new providers.

Disease-Specific Quality Measures. Few data exist regarding the impact of health insurance on disease-specific measures. The study of asthma and SCHIP noted improvements in several asthma-specific quality measures (recommended by the National Heart, Lung, and Blood Institute)⁵⁷ including an increase in asthma tune-up visits, a decrease in asthma-related attacks, and a trend toward greater use of anti-inflammatory medications. Studies have found that insured children with special health care needs have more oral health visits than those without insurance, but studies documenting an actual reduction in dental caries as a result of dental insurance are not available.⁵⁸ The study of SCHIP in New York State noted that among children with mental health conditions, parent ratings of overall care and parent worry both improved substantially following enrollment in SCHIP.⁵⁹ However, few studies evaluate the impact of health insurance on quality of mental health care. One study found no difference in the way primary

care pediatricians managed mental health problems among insured versus uninsured children in their practices.⁶⁰ Another study noted that uninsured children with autism spectrum disorders were more likely than insured children with the condition to have unmet needs, delayed care, and difficulty obtaining referrals and family-centered care, adjusting for confounders.⁶¹ Overall, some data exist to support the link between health insurance and improved disease-specific measures, but much more research is needed.

Insurance and Health Outcomes

An assessment of health outcomes should consider outcomes for both the child and the family, because child disability can affect both. At the level of the child, one would expect that if health insurance improves access to health care and many quality measures, then it should also improve child health outcomes, at least to the degree to which health care contributes to outcomes (many serious disabilities have poor outcomes regardless of quality of care). Child health outcomes could be conceptualized as general outcomes (such as functional status or school attendance) or disease-specific outcomes (such as asthma severity or depression scores). Further, both short- and longer-term outcomes are important. But very little exists in the literature regarding the effect of health insurance on child outcomes. The study on SCHIP and asthma noted improved short-term outcomes such as reduced asthma morbidity.⁶² Clearly, studies are needed in this area.

Family outcomes have a number of components: expenditures (out-of-pocket and total); effects on parents' employment and use of time; stress, including parental worry and marital strain; and overall quality of life or functioning. While an enormous body of literature has documented the pervasive family

burden of a child with disabilities,⁶³ few studies have attempted to assess the role of health insurance in attenuating this burden. Two found enrollment in SCHIP to be associated with reduced parental worry.⁶⁴ Several studies noted lower out-of-pocket costs and financial burden associated with health insurance.⁶⁵

In summary, there is reasonable evidence showing that provision of health insurance improves several quality-of-care measures including aspects of the medical home, family satisfaction, some disease-specific measures, and a few measures of family burden. Further studies are needed to better distinguish the impact of health insurance from other factors.

Impact of Various Types of Insurance

A number of studies have attempted to assess whether specific types of insurance (such as managed care) or differences between public and private insurance affect health care for children with disabilities.

Most children who are covered by either public or private insurance are enrolled in managed care plans. Early concerns that managed care would result in reduced quality of care for children with chronic conditions have not been consistently demonstrated.⁶⁶ Areas of concern include access to mental health or some subspecialty services, barriers to referrals, and problems obtaining ancillary services. It is possible that the combination of increased sophistication of managed care leaders, federal and state guidelines and oversight, quality reporting among managed care plans, increasingly savvy primary care providers, and strong involvement of parents have all played a part in maintaining quality of care for children with disabilities despite the financial and time pressures associated with managed care. Further, the dominance

of managed care means that studies now need to examine more specific processes of care rather than the impact of managed care itself. In summary, the preponderance of evidence suggests that quality of care under managed care is not consistently lower or higher than under other types of care. But, again, further research is needed to assess more specific characteristics that lead to improved quality of care.

The latest shift among private insurance is toward plans in which families pay lower premiums but a greater share of health care costs until a threshold is reached.⁶⁷ While there are concerns that care for children will be compromised under these high-deductible health plans, little evidence exists to inform policy.

Comparing the impact of private versus public insurance is challenging because of the difficulty in disentangling insurance effects from other socioeconomic and behavioral factors. Studies on access have noted mixed results—some found that access and use of services were higher among privately insured children with disabilities than among those who were publicly insured, while other studies found the opposite.⁶⁸ One national study, for example, noted that the privately insured were more likely than the publicly insured to have a regular provider, access to after-hours primary care, and higher parent satisfaction, but both had similar levels of unmet needs, delayed care, and utilization of outpatient care.⁶⁹

One consistent finding is that Medicaid reimbursement for providers has tended to be lower than private insurer reimbursement, making some providers reluctant to care for the publicly insured, particularly publicly insured high-risk populations.⁷⁰ Inadequate

Medicaid payment has been a concern for both primary care and specialty providers (including mental health and oral health providers). Increased payments for primary care providers under health reform and increased support for medical homes may improve this situation.

At the same time, Medicaid provides substantially more comprehensive coverage than do most private plans, which is a benefit for children with disabilities if they can access the needed services. Finally, families of children with disabilities who are privately insured (and thus have higher incomes) tend to pay a higher amount out of pocket than do families of children with disabilities who are publicly insured. Nevertheless, lower-income families who tend to be publicly insured are more likely to experience financial burden from their out-of-pocket expenditures (financial burden is defined as costs exceeding 5 percent of family income) than are higher-income, privately insured families.⁷¹ Thus, the level of out-of-pocket financial burden is a combination of family income and the benefit structure of the health insurance program. The recent trend toward greater cost-sharing among families primarily affects privately insured families.

In sum, the evidence is mixed regarding the advantage of private versus public insurance for children with disabilities, with each type having some advantages and some disadvantages for families.

The Future: Improving Health Insurance for Children with Disabilities

Most children with disabilities have health insurance, and the 2010 health care reform will likely increase that number. At the same time, a large proportion of those who do not

have insurance are eligible for it under existing programs.⁷² Thus, the dominant insurance-related themes in the next decade should be to enroll eligible children in appropriate programs and to optimize quality through health insurance while minimizing costs.

The cost of health care is an overriding concern in the current economic environment. Overall, children consume only about 13 percent of total U.S. health care expenditures, or thirteen cents of every dollar spent on health care.⁷³ Children with special health care needs make up 12–20 percent of the child population, depending on the definition, and consume about half of all pediatric expenditures, or about seven cents for each health care dollar. Not all of these special needs children would be considered to have disabilities.⁷⁴ In sum, about a nickel of the U.S. health care dollar is spent on children with disabilities. Therefore, changes in health insurance policy targeting children with disabilities are unlikely to have much influence on the overall costs of U.S. health care in either direction. In other words, more restrictive insurance policies that limit coverage of these children would not save substantial amounts, and expansions in coverage would not likely add a large amount to health care expenditures.

The evidence is clear that health insurance improves some aspects of quality of care for children with disabilities, particularly primary care, referrals to specialists, and some aspects of the medical home. Insurance also reduces the family's financial and emotional burden. The key policy issues should therefore focus on strategies to improve specific aspects of the medical home,⁷⁵ methods to enhance family functioning while caring for children with disabilities, and ways to improve

long-term outcomes. Similarly, further study is needed to evaluate new strategies to improve quality of care for this vulnerable population.⁷⁶

The increasing prominence of quality metrics, such as the recently released quality measures under the Children's Health Insurance Program Reauthorization Act (CHIPRA),⁷⁷ may help governments, health plans, and health systems assess, track, and target important measures for improvement. Quality metrics for children with disabilities should be incorporated into standard metrics, perhaps using the now-established definition for children with special health care needs. Among other new strategies, state experiments that financially reward managed care plans for high performance show promise,⁷⁸ particularly if the plans use the additional revenues to improve services that then lead to continuing improvements. For example, some Medicaid managed care plans in New York State that have been rewarded for achieving high quality scores have used the bonus revenue to improve outreach and coordination of care for vulnerable children.⁷⁹

At the federal level, the overriding issue for the next several years will be implementation of health care reform, including the mandate for health insurance coverage. This review supports such a requirement for health insurance for all children with disabilities: because the preponderance of evidence indicates that health insurance improves the health care for these children, extending insurance to all of them should magnify that result. In addition, because the majority of uninsured children are actually eligible for either Medicaid or CHIP, universal coverage for all children would be an incremental step and not a major overhaul of the health care system.

Changes in health insurance policy targeting children with disabilities are unlikely to have much influence on the overall costs of U.S. health care in either direction.

The next question involves the breadth of coverage and the extent of family cost-sharing that should be part of the health insurance system of the future. The evidence is mixed in this area. For example, while medical coverage improves preventive health care, coverage for oral health has not been shown to reduce dental caries, probably because of other barriers to oral health care. Thus the extent of coverage needs to be balanced with other strategies that improve care. A good example is the immunization delivery system. Studies have noted that reductions in financial barriers to immunizations substantially improved rates of childhood immunization, yet additional strategies were needed to raise rates to near universal levels.⁸⁰ The same point holds for children with disabilities. Clearly, strategies beyond insurance, such as a focus on enhancing the effectiveness of medical homes and using information technology, will be needed to raise quality of care substantially.⁸¹

Together, these issues and considerations lead to a series of suggestions to improve future health care policy. Many of these recommendations will benefit not only children with disabilities but all children.

Support the provisions in the 2010 health care reform law that address children with

disabilities (see table 2). These provisions include extending coverage to preventive care; following quality metrics; reauthorizing CHIP before its scheduled expiration in 2015; expanding Medicaid, which has a superior benefit structure; prohibiting exclusions; and supporting demonstration projects. The preponderance of evidence supports the benefit of coverage for all children and adolescents with disabilities.

Include wraparound services. Optimally, all publicly funded insurance programs should offer the same set of benefits. Because some evidence supports the importance of coverage for wraparound services for children with disabilities, CHIP programs that offer a more restricted benefit package should extend the package to offer the same coverage as Medicaid. As increasing research demonstrates the importance of these services for children, coverage should expand accordingly. The difficulty is that research cannot possibly demonstrate conclusively the value of every single service. Thus some consensus process should be developed to determine types of services that are legitimate to cover under private and public plans.

Enhance outreach to enroll children in health insurance as well as other programs. Because a multitude of programs for children with disabilities will exist even under health care reform, and because many children are eligible but not enrolled, effective outreach is needed to help enroll children not only into health insurance but into other special programs serving those with disabilities.⁸² For example, a simplified application procedure and cross-linkage process could help enroll children who are already eligible for services under more than one program. Finally, having an established, systematic process to identify children with disabilities is an

important step to track this population and monitor care.

Support medical home initiatives and efforts to optimize medical homes. The bulk of the evidence supports the medical home as a mechanism that can improve quality of care for children with disabilities. Some aspects of the medical home, such as cultural sensitivity and care coordination, have been particularly challenging to implement, and barriers differ for the seven components of the medical home. Therefore, future efforts should support the implementation of the medical home. Currently, many states are developing and implementing standards for assessing medical home criteria for primary care practices, and rewarding with higher payments those practices that meet the highest standards. These efforts are likely to yield improved quality of care because studies suggest that many of the activities within a true medical home (such as care coordination) are not adequately financed. Thus, public and private insurance plans should implement appropriate financial payment mechanisms and other support to help primary care practices and systems improve their medical homes. Support beyond financial payments could include provision of lists of children with special health care needs (to help providers track and recall patients in need of services), centralized outreach at a managed care level (such as targeted outreach to urge children to receive preventive care and chronic care follow-up visits), links with other programs that serve children with disabilities, and technical or information technology support.

Use appropriate financial incentives. The current movement toward risk-adjustment strategies reduces concern that insurance plans, health systems, and providers may shy

away from caring for expensive populations including children with disabilities.⁸³ Risk adjustment should be expanded for children, classifying health conditions according to risk of health care expenditures and adjusting payments accordingly. If used in conjunction with rigorous quality-assurance monitoring techniques, these risk-adjustment strategies can provide appropriate financial incentives to serve children with disabilities. Other types of financial incentives are also promising. Some states such as New York are providing added financial incentives for Medicaid managed care plans that exceed certain quality metrics, and some plans are using these incentives to funnel additional resources into outreach and other activities that specifically increase quality measures.⁸⁴ Such financial incentives could be powerful levers for improving care of children with disabilities, if metrics for this population were included.

Develop and disseminate best practices. Through demonstrations, projects, financial incentives, and collaborations between government, researchers, clinicians, and other health care experts, private insurance companies and professional organizations should develop and disseminate best practices for serving children with disabilities whether they are publicly or privately insured.⁸⁵

Monitor quality and outcomes of care within states and insurance plans. Because nearly half of children with disabilities are already enrolled in public plans and these numbers are rising, Medicaid and CHIP should track and monitor their care. The CHIP reauthorizing legislation already requires monitoring of quality measures for both programs.⁸⁶ Further, the ten-year Maternal and Child Health Bureau plan to improve care of

children with special needs calls for the development of feasible processes to identify children with special health care needs and to track and monitor their care.⁸⁷ The United States is therefore heading toward more standardized quality measurement and reporting. Commercial health insurance plans are already accustomed to using the federal Healthcare Effectiveness Data and Information Set to report on quality of care for their enrollees; these commercial plans also should adopt the quality metrics of the CHIP reauthorization to report on quality of care for children. Insurers, working with federal policy makers, should reach a consensus on core measures for children with disabilities (likely using the CSHCN Screener to identify the population), and these CSHCN-specific measures should be added to core measurement reporting by public and private health care plans (see James Perrin's article in this volume for further discussion of quality measures).⁸⁸ Governments (federal and state) will need to provide a measurement

infrastructure and also support for states to report on their public programs and for private plans to report on their quality metrics. The old adage that "what gets measured gets done" does apply here. The process of measuring quality should bring about improvements in quality.

In summary, health insurance for children with disabilities represents a complex system, but studies have clearly demonstrated the benefit of health insurance for this vulnerable population. In the coming decades, major national goals should be to provide adequate health insurance to all children with disabilities, to develop a set of best practices in health insurance to cover important services needed by this population, to develop strategies and policies to support medical home and other quality initiatives, and to monitor quality and health outcomes to ensure that children with disabilities receive cost-effective and equitable health insurance.

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How Can Quality Improvement Enhance the Lives of Children with Disabilities?

James M. Perrin

Summary

Much attention has aided measurement and improvement in the quality of health care during the past two decades, with new ways to define and measure quality, recognition that doing so can identify strategies to enhance care, and systematic efforts by both government and private insurers to apply these principles. In this article, James Perrin reviews these gains. Although children have benefited, these quality measurement efforts have focused mainly on adult health care. Now, two recent federal programs promise to expand quality measurement of child health care.

Enacted in 2009, the Children's Health Insurance Program Reauthorization Act provides systematic support for efforts to develop and implement a set of child health quality measures. This federal support represents the first major public investment in improving child health care quality. The Affordable Care Act, which became law in 2010, extends those activities by focusing attention on improving care for people with chronic conditions, including new ways to organize care using teams of doctors, nurses, and others focused on improving chronic care outcomes. For children especially, this team care should also focus on prevention of chronic conditions and their consequences.

Despite these significant efforts to expand quality measurement among children and youth, Perrin finds that most measures and improvement activities focus on children without chronic conditions, and few measures of chronic conditions go beyond examining what kinds of monitoring children with specific conditions receive. Only limited attention is paid to how well the children are functioning. A number of networks working with children with specific chronic health conditions (such as cancer, cystic fibrosis, and sickle cell disease) have developed effective measures of functioning for children with those conditions and active programs to improve such outcomes. These networks offer the best examples of how to improve care and outcomes for young people with disabilities. Broadening their impact to larger numbers of children with disabilities will require developing measures of functioning and quality of life and targeting interventions and efforts to improve those outcomes.

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The past fifteen to twenty years have seen substantial growth in the measurement of quality in children's health care and in systematic attempts to improve quality. Although support for and expansion of the quality of children's health care have lagged behind that for adult and elderly populations amid tremendous investments in Medicare since the 1960s, public and private support has fueled real growth in the number of organizations and investigators working on the quality of health care for children and adolescents. The National Association of Children's Hospitals and Related Institutions and the Child Health Corporation of America,¹ the National Initiative for Children's Healthcare Quality, the American Board of Pediatrics, the American Academy of Pediatrics, and the Child and Adolescent Health Measurement Initiative, as well as efforts at several major children's and other hospitals, have all added substance to efforts to examine and improve the quality of children's health care. This work has led to the development of new measures of quality, specific efforts to improve quality, and multiple studies of how well the health care system meets the needs of children. Some of this work has moved toward transforming clinical care and redesigning systems of care. The federal Agency for Healthcare Research and Quality (AHRQ), along with a few private foundations, has provided significant financial and organizational support to the development of quality efforts for children's health care.

This article reviews key progress in quality measurement and improvement and considers how well these efforts address the needs of children with disabilities. For the purposes of this article, several definitions of quality are used. The Institute of Medicine (IOM), the health arm of the National Academy of

Sciences, defines quality as "the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge."² Stephen Campbell and others consider two principal dimensions of quality—access and effectiveness—with effectiveness separated into clinical care and interpersonal care.³ One part of this article applies these notions—access, effectiveness, care processes, and outcomes—to children and youth with disabilities. Key leaders in quality, such as W. Edwards Deming and Joseph Juran,⁴ have advocated processes to improve quality that include planning change, carrying it out, studying its effects, and then taking action to achieve better outcomes, generally viewed from the perspective of the end user. These leaders call for continuous cycles of improvement. This article thus also examines improvement (as distinct from quality measurement), looking closely at what is known about improvement among children and youth with disabilities and the opportunities that exist for applying the Deming-Juran strategies of continuous quality improvement and system redesign to improve outcomes for children and youth with disabilities.

The phenomenal growth in the number of children with diagnoses of chronic health conditions during the past two decades (see Neal Halfon and others in this volume)⁵ indicates the importance of developing quality measures for these populations along with efforts both to prevent the conditions and improve the care of children who have them. Relative to other children, children and youth with disabilities have, as part of the broader work in children's health care quality, had greater attention paid to defining their service needs, developing better health status measures, and initiating improvement

efforts focused at least on some of the more prevalent chronic health conditions and disabilities.

Some of the best work to improve care for children with disabling conditions comes from efforts by condition-specific networks such as those that target cystic fibrosis, sickle cell disease, inflammatory bowel disease, and autism.⁶ All of these networks have some focus on quality assessment and improvement, although they generally have not led to the development of quality measures for use beyond their specific conditions. In general, these condition-specific efforts build from some consensus on best clinical practices and activities, with collaborative centers agreeing on common standards of care. In many cases, the limited evidence in support of many practices drives the use of consensus as the basis for guidelines and improvement, while research continues to provide better evidence about effective interventions.

Despite this substantial body of work, most activities that aim to address health care quality for children and youth have addressed issues other than chronic conditions. Most of the efforts related to chronic conditions have focused on narrowly defined biological outcomes (for example, indicators of diabetes control) rather than on broader measures of disability and functioning. Although improving clinical outcomes has clear value, especially when clinical improvement can be linked with longer-term functioning and improved ability, this article argues for a focus on measures that directly address disability and functioning.

The Importance of Prevention and Choosing the Right Outcomes

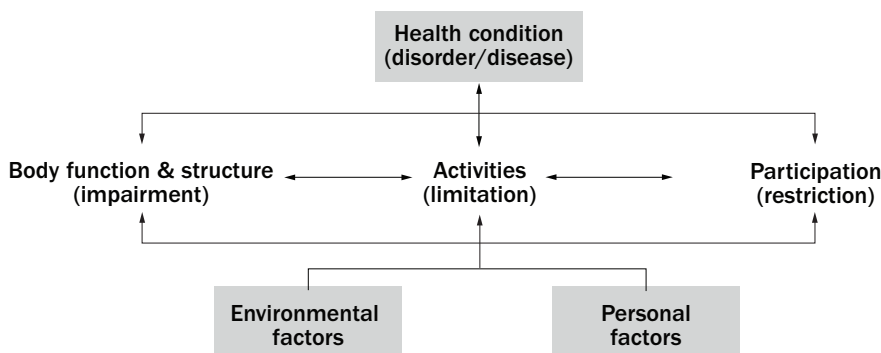
Any examination of chronic conditions affecting children and youth should distinguish

between the higher prevalence conditions (obesity, asthma, and mental health conditions) and less common chronic conditions that nonetheless cause substantial morbidity for affected young people (such as congenital heart disease, childhood arthritis, cancer, or sickle cell disease). Some of these conditions—perhaps especially the high prevalence ones—are appropriate targets for preventive efforts. Quality and improvement activities should address prevention of these conditions and especially the disabilities arising from having them.

Childhood chronic conditions provide opportunities for both primary and secondary prevention, that is, preventing the onset of a condition and preventing the consequences of a condition, including disability and dysfunction (see the article by Stephen Rauch and Bruce Lanphear in this volume).⁷ Nonetheless, as with medical research in general, relatively little work and attention have gone into measuring and improving prevention, primary or secondary. Given the dramatic growth in diagnoses of some conditions and the resulting increase in rates of recognized disabilities among children and young adults, public health and welfare systems will face extraordinary demands in the next decade unless greater resources are allocated to prevention.⁸

Work undertaken by the World Health Organization with the recently revised International Classification of Functioning (ICF) provides a framework to clarify the relationships among disease, disability, and functioning and particularly guides concepts of secondary prevention (figure 1).⁹ The ICF framework describes areas of concern that have led to new measures that support broader definitions and assessments of quality. Some promising work regarding

Figure 1. The International Classification of Functioning (ICF) Model



Source: World Health Organization.

secondary prevention of disability focuses on measuring quality of life among children and youth with various chronic conditions, recognizing that these measures provide important indicators of status beyond traditional biological or physiologic assessments.

The choice of measures and areas of concern must in part reflect the values of a society or the purposes of study, but researchers also should consider the items or areas that services might be expected to improve. Social and community factors have a major influence on functioning and participation in the activities of everyday life, and this influence may go well beyond the physical impact of a disability. Treating the disease directly may have limited impact on participation or functioning, while targeting functioning or quality of life could lead to a change in chosen interventions. In general, traditional medical treatments may have greater impact on biological measures (for example, blood pressure) but less effect on functioning or participation (such as getting to school or playing games). Improving disability among children and youth thus calls for comprehensive programs with sharply focused goals.

Issues in Quality Assessment

Several measurement issues are of particular salience to assessments of health care quality. These include the scope of the evaluation (whether the measurements are conducted at a single point in time or over a period of longer duration), the area being evaluated (type of disability, functioning, or quality of life), and whether the unit of observation and intervention is the child, the family, or society.

Short Term versus Long Term; Cross-Sectional versus Longitudinal

Much measurement of child health derives from cross-sectional (that is, point in time) data, a strategy that makes little sense in efforts to measure and improve chronic health conditions and their impact. Although cross-sectional studies allow assessment, for example, of access to or use of services, they do not allow measurement of whether the use of those services is associated with improvements in health and reductions in disability over time. That type of measurement clearly requires following individuals before and after the use of services. A critical issue for children's health, of course, is the

understanding that the full benefits of high-quality care often emerge many years in the future. Typical preventive services such as those aimed at curbing tobacco use or involving exercise and diet may translate into improved health years or decades later.¹⁰ For children with disabling conditions, improved outcomes also may result in the prevention of more serious disability in adulthood and improved social, educational, and vocational functioning.¹¹ Ideally, children should be followed for a long period in order to assess the effects of services on disability.

Nonetheless, some short-term targets merit attention, including the use and efficacy of medications, hospital and emergency department use, and the use and efficacy of specialized treatments such as speech, language, and occupational therapies. Quality measures must be developed in each of these areas. The use of psychotropic medications, especially stimulants and atypical antipsychotics, has grown markedly during the past two decades for a variety of conditions including attention deficit/hyperactivity disorder (ADHD), autism spectrum disorders, depression, and schizophrenia.¹² Although some of this use has support based on solid evidence, other practices (especially the use of multiple drugs concurrently) lack strong research support. The need to improve the evidence base for these treatments and to apply quality-improvement strategies based on solid evidence seems particularly critical in pediatric psychopharmacology.

Much pediatric hospitalization today involves children with very complex, often multi-system diseases.¹³ Are there opportunities to improve that care and diminish hospital use?¹⁴ Imaginative use of team care, meeting all the characteristics of the chronic care model,¹⁵ may decrease hospital use and costs

while improving outcomes, especially participation in normal childhood activities.¹⁶

Although there is much evidence on the general value of various specialized therapies such as speech and language therapy, occupational therapy, physical therapy, and respiratory care, little research has assessed the necessary scope and duration of these therapies or how they might be better tailored to individual circumstances. How much physical therapy should a child with cerebral palsy receive, how frequently, and for how long? What about behavioral interventions or speech therapy for young people with autism spectrum disorders, again areas where good evidence supports use in general but few data are available regarding scope and duration?¹⁷

Areas of Concern: Disability, Functioning, and Quality of Life

One can measure both condition-specific indicators of disease and its severity (for example, factor level in hemophilia, frequency and extent of bleeding into joints), as well as more generic indicators of disability such as mobility impairment and ability to participate in certain activities. The ICF has helped to define the main realms of disability and functioning, including indicators of performance and functioning that disability may affect. It focuses attention on the effects of conditions on mobility and body function and structure, activities and limitations, and social participation, and provides a framework to examine how conditions interact with the environment (including family factors) to affect functioning.¹⁸ The ICF spectrum of measurement ranges from biological indicators to functional measures to assessments of quality of life.¹⁹ It is important to recognize that rates or scores on many of these measures do not correlate highly. For example, two people may have the same fairly severe disease as indicated by

Table 1. Typical Domains of Quality of Life Measures

Physical functioning/role performance
Psychological/emotional state
Social interactions and functioning
Education functioning
Physical (somatic) symptoms*
Disease-specific symptoms*
Treatment effects*
Other, less common domains:
Views of the future
Role of the family

Source: Author.

*Typically limited to disease-specific quality of life measures.

biological measures but also may have very different observable characteristics of the illness, and the illness may have different effects on each person's functioning and perceptions of quality of life.²⁰

Several other measures address functioning among children with disabilities. Some focus mainly on physical functioning and ability (the WeeFIM and PEDI²¹), while others such as the FS-IIR²² address broader concepts of functioning, for example, whether a chronic condition affects a child's participation in school or play. These measures have the value of applicability across conditions, providing a way to compare degrees of functioning and ability regardless of the specific disorder. They have proven useful in general studies of childhood disability and in assessing improvement.

Quality of life reflects an individual's perceptions of how (s)he is doing in several key life areas such as school activities, peer relationships, emotions, and play. Although subject to various interpretations (for example, adolescents with chronic conditions and their

parents often differ in their assessments of the adolescents' quality of life), these measures provide a more substantial and relevant indicator of disability in most cases than biological measures. Quality of life measures assess characteristics across a broad spectrum, ranging from general factors (such as relationships, psychology, and participation) and general health-related considerations (for example, how much illness a person experiences or the extent to which illness interferes with important functions) to condition-specific measures such as abdominal pain in inflammatory bowel disease and joint pain or bleeding in hemophilia. Frequently used measures include the PedsQL model, the Child Health Questionnaire, and the Disabkids module, as well as condition-specific measures.²³ Table 1 indicates typical areas of focus in quality of life measures.

Unit of Observation and Intervention: Child, Family, or Society?

The prominence of family and community as determinants of child health raises the question of what unit of observation to use in measuring quality (and providing services). Parents in poor health face greater burdens in raising healthy children. Ill health among parents increases the risk of ill health among children, in part reflecting the continuing or aggregate burden of adversity and in part family or genetic predisposition. Providing better care for children can produce better results when the care needs of their parents are addressed at the same time. Investing in parent health and well-being will likely improve child health and disability and diminish the impact of disability on a child's functioning and participation in common childhood activities.²⁴ Similarly, the measurement of quality in child health care will benefit from recognizing the value of measuring the quality of care for parents and

communities. In earlier work, my colleagues and I have described the system of services that children with chronic conditions make use of, recognizing that an understanding of how these services interact can lead to a better assessment of the variety of activities and improvements that can affect children's health, disability, and functioning.²⁵

The social impact of childhood disability involves both the present, through health care and other social costs, and the future, through growing demands on public support for basic needs as well as health care.²⁶ Thus, measurement should go beyond the child and family to populations and services, as well as service providers.

Current Efforts at Measurement

Several groups have worked to improve the measurement of children's health and functioning. The Child and Adolescent Health Measurement Initiative, based at Oregon Health and Science University, has specifically addressed issues of children with chronic health conditions, including some measurement of functioning, although the initiative's focus has been mainly on health care services and consumer views of those services.²⁷ In its work to improve care for children with various chronic health conditions such as asthma, autism, and sickle cell disease, the National Initiative for Children's Healthcare Quality has defined and implemented various measures of health care quality, appropriately more focused on short-term health care considerations than longer-term functioning or ability but providing a strategy for the application of such measures to child health. The National Quality Forum has addressed the current state of measurement in child health, noting gaps but also recognizing the availability of a number of measures that could have wider use.²⁸

The 2009 Children's Health Insurance Program Reauthorization Act (CHIPRA) included new provisions for the measurement of quality, including the first major investment to examine children's health care quality in publicly insured populations. Several activities have helped to determine the characteristics and foci of this investment. The AHRQ impaneled a group to develop an initial core set of child health measures. This set of twenty-four measures included a few that address the needs of children with chronic health conditions (such as emergency visits for children with asthma, follow-up for ADHD or mental health hospitalization, and diabetes monitoring), although none that directly address functioning or disability. The AHRQ recently funded seven centers around the country, the Pediatric Quality Measures Program (PQMP) Centers of Excellence, to develop focused measures for children's health care.²⁹ Based on the areas listed in the CHIPRA legislation, the agency recently announced priority measures for this program. Some of these measures, shown in table 2, reflect the original twenty-four, but all of these lists notably lack attention to functional measures.

A recent IOM report helps to frame the future of quality measurement in child and adolescent health.³⁰ The document emphasizes the need for broad measures beyond clinical care and health status to include assessments of the physical and social environment, much like the ICF. It also notes the necessity to collect longitudinal data to be able to assess the effects of any efforts to improve quality. Although focused on strategies for measurement, the report clearly lays out how better measurement supports innovation and experimentation in broad system redesign. Finally, the report acknowledges the value of a life-course approach to

Table 2. Priorities for the Pediatric Quality Measures Program (PQMP) Developed from CHIPRA

CHIPRA topic	Initial core set*	PQMP first set of priorities**	
<i>Cross-cutting topics</i>			
Duration of enrollment and coverage	None met criteria	Two approaches: stand-alone measure (for quality of health care system) and case-mix adjustment (to use with other measures)	
Availability of services	Child and adolescent access to primary care practitioners	Availability of services (focus on subspecialty care, mental health, high-risk obstetrics, dental)	
Most integrated health care delivery setting	None met criteria	Care coordination within the context of a medical home	
Outcomes	See below for condition-specific outcome measures and family experience of care as outcome measure	Outcome measures to be determined	
Disparities identification of children with special health care needs	Stratifier and potential case-mix adjuster—not in use by measures in initial core set	Identification of children with special health care needs	
Disparities identification by race and ethnicity	Stratifier and potential case-mix adjuster—not in use by measures in initial core set	Identification of approaches to identify disparities by race and ethnicity Framework for aggregation of measures by various levels of accountability and improvement (provider, plan, state, Medicaid, and CHIP programs)	
<i>Preventive services</i>			
Prenatal care	Frequency of ongoing prenatal care	Content of prenatal care	
	Timeliness of prenatal care	Content of prenatal care	
	Percent of live births weighing less than 2,500 grams	Not included***	
	Cesarean rate for nulliparous women with a singleton birth	Not included	
Immunizations	Childhood immunization status	Not included	
	Immunizations for adolescents	Not included	
Other preventive services	Cross-cutting	Content of well-child and well-adolescent care	
	Weight assessment	BMI assessment follow-up	
	Developmental screening in the first 3 years of life	Not included	
	Chlamydia screening	Not included	
	Well-child visits in the first 15 months of life	Content of well-child care	
	Well-child visits in the 3d, 4th, 5th, and 6th years of life	Content of well-child care	
	Adolescent well care visit	Content of well-adolescent care	
	Total eligibles who received preventive dental services as a percent of eligibles	Not included Adolescent depression screening and follow-up Vision screening and follow-up	
	<i>Acute care</i>		
		Appropriate testing for children with pharyngitis	Not included
	Otitis media with effusion—avoidance of inappropriate use of systemic antimicrobials in children—ages 2 through 12	Not included	
	Total eligibles who received dental treatment services	Dental treatment	

Source: Agency for Healthcare Research and Quality (AHRQ), *Crosswalk of the First Set of Priorities for the Pediatric Healthcare Quality Measures Program Centers of Excellence with the CHIPRA Initial Core Measure Set* (Rockville, Md.: June 2011) (www.ahrq.gov/chipra/crosswalk.htm).

*These represent some of the initial set of measures from the group impaneled by AHRQ.

**Areas of current focus by PQMP Centers of Excellence.

***Some of the items labeled “not included” are ones for which effective measures currently exist.

CHIPRA topic	Initial core set*	PQMP first set of priorities**
<i>Acute care (continued)</i>	Ambulatory care: emergency department visits	Not included
	Pediatric central-line-associated bloodstream infections—NICU and PICU	Not included
		Clinical subspecialty care—sickle cell disease
		Inpatient—neonatal care Hospital readmissions
<i>Chronic care</i>	Annual number of asthma patients 2 through 20 years old with one or more asthma-related emergency room visits	ED visits for asthma care
	Follow-up care for children prescribed ADHD medication	ADHD diagnosis and follow-up
	Annual hemoglobin A1C testing of children with diabetes	Not included
	Follow-up after hospitalization for mental disorders	Not included
<i>Family experiences of care</i>	CAHPS® 4.0 with Medicaid and Children with Chronic Conditions supplements applied to all children	Inpatient family experience of care

Note: Compiled June 2011 by the Agency for Healthcare Research and Quality.

ADHD = Attention-deficit/hyperactivity disorder

BMI = Body mass index

CAHPS® = Consumer Assessment of Healthcare Providers and Systems

ED = Emergency department

NICU = Neonatal intensive care unit

NCQA = National Committee for Quality Assurance

PICU = Pediatric intensive care unit

measurement to understand the complex interactions among development, health care, and environment over time. It is likely that a number of topics in these reports as well as from the PQMP will relate to disabling conditions among children. This systematic program of research should bring needed attention to the broad array of children's quality measures, including those for children with disabilities.

How Good Is the Quality of Care for Children with Disabilities?

Summary information about the quality of children's health care remains sparse, especially for children with disabilities. The systematic work of Rita Mangione-Smith and

colleagues provides some overview of children's health care quality, although their focus was limited to ambulatory care, with attention to only a few common chronic conditions such as acne, ADHD, allergic rhinitis, asthma, depression, and otitis media.³¹ Measures for these chronic conditions generally—and appropriately—addressed aspects of medical treatment and follow-up. They did not address any indicators of functioning or (dis)ability, for example, interference with school attendance or social participation from a health condition.³²

For children, as for adults, a large proportion of health care expenditures reflects in-hospital treatment. Most pediatric inpatients have

chronic illness and disability, with relatively few children hospitalized without having ongoing health-related problems. Although some have argued that marked decreases in childhood hospitalization rates have eradicated opportunities to lower health care costs by avoiding unnecessary hospitalization, some studies of hospitalization, especially among Medicaid-insured children, suggest that many cases still reflect preventable hospital use.³³ These cases often involve complex interactions among social and environmental factors and a child's illness. For asthma, one of the more common causes of childhood hospitalization, improved medical care can decrease hospitalization rates.³⁴ In many other cases, though, hospitalizations could be avoided by bolstering community support to help families care better for sick children at home. Major changes in these rates will require substantial investment in community and social services to make families less dependent on the health care sector for their children's needs. A key area of research relates to understanding the right mix of medical care improvement and systemic environmental efforts.

There are likely some opportunities to improve care for children with particularly complex chronic conditions, although the relative rarity of most individual conditions has hampered systematic approaches to assess quality; efforts to improve quality have been even more difficult to develop. Some recent work has identified the characteristics of children with recurrent hospitalizations, potentially providing an opportunity to augment care management, decrease hospital use, and improve functioning.³⁵ As discussed later, promising efforts in these areas often arise from the growth of condition-specific networks that pool patients and scientists across many sites to enhance quality measurement and seek care improvements.

Improving Quality and the Processes of Improvement

Beyond measurement, a number of efforts indicate promise in *improving* quality and outcomes for children with disabilities. Most of these efforts use measurement to support actions to drive learning and the redesign of health care systems. The National Initiative for Children's Healthcare Quality, building on models developed by the Institute for Healthcare Improvement, has carried out a number of collaborative efforts addressing several childhood chronic conditions, especially asthma, ADHD, autism, and sickle cell disease.³⁶ These collaboratives call for the definition of appropriate (generally short-term) objectives that indicate meaningful improvement in the health of targeted children. While often medical in nature, some of the outcomes addressed include measures of child and family functioning. Nonetheless, as with many efforts in quality improvement, the focus has been more on improving processes of care than in measuring outcomes. Similarly, measurement sets offered by the National Committee on Quality Assurance (NCQA) focus generally on care processes rather than outcomes.³⁷

Links between these process improvements and enhanced functioning among children remain fairly tenuous. Other promising efforts at care improvement have come from the Child Health Corporation of America, the American Board of Pediatrics, and the National Association of Children's Hospitals and Related Institutions, which have supported efforts to measure and improve the quality of inpatient care, for example, for children with bronchiolitis or sickle cell crises.³⁸ These efforts, however, aim more to address acute exacerbations of chronic conditions than to improve long-term functioning and ability. All of these activities point

to a need to broaden the focus to include functional measures and change over time. Indeed, Michael Porter's call for determining value in health care demands more complete sets of measures, used over time and assessed against the costs of multiple care services.³⁹ The ICF provides guidance regarding which areas to assess.

CHIPRA, in addition to supporting the AHRQ efforts in measurement development, also authorized the Centers for Medicare and Medicaid Services (CMS) to fund ten state initiatives to improve quality for CHIP-insured children. States have broad flexibility in their strategies, including improving both care and assessment. Among those with some focus on childhood chronic conditions or disabilities are Colorado and New Mexico, which are using school-based health centers to improve management of chronic conditions; Maryland, Georgia, and Wyoming, which are focusing on serious behavioral health needs; Massachusetts, which is using collaboratives to focus on ADHD, asthma, and obesity; North Carolina, which is focusing on special health care needs; and Pennsylvania, which is targeting early identification of children with developmental and behavioral issues and other complex medical conditions.⁴⁰ Still in development, these programs may draw attention to changing rates or impacts of disability. Collectively, they represent a major and serious effort toward quality improvement for children's health care.

Promising results have come from condition-specific clinical practice and research networks, such as pediatric oncology groups and the Cystic Fibrosis Foundation. Especially in their early work, the oncology collaboratives had an easy outcome to measure—mortality. Collaborative experiments to modify treatments in a systematic fashion led to significant

improvements in mortality for many childhood cancers.⁴¹ As mortality improved, the networks turned increasingly to improving clinical and functional outcomes for children surviving cancer, resulting in important changes that reduced central nervous system damage and other long-term consequences of treatment.⁴² Part of the work of the oncology groups (and similar work regarding long-term outcomes for children with acquired immune deficiency syndrome, or AIDS)⁴³ emphasized broad measures of functioning.

The cystic fibrosis (CF) network has taken approaches similar to those of the oncology groups. Here, a common agreement on health-status measures for young people with CF allowed network participants to identify differences among CF centers and seek explanations for those differences. These investigations led to changes in the management of infectious diseases and nutrition among young people with CF, and the combined work of forty years by the CF group has dramatically improved life expectancy for this population.⁴⁴ CF investigators and clinicians also have increased their efforts to measure quality of life and other aspects of functioning and to examine potential precursors of variations in these outcomes. Indeed, this work exemplifies some of the best strategies aimed at decreasing disability among young people.

The lessons that arise from this work have major implications for children with many other disabilities. These lessons include the use of a broad array of measures and the involvement of scientists skilled in their use. The important elements of these networks include collaboration across a wide number of sites, common assessments allowing data sharing and examination across sites of natural clinical experiments, involvement of

parents in helping to define research priorities, and the inclusion of more robust measures of outcomes as the networks grow and mature.

The impetus for much of this research into better care for children with specific disabilities has come from vigorous advocacy by parent groups seeking better answers for how to treat their children. Advocacy has led to direct support through fundraising for research as well as to public financing of substantial research through the National Institutes of Health and other federal agencies.

Building on earlier networks, new networks have begun for such diverse conditions as inflammatory bowel disease, sickle cell disease, congenital heart disease, and autism. Their learning from oncology and CF experiences should help speed the process of improving long-term outcomes and diminishing disability in these conditions. As networks develop, they increasingly carry out comparative effectiveness research and clinical trials to seek improved treatments.

The major causes for the increase in child and adolescent disability during the past few decades have been asthma, obesity, and mental health conditions such as ADHD, depression, and autism spectrum disorders (see Neal Halfon and others in this volume). These conditions may lend themselves particularly to prevention, especially in earlier childhood, although currently few options are available for prevention of conditions such as inflammatory bowel disease, leukemia, and cystic fibrosis. For high-prevalence conditions, quality and improvement efforts should address prevention, which in pediatrics has often been limited to screening and immunizations. A further challenge will be to determine whether the lessons from

It may be difficult to build a case for quality improvement in the care of children and youth with disabilities on the basis of medical cost savings alone, but improving care for children with disabilities can improve their parents' workforce participation and productivity.

condition-specific work on rarer diseases can be applied effectively to high-prevalence conditions.

Leadership, sometimes from federal agencies and sometimes from private insurers with an interest in quality, has supported increasing experimentation in clinical redesign, often with a focus on what is termed the medical home, a model of coordinated and comprehensive health care meeting the preventive and treatment needs of people with and without chronic health conditions. Academic groups and condition-specific associations increasingly recognize the redesign of complex social and health care systems as an experimental problem. That is, while it is important to conduct basic scientific research to understand the roots of disability, it may be possible to effect substantial improvements in the everyday lives of children with disabilities through experimentation and dissemination of successful strategies. Hence, the system redesign opportunity merits the attention of experts in improvement science.

The Affordable Care Act pays significant attention to chronic conditions and their impact on health care costs and utilization, and offers incentives to transform primary care practices into medical homes as well as other incentives and programs to improve community services for the management of chronic health conditions. Increasing evidence supports the need for a comprehensive model of coordinated and often team-based care for children with chronic conditions and disability, and in most ways the concept of the medical home fits this model (see the article by Peter Szilagyi in this volume).⁴⁵ The transformation of clinical practice to a medical home requires substantial commitment on the part of clinicians and staff, as well as financial incentives and support to bring about change and to sustain it.⁴⁶ Yet, without such arrangements, children with disabilities will likely continue to receive episodic, fragmented care that meets some of their needs but lacks a coordinated approach to enhancing long-term outcomes and limiting the negative effects of disability.

Arguments in support of the medical home often claim substantial cost savings from such care. Experience so far is sobering, however, with only a few experiments (for example, the North Carolina Medicaid experiments) suggesting major cost savings.⁴⁷ Many other experiments indicate that the costs of change are substantial and provide only incremental cost reductions that may not cover the costs of change. As noted earlier, much of the discretionary or avoidable hospitalization among children and youth likely reflects the interaction of social and environmental factors with clinical ones. As a result, programs to diminish such hospitalization will need to go well beyond improving the traditional medical home to include substantial family and social support services, a concept that

the Affordable Care Act to some degree recognizes.⁴⁸

Recent efforts have explored ways to assess the qualities of a medical home, including development of an NCQA accreditation method, as well as more intensive measures such as the Medical Home Index.⁴⁹ The NCQA medical home measure has gained respect, although observers note that a large majority of items in the assessment reflect information technology capacities in clinical care rather than more robust measures of what constitutes a medical home. Recent revisions have broadened the areas of interest to include more indicators of patient-centeredness, attention to patient self-care, and access to community services. Research into whether the medical home or a chronic care model works has generally focused on improvements in specific disease management for adults (especially metabolic measures in diabetes), despite increasing recognition that most patients do not fall into simple single-disease categories but rather bring a combination of issues such as vascular disease, kidney disease, and diabetes. A systematic review of the pediatric medical home literature provides evidence that medical homes improve effectiveness (mainly in asthma care), family-centeredness, and some aspects of health status.⁵⁰ To address issues of functioning and ability among people of all ages, measurement will likely need to involve combinations of conditions among people with chronic conditions. Children similarly need generic as well as condition-specific measures.

Financing Improvement: Gaining Value

As noted, it may be difficult to build a case for quality improvement in the care of children and youth with disabilities on the basis

of medical cost savings alone.⁵¹ A good deal of work, however, has shown the impact of children's disabilities on parents' health, well-being, and workforce participation.⁵² Fathers and mothers are more likely to be partly or fully unemployed if they have a child with a disability; parents of children with major mobility impairment or developmental disability are particularly affected.⁵³ Thus, improving care for children with disabilities can improve their parents' workforce participation and productivity (see Mark Stabile and Sara Allin's chapter in this volume).⁵⁴ Among employed parents, extra worry about their child's health and the nature of care or community services can significantly affect how well parents do on the job, their attention to their work, productivity, and morale. Measurement of the effects of interventions should include these parent outcomes among assessments of interventions to improve care for children and youth with disabilities.

New public funding for measuring and improving children's health care quality is promising. Meeting the needs of children and youth with disabilities will require targeting key clinical, developmental, functional, and quality of life outcomes and building efforts focused on their improvement.

The Future: Promising Next Steps

The important efforts now under way to develop and expand on a comprehensive library of measures of child health care quality should support a much broader and more consistent approach. Such an approach would be most beneficial if it were adopted across the panorama of funding agencies for such care and across the spectrum of childhood conditions. The recent IOM report lays out a comprehensive strategy for measurement, including broad definitions of areas to monitor, the need to follow children over time,

and the concept of a life-course approach to understanding what affects child and adolescent health and how childhood health affects future outcomes. It will be important to ensure that this effort includes systematic approaches to assessing care quality for young people with disabilities, including attention to disability and functioning, quality of life, and participation, all consistent with the IOM recommendations. Critical, of course, will be the translation of measurement work into actual improvement of care, that is, translating findings into specific interventions to improve outcomes. The IOM report provides a clear path for translating measurement into opportunities for improvement at multiple levels and support for the type of system redesign needed for children with disabilities. New activities supported by AHRQ and CMS are important steps in this process.

Efforts to strengthen both measurement and improvement of care for children with disabilities should distinguish between important groups of conditions. As noted, the major epidemics of common chronic conditions, accounting for much of the increasing disability rates among children, merit strong attention to prevention as a critical quality venture. Without prevention, rates of disability among people aged ten to forty may balloon over the next two decades. And for these populations—including children and youth with asthma, obesity, and mental health conditions—much work should address both primary prevention and the prevention of secondary morbidity and disability. What are the ways to provide care for ADHD and depression so that young adults with these conditions can find employment, personal satisfaction, and improved quality of life? Improvements for obesity and asthma should address similar questions and outcomes.

For less common conditions, much improvement will take place through the expansion and use of multisite collaboratives that enable attention to larger numbers of children and youth than any single site can amass and that allow systematic efforts at measurement and improvement. Some conditions fit between these common and rare groups, perhaps best exemplified by autism spectrum disorders. This category includes almost 750,000 people under age eighteen in the United States,⁵⁵ fewer than asthma or obesity but far more than cystic fibrosis, inflammatory bowel disease, or sickle cell anemia. Here, the notion of centers of excellence providing and improving care for children—the cystic fibrosis model—does not quite work (unless one envisions a few hundred centers, each providing care for thousands of affected children and youth). Defining the goals of improvement and especially the processes for improvement in autism spectrum disorders is particularly challenging, given the need to involve both primary care clinicians and likely many subspecialists, and recognizing that some of the main outcomes of behavior and academic performance lie in sectors other than health.⁵⁶

Following are some of the key elements of a system redesign that may improve care quality for children with disabilities.

Development of comprehensive and integrated systems of care, linked in ways to ensure that children and youth with disabilities receive the types and scope of services that can diminish their long-term disability and improve their functioning and participation in common social, educational, and economic activities.

Transformation of child health practice along the lines of a comprehensive, team-based,

multidisciplinary medical home, with comprehensive care provided in both primary care and subspecialty units. Elements should include team care, coordination of care, information systems to support monitoring and improvement, and effective communication among levels of care and with parents and children.

Alignment of incentives with improvements in quality to extend best practices, for example, using pay for performance systematically to enhance quality.

Development of a strong focus and consensus on important short-term and long-term outcomes for children with disability.

Conclusion

Promising recent work has increased attention to long-term outcomes and ways to diminish disability among children and adolescents, building on the larger body of work that has addressed short-term health care processes and near-term improvements in health status among children in general. The most promising results for chronic conditions have come from condition-specific groups, where like-minded scientists, clinicians, and families have banded together with a common goal of improving critical outcomes for children with specific chronic conditions. These groups increasingly recognize the need to consider broad functional outcomes to judge the effects of treatment.

If action is not taken, growing numbers of children with chronic conditions and associated disabilities will lead to substantial public burdens on health care and social services in the next decade. There is a substantial possibility that children with disabilities will reap only limited gains from current efforts to assess and improve child health care quality.

A critical first step is the recognition of the importance of disability among young populations and the substantial risk that ignoring that disability will lead to major health and functional impairments among a large swath of young adults in the coming decade.

Improvement will require similar efforts broadened to the major causes of child and adolescent disability as well as efforts to prevent those conditions and their secondary effects. Substantial measurement already exists for quality in childhood illness and health care. For young people with chronic conditions, it is critical to build a stronger conceptualization of child health and well-being, based on formulations such as the ICF, which will allow systematic attention to key areas of child and adolescent short- and long-term functioning, along with better assessment of their physical and social

environment. Quality measurement needs to expand to include these areas of concern. Having agreement on these areas and on the best ways to measure them will help a good deal in efforts to improve long-term functioning and quality of life for people with disabilities.

Real improvement must follow from active use of measurement to identify promising targets for change. The increasing evidence that quality improvement based on clinical and system redesign can bolster care and outcomes, much of it currently from disease-specific applications, provides a framework for broader dissemination. The lessons learned—collaboration across sites, data sharing with transparency, implementation of quality improvement cycles, and involvement of parents—can apply to a wide variety of childhood disabilities.

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Emerging Technologies and Their Impact on Disability

Paul H. Wise

Summary

Technological innovation is transforming the prevalence and functional impact of child disability, the scale of social disparities in child disability, and perhaps the essential meaning of disability in an increasingly technology-dominated world. In this article, Paul Wise investigates several specific facets of this transformation. He begins by showing how technological change influences the definition of disability, noting that all technology attempts to address some deficiency in human capacity or in the human condition.

Wise then looks at the impact of technology on childhood disabilities. Technical improvements in the physical environment, such as better housing, safer roads, and poison-prevention packaging, have significantly reduced childhood injury and disability. Other technological breakthroughs, such as those that identify genetic disorders that may lead to pregnancy termination, raise difficult moral and ethical issues. Technologies that identify potential health risks are also problematic in the absence of any efficient treatment.

Wise stresses the imbalance in the existing health care delivery system, which is geared toward treating childhood physical illnesses that are declining in prevalence at a time when mental and emotional conditions, many of which are not yet well understood, are on the rise. This mismatch, Wise says, poses complex challenges to caring for disabled children, particularly in providing them with highly coordinated and integrated systems of care.

Technology can also widen social disparities in health care for people, including children with disabilities. As Wise observes, efficacy—the ability of a technology to change health outcomes—is key to understanding the relationship of technology to social disparities. As technological innovation enhances efficacy, access to that technology becomes more important. Health outcomes may improve for those who can afford the technology, for example, but not for others. Hence, as efficacy grows, so too does the burden on society to provide access to technology equitably to all those in need. Without such access, technological innovation will likely expand disparities in child outcomes rather than reduce them.

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Technology has long been recognized as a potential way to help ensure that children with disabilities will have optimal opportunity for a long, healthy, and socially engaged life. Traditionally, technology and other interventions designed for children with disabilities were focused on strategies aimed at correcting a child's specific impairment or deficit. New scholarship and decades of disability advocacy have expanded this purview to include a wide variety of environmental and societal factors that are now recognized to be essential in optimizing health, development, and social engagement for children with disabilities. This more comprehensive understanding emphasizes the dynamic interaction between the physical environment and the technological and social forces that can reshape it.

Today the prevention and treatment of disability in childhood are being recast by unprecedented technological innovation. In essence, the nature and cadence of this innovation are transforming the prevalence and functional impact of child disability, the scale of social disparities in child disability, and perhaps the essential meaning of disability in an increasingly technology-dominated world. This article investigates several specific facets of this transformation: the influence of technological change on the definition of disability, the impact of preventive and therapeutic interventions on disabilities in childhood, and the ability of the current delivery system to afford access to emerging technologies designed to prevent and reduce the impact of disabling conditions in children. The article also discusses the interaction of technical innovation and the social determinants of health in shaping patterns of childhood disability as well as the interaction between the diffusion of science

and technology design and disparities in child health. Understanding these issues and interactions is helpful in designing the health care delivery systems, programs, and public policies that will ultimately prove most effective in addressing childhood disabilities in the years to come.

Defining Disability and Assistive Technology

The definition of technology used in this discussion is comprehensive in nature and refers to the application of scientific knowledge for practical, applied purposes, here directed toward improving health and well-being. The definition of disability has undergone dramatic evolution over the years, conforming to evolving analytical frameworks and societal perceptions. For the purposes of this discussion, I use the definition of disability proposed by Neal Halfon and his colleagues in their article in this volume:

A disability is 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.¹

In relation to this definition, technology can refer to both preventive and therapeutic interventions and can take on a variety of forms, including vaccines, other pharmaceuticals, engineering, or alterations to the physical or social environment. A primary objective is the maximization of a child's ability to function independently, which is in many ways determined by the ability to perform essential daily tasks, including those involving hygiene, mobility, and social interaction.² Another central objective is the minimization of the impact that the child's disability has on caregivers, both in their

provision of direct assistance and more generally as part of day-to-day family life.³

A careful examination of the relationship between disability and technology, however, raises important questions related to the definition and societal meaning of disability in the face of rapidly changing technological capabilities. First, a changing technological environment can dramatically alter the functional impact of any given disability. For example, the development of the telephone greatly enhanced communication in general society. At the same time, the central importance of aural communication in a telephone-dominated society made deafness an increasingly debilitating disability. Similarly, the emergence of a computer-dominated society and its text-based reliance on e-mail and cell phone texting has placed new burdens on the blind. Second, the dynamic interaction between disabilities and technology development underscores the rather arbitrary nature of disability definitions. Virtually all technologies attempt to address some deficiency in human capacity or in the human condition. Automobiles address human inability to move quickly over long distances; telephones address their inability to communicate with their voice over long distances; typewriters and their successors compensate for poor and slow penmanship. At some level, therefore, the definition of disability and the role of technology reflect both the prevalence of a lack of a particular capability and the social response to it. The interactions between disability and technology are, therefore, intensely dynamic and generally evade static categorization or definitions. Indeed, these interactions are undergoing such rapid evolution that they have generated a proliferation of philosophical challenges that have transcended the meaning of disability to seek the meaning of being human.

The Impact of Preventive and Therapeutic Technologies on Childhood Disabilities

Technological innovation has dramatically altered the landscape of both preventive and therapeutic approaches to childhood disability. Advanced preventive strategies reflect new capacities to reduce the occurrence of a disabling condition. The development of a broad array of new vaccines has helped prevent a variety of infectious diseases, such as meningitis, which in turn can result in serious disabling sequelae. Technologies have also played an important role in the early diagnosis of potentially disabling conditions, such as phenylketonuria and other genetic disorders; early diagnosis can permit the early implementation of preventive interventions, including dietary alteration. Rapid progress in therapeutic interventions has also in many instances reduced the impact of disability on daily functioning and social engagement.

Preventive Technologies

Technical innovation has had a dramatic impact on a central arena of primary disability prevention: the reduction of serious, disabling injuries in children. The importance of this preventive domain stems not only from the significant contribution that injuries make to disabling conditions in childhood but also from the strong evidence that injuries are highly preventable. Technical improvements in the physical environment of children, including housing, automobile travel, pedestrian and water safety, medication and poison packaging, and playground design, have led to significant reductions in injury-related mortality and disability in children.⁴ These examples also highlight the interactions between the legal environment, which has mandated safety improvements, and the development of technologies to meet these standards.

Many of these technical improvements benefit all their users because they are based on general design enhancements such as safer roads and automobiles. Other interventions that prevent injuries to children depend for their effectiveness on financial access (buying a child car seat, for example), parental behaviors (using a child car seat or a child-protective car window lock), or both. Many of these interventions are mandated by law, but persistent social disparities characterize their actual use and, consequently, patterns of serious childhood injury.⁵ Technical innovation has also revolutionized the identification of children at risk for childhood disabilities. In large measure, this technology has taken the form of screening initiatives designed to identify and respond to genetic or other indicators of disability risk before a child is conceived, during gestation, or shortly after birth. Genetic screening of prospective parents has dramatically reduced the prevalence of certain relatively rare conditions, such as Tay-Sachs disease.⁶ The ability to identify risk-associated genetic profiles or biomarkers in pregnancy, however, has proven to be the most active, and a highly controversial, arena of technical innovation in disability prevention. The ability to identify the presence of genetic disorders such as trisomy 21 and cystic fibrosis in the fetus, as well as biomarkers or anatomical indicators of disabling pediatric conditions, has traditionally been linked to pregnancy termination, raising difficult ethical and moral questions. Technology, however, is also developing new prenatal interventions, including fetal surgery, that may be able to correct conditions likely to produce disabling damage either later in pregnancy or subsequent to birth.

The use of prenatal diagnostic technology is also characterized by significant social disparities, particularly when complex

medical procedures or delivery infrastructures are required.⁷ Yet, the continued link of prenatal diagnosis to pregnancy termination has made the disparate use of prenatal screening hard to interpret. Social differences in the acceptability of abortion and in access to abortion could also be contributing to observed disparities in the use of prenatal diagnostic procedures.⁸ Differences in access to and use of abortion are likely to be important in explaining disparities in the number of children born with fetal conditions that can be identified through widely available screening approaches, such as ultrasound.

Preventive strategies have also been directed at identifying disabling conditions in newborn infants. These strategies have traditionally involved screening programs designed to identify affected children early enough to implement preventive interventions. This approach, in turn, has usually required that the condition be present but not clinically recognizable at birth and that the condition be amenable to early intervention. Newborn screening programs were initiated in the 1960s to identify children with phenylketonuria. This genetic disorder can cause cognitive impairment that can be prevented by the early initiation of a special, phenylalanine-poor diet. Over the subsequent decades, state health agencies have implemented universal newborn screening programs, and tests for a number of other conditions, including sickle cell disease and cystic fibrosis, have been added to screening protocols.⁹

The recent development of new testing technologies has made it practical to screen for a broad range of metabolic and genetic disorders, but many of these conditions are still poorly understood or have no effective treatment. Genetic testing for a large number of gene variants associated with various

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health conditions, including cardiovascular disorders and Alzheimer's disease, has been directly marketed to consumers even though the strength of these associations may be weak. Therefore, while the technical ability to identify risk continues to grow, so too does the challenge of making sense of this knowledge and using it to craft an efficient, effective, and humane response.¹⁰

Therapeutic Technologies

In general, children with disabilities rely more heavily than other children on technical interventions, including medications, specialized medical and educational services, and a variety of assistive devices. The term "assistive technology device" was initially documented in federal legislation in the United States as part of the Technology-Related Assistance for Individuals with Disabilities Act of 1988. The proposed definition was "any item, piece of equipment or product system—whether acquired commercially, modified, or customized—that is used to increase, maintain, or improve functional capabilities of individuals with disabilities." Despite changes in the supporting legislation in 1994 and 1998, this definition has remained largely intact and in widespread use.

Between 9 and 15 percent of children in the United States need or use a prescription medication for an ongoing health condition. Indeed, a requirement for prescription medication is the most commonly met criterion for designating a child as having a special health care need.¹¹

One study found that approximately 36 percent of children with special health care needs had a reported need for eyeglasses or vision care; 7 percent required hearing aids or care; and 5 percent required mobility aids or devices.¹² Several national studies reported that approximately one in seven children with special health care needs had at least one unmet need for medical, dental, mental, or other health service.¹³ Approximately half of all children with special health care needs require assistive or medical devices, with 12 percent requiring communication, mobility, or hearing devices. Fourteen percent of these children were found to have unmet assistive technology needs.¹⁴

Studies of specific conditions, particularly cerebral palsy, have documented the importance of technologies designed to improve the functional abilities of children with cognitive and motor disorders¹⁵ and to enhance education, social functioning, and lifelong learning among children and youth with intellectual disabilities.¹⁶ A study of disabled children in an urban area of Finland found that 77 percent of surveyed families benefited from assistive devices for feeding, dressing, and hygiene, particularly if the child had significant motor but mild cognitive disabilities.¹⁷

While access to therapeutic and assistive technology is important, evaluations of the effects of these technologies on child functioning and quality of life remains spotty.

Using classification domains outlined in the World Health Organization's International Classification of Functioning, Disability, and Health,¹⁸ a recent systematic review¹⁹ found that most studies of functioning and quality of life were concerned with technologies designed to enhance communication through new, computer-based modalities²⁰ and to improve mobility through advanced engineering and robotics.²¹ One striking finding was the paucity of assessments of the impact of assistive technology on caregivers and on the children's families.

Overall, this literature suggests that therapeutic and assistive technologies can improve daily functioning primarily through enhancing activity levels and participation in normal activities. However, these published studies reflect a wide variation in the conditions and types of assistive technologies examined, methodological rigor, analytical strategies, and child and family outcomes. Moreover, there may be a significant bias against reporting negative findings because many of these studies evaluated novel or prototypical devices or programs.

The intense interaction of impairment and social context is reflected in significant regional variation in the ways that technology can affect activity levels, participation in normal activities, and the quality of life among disabled children. A recent study of children with cerebral palsy in six European countries documented considerable variation across the eight study regions in the intensity and nature of a child's participation in daily activities and in children's social roles.²² Another far-reaching study of childhood disability in Europe strongly suggested that a substantial portion of this variation resulted from variation in state policies addressing the use of assistive technologies among children

with disabilities.²³ For example, in Denmark, the country with the highest reported levels of participation in daily activities, advocates for disabled children worked closely with the government to facilitate the provision of assistive technologies and the participation of disabled children in a variety of school and after-school activities.²⁴

The Impact of New Technologies on the Prevalence of Childhood Disability

Despite a strong record of successful preventive and therapeutic strategies, there remains a powerful undercurrent of concern that technical innovation has also increased the prevalence of disabilities in childhood. The first mechanism by which technical innovation could be increasing the number of children with disabilities is by shifting mortality into chronic morbidity. While this shift can occur for a variety of serious conditions affecting young children, the decline in neonatal mortality among high-risk newborns, particularly those born prematurely, is of special concern.²⁵ The well-documented reductions in neonatal mortality over the past several decades are attributable primarily to dramatic improvements in the survival of extremely premature infants. While surviving, however, many of these infants go on to suffer from a variety of medical and developmental sequelae, including lung and eye disease, neurologic deficits, and learning disorders.²⁶ Still, the increase in the survival of premature infants is not large enough to account for a major portion of the observed increases in rates of disability.

The improvements in the care of high-risk newborns that have shifted mortality to morbidity in extremely premature neonates have also reduced long-term morbidity in somewhat less premature newborns who previously would have experienced high rates of serious illness and disability.²⁷ The

year-to-year reductions in morbidity lag somewhat behind those in mortality, however, a trend that indicates a rising prevalence of serious disabling conditions emerging from the newborn period. Nonetheless, the impact of technical innovation on both the reduction and the generation of disabling childhood conditions is exceedingly dynamic and should be examined with an informed, analytical eye.

A second, more direct mechanism by which technical interventions could increase the prevalence of serious childhood disabilities is through increasing the number of infants born with a high risk for disabilities. A variety of medications, such as anticonvulsants and retinoids, have been associated with congenital anomalies and other childhood disorders when taken during the prenatal period.²⁸ Assisted reproductive technology, including in vitro fertilization, has been associated with premature birth and low birth weight, in part because of its tendency to result in multiple gestations (twins, triplets, quadruplets). In fact, a significant portion of the increase in the prematurity rate in the United States over the past two decades is estimated to be the result of the growing use of assisted reproductive technology.²⁹

Beyond these discrete, well-documented examples, broader misgivings regarding the potential health impacts of new technical interventions can emerge even for highly efficacious interventions, such as immunizations, when the etiology of a major disabling condition, such as autism or asthma, is poorly understood.³⁰ Although there remains no evidence that immunizations heighten the risk of autism or asthma, these concerns reflect a broader distrust of the professional and regulatory entities responsible for the approval, use, and ongoing evaluation of new health interventions. Significantly, this distrust can

be rooted in complex public sentiments or troubled historical experiences and can play an important role in shaping public acceptance and patterns of use of any new health intervention.³¹ It is sobering, for example, that although none of the concerns about vaccine use have been supported by research, a significant number of parents still refuse or delay vaccinating their children.

In addition to these broad concerns, actual access to appropriate assistive technologies for disabled children depends heavily upon the health care and education systems, both of which are increasingly vulnerable to political pressure to reduce expenditures on public programs. Beyond this general financial pressure, however, lies a series of specific challenges within pediatrics and the child health care delivery system that must also be confronted if any real improvements in the quality of services provided to children with disabilities are to be made.

Assessing the Capacity of Current Delivery Systems

Any assessment of the delivery mechanisms for new technologies available for children with disabilities must begin with an examination of the capacity of the pediatric community to provide high-quality care for children with chronic conditions. In this respect, there is substantial reason for concern. Without important reforms, the current system of child health care in the United States will prove increasingly incapable of ensuring the dissemination and appropriate use of innovative technologies for children with serious disabling conditions.

Pediatric Capability for Comprehensive Care

Over the past several decades, the threat of serious, acute infection in young children has

fallen dramatically, largely in response to the widespread use of a series of new immunizations. Even as the incidence of serious acute disease has decreased, evidence suggests that the prevalence of serious chronic conditions has steadily risen. This historic shift in the epidemiology of childhood, with chronic conditions accounting for a growing portion of childhood morbidity and mortality, has outpaced current child health care systems, which were developed in the 1950s and 1960s and designed primarily to address the risk of acute, infectious diseases. Changing childhood epidemiology coupled with an archaic system of delivery has created a troubling mismatch between child health care delivery structures and emerging patterns of need. This mismatch is posing several complex challenges to the provision of care to disabled children, particularly in the development of highly coordinated and integrated systems of care.³²

In pediatrics, the concept of the “medical home” is driving efforts to develop integrated systems of care. Although the parameters of the ideal medical home for children have been subject to some variation,³³ it is generally considered a locus of care that ensures “accessible, continuous, comprehensive, family-centered, coordinated, compassionate and culturally effective care.”³⁴ Despite numerous pronouncements regarding the importance of the medical home in child health care, however, several studies document the great difficulty of actually implementing such integrated care for large populations of children.³⁵ Moreover, it appears that children who require complex care coordination or assistive technologies may be particularly sensitive to the lack of a high-quality medical home.³⁶

The obstacles inherent in implementing highly coordinated care for children with

complex medical needs are particularly apparent in the troubled relationship between our current health care and education systems. Since the early 1970s, federal law has required that school systems provide children with disabilities with educational and related supportive services that permit them to function as independently as possible. This requirement was extended to infants and toddlers through a reliance on early intervention programs by a law (Public Law 99-457) enacted in 1986 and later expansions in the Individuals with Disabilities Education Act (IDEA) of 1990. These expansions, clearly recognized by the pediatric community,³⁷ supported services such as mobility devices; occupational, speech, and physical therapy; and other medical requirements. (See the article by Laudan Aron and Pamela Loprest in this volume.)³⁸

The prescribed role of primary care physicians in facilitating and coordinating these services has eluded a clear consensus. IDEA describes the physician’s responsibility in terms of clinical diagnosis, evaluation, and consultation. The American Academy of Pediatrics criticized this delineation of responsibility, however, because it failed to recognize the physician’s role in the management, supervision, and planning of services for these children, basically denying a central role for the physician in the medical home.³⁹ Regardless of the specific responsibilities of the primary care physician, however, a highly collaborative team is clearly required to coordinate care effectively across the various domains in which the child functions, including the home, the school, and the larger society.

The public education system can play an important role in facilitating access to assistive technology. IDEA specifies that children

should be provided with the assistive technologies they need to reach the goals identified by an individualized education plan or individualized family services plan. In addition to educational programs, schools can facilitate the engagement of other crucial services, including occupational, physical, and speech therapy. Often, these service providers are highly knowledgeable in the detailed use of relevant technologies as well as the administrative mechanisms required to facilitate access to them.

Considerable change has occurred in the educational and reimbursement policies supporting the involvement of school-based and nonphysician providers in care teams for children with assistive technology needs, such as wheelchairs, communication devices, and corrective glasses. But so far there has been very little insight into how these changes are affecting the nature or quality of services provided by schools. Moreover, the growing financial pressure on both the child health care and educational systems could undermine local capacities to provide highly coordinated, high-quality services for disabled children.

The Promise and Limits of the Medical Home

No comprehensive assessment has been conducted of why the medical home has been so difficult for the child health care system to implement, but several important concerns may play a role. The availability and affordability of insurance coverage is strongly associated with access to services for children with complex health problems, affecting both out-of-pocket family expenditures and the use of those services.⁴⁰ The role reimbursement policies play in shaping physician practice, particularly physicians' willingness to care for children with special health care

A highly collaborative team is clearly required to coordinate care effectively across the various domains in which the child functions, including the home, the school, and the larger society.

needs, is less clear, however. Relatively low or inflexible reimbursement levels may be generating strong disincentives for physicians to allot the necessary time and practice infrastructure to coordinate the care of children with complex needs.⁴¹ Current reimbursement policies appear to be placing growing pressure on pediatric practices to increase patient volume, primarily for relatively well children. This pressure is also evident in the increased likelihood that primary care pediatricians are more likely now than they were a decade ago to refer complicated patients to specialists.⁴² Although the American Academy of Pediatrics has consistently advocated for a strong pediatric role in the care of children with special health care needs, considerable evidence indicates that the training of pediatricians has been lacking in this regard.⁴³ Physician comfort with prescribing special therapy and assistive technology may also be problematic.⁴⁴

Medicaid and Access for Poor Children

Medicaid remains the central publicly funded health insurance program for poor children in the United States. Its reach is wide—it now covers approximately a third of all children in the country and almost half of all births in many states such as California. The

importance of adequate health insurance in generating access to high-quality care is difficult to overstate (see the article by Peter Szilagyi in this volume).⁴⁵ Therefore, the prospects for the continued capacity of the Medicaid program to address the needs of poor, disabled children are worthy of special scrutiny.

Unlike the Medicare program, which is a federally funded entitlement providing broad health coverage for all elderly citizens, the Medicaid program is a combined federal- and state-funded program, specifically dedicated to providing coverage for the poor, the disabled, and elderly nursing home patients. State budgets have become increasingly dominated by Medicaid expenditures, largely because of increases in payments for the care of elderly patients. In mid-2011, thirty-seven states were planning significant reductions in their state Medicaid allocations. These reductions most often take the form of reduced payments to providers and hospitals. In the past, such reductions have had the effect of reducing program participation among low-income women and children. In addition, many states are eliminating “optional” expenditures, those not mandated by federal legislation, that often relate to specialized technical interventions or devices.

Recent legislative actions designed to enhance primary care reimbursement for children could provide a basis for expanding access to Medicaid and perhaps for expanding the presence of the medical home in pediatrics. In addition, new managed care structures currently being developed, such as the accountable care organization (ACO), may be adopted by the Medicaid program. An ACO is an organization that seeks to tie provider reimbursements both to measures of the quality of care provided and to reductions in the

cost of care provided to groups of patients. Medicaid’s adoption of the ACO could provide a financial foundation for improving the quality of care for children with special health care needs. But such structures have not yet shown that they can appreciably reduce expenditures, so their implementation should not be viewed as permitting major reductions in Medicaid funding for children. In addition, these managed care structures use primary care providers not only as facilitators but also as gatekeepers for a range of specialized services and assistive technologies. Without reimbursement and structural reforms that would provide clinicians the opportunity to coordinate the care of disabled children, including providing them with a medical home, the current child health care delivery system will make it difficult for primary care providers to play such a comprehensive role in an informed and constructive manner.⁴⁶ Rather, the exploration of new kinds of health financing structures should be seen as a historic opportunity to enhance the ability of the pediatric community to focus its expertise and coordination efforts on children with disabling conditions as part of a more innovative and coherent child health care system.

The Impact of Technical Innovation on the Social Determinants of Health

A full understanding of the relationship between technical innovation and social patterns of health and disease has long been hampered by antagonisms in disciplinary approaches and political ideology. Social disparities in health are rooted in social forces and societal stratification virtually by definition. A World Health Organization Commission on Social Determinants of Health and a televised documentary series on this issue have recently emphasized this point.⁴⁷ However, recent decades have also

witnessed unprecedented technological advances in health care driven by a strong belief in the capacity of medical, largely technical, interventions to improve health outcomes. The task of understanding the role of technology in improving the health and well-being of children with disabilities will, therefore, require some reconciliation, if not integration, between these two perspectives and domains of empirical analysis.

A History of Antagonism

Tensions between the social and technical perspectives can be traced to the earliest use of health statistics to support improvements in public health. Victorian reformers, making good use of newly available vital statistics data, drafted a series of public reports calling attention to the distressingly high levels of mortality among children living in poor areas of industrializing Europe.⁴⁸ This documentation, particularly the classic *Report on the Sanitary Condition of the Labouring Population of Great Britain* in 1842, brought long overdue public attention to the plight of the urban poor by laying out in cold statistics the unmistakable message that poverty meant more than hardship: it also meant death.⁴⁹ While progressives of all types saw these reports as strong justification for reforms, there quickly emerged some very real tensions in the precise role that social and technical approaches should play in any public response. An influential group of reformers, led by Florence Nightingale and Edwin Chadwick, framed the disparities in mortality as the product of poor sanitary conditions, including overcrowded housing, inadequate sewage, and contaminated water. For this group, the focus was on improvements in public engineering, largely technical sanitary reforms, with little direct concern for the social or political claims of the poor.⁵⁰ This perspective tended to elevate the technical above the social, hygiene above

injustice. Although clearly a call for remedial public action, this call was advocating the eradication of unsanitary exposures rather than of the social forces that shaped them.

Other reformers, however, saw the alarming disparities in health and disease as evidence of inequities in economic relations and political power. For example, Friedrich Engels used tabulations of disparate child mortality to support calls for systematic changes in basic economic structures and political control.⁵¹ Similarly, Rudolf Virchow, a father of modern pathology, recast epidemics and inequalities in health outcomes as the product of social forces and local political conditions.⁵²

In many ways, these tensions between technical and social perspectives have continued to characterize analytical approaches to disparate child health outcomes both in the United States and globally.⁵³ In the early 1900s, the Children's Bureau, the major federal agency concerned with improving maternal and young child health at that time, attempted to link the establishment of technical programs with more basic arguments regarding the social plight of young families in poor urban and rural settings.⁵⁴ Later in the century, growing technical capacity and a strengthened medical profession led to a refocusing of federal attention on technical approaches to improving child health.⁵⁵ This trend was greatly accelerated by the creation and rapid expansion of the Medicaid program, which dramatically shifted federal funding to frankly medical interventions.

The Interaction between Technical Innovation and the Social Determinants of Health

In some measure, the recent elevation of the social determinants of health in public

discourse is a regulating response to the dominance of the technical world during the past several decades. In addition, strong disciplinary impulses help generate tensions between these two different approaches. For those who elevate social causation as a focus for public response, the utility of a health indicator like the child mortality rate lies in its capacity to reflect the human impact of larger societal forces. In this sense, child mortality acts as a kind of social mirror, serving as a stark, ultimate expression of deep, often complex social influences. For those who embrace clinical or technical strategies, on the other hand, the very purpose of technical intervention in a setting of material deprivation is to uncouple poverty from its implications for health. Here, the intent is to use technical capacity not to alleviate poverty but to reduce or eliminate its power to alter health outcomes. In this manner, the goal of technical intervention is to eradicate child mortality's linkage to social causation; the ultimate goal is to create equity in child mortality regardless of the scale of persistent social stratification. For the clinician, success is defined as eliminating child mortality as a social indicator, thereby challenging the very premise of the disciplines that use child mortality as a reflection of the social determinants of health.

The reality is that technical innovation does not truly undermine the power of social causation; but it can radically transform the mechanisms by which social forces exert their profound influence. At a basic level, adverse social influences on a health outcome elevate risk in a population or reduce access to effective interventions, or both.⁵⁶ This "dual currency" approach to the etiology of social differences in health outcomes, while simplistic, can nevertheless help disentangle complex disciplinary discourse and offer an

analytical footing that can begin to bridge the perspectives that have traditionally separated the social causation and technical realms. This general approach has also been constructively used to reframe socioeconomic status less as a modifier of a disease pathway than "as a fundamental cause of disease."⁵⁷ This formulation has stressed the multiple and often complex means by which social forces can exert their influence on health and the variation by which these influences can act over time.

Of central importance, and what ultimately determines the relative role of risk and access in shaping patterns of outcomes, is the efficacy of the intervention in question. Here, efficacy is defined as the power of an intervention to alter outcomes. Interventions wholly without efficacy are not likely to generate differences in outcomes regardless of whether differences in access exist. When interventions are ineffective, differences in underlying risk status will be the dominant cause of disparities in outcomes. When the efficacy of intervention is high, however, then differences in access to these interventions may be the dominant source of disparities in outcomes. The nature of the intervention, be it preventive or therapeutic, low-tech or high-tech, makes little difference; the crucial issue is its proven efficacy. This pivot on efficacy helps underscore the role that technical innovation can play in shaping disparate patterns of health outcomes.

In a period of unprecedented technical innovation, efficacy must be viewed as being exceedingly dynamic, reshaped and expanded with each new discovery or invention that is shown to alter outcomes or improve function. If technological innovation enhances efficacy, then access to technology will become more important. Hence, as efficacy grows, so too

does the burden on society to provide access to technology equitably to all those in need. In this sense, when equity in health outcomes is an agreed-upon social goal, technical innovation places a burden on delivery systems, making outcomes increasingly sensitive to even small differences in access.

A consequence of this role of efficacy is that in a socially stratified delivery system, technical innovation has the ability to widen disparities in outcomes as well as to reduce them. A growing body of evidence is showing that social disparities in mortality are greater for diseases that are considered preventable, in essence, those that have known, efficacious, technical interventions.⁵⁸ Virginia Chang and Diane Lauderdale documented a reversal in social disparities in cholesterol levels after the introduction of statin medications: before statins were introduced, higher social status conveyed an elevated risk for high cholesterol, but after they were introduced, high socioeconomic status was associated with lower risk of high cholesterol.⁵⁹ Disparities have also widened after the introduction of some highly efficacious interventions, such as immunizations, cardiac surgery, and antiretroviral therapy. Similarly, if new technologies worsen outcomes or have adverse side effects, then enhanced access to these technologies among socially advantaged groups could reduce observed disparities in outcomes. For example, while assisted fertility therapy has proven highly efficacious in enhancing fertility among women and couples desirous of childbearing, it is also associated with multiple gestations and premature birth. It was not surprising to observe, therefore, that as wealthier populations were able to make greater use of these new fertility therapies and techniques, white prematurity rates rose, reducing the disparity in premature birth rates between white and

African American women. Technical innovation, therefore, is inherently neutral in its effect on health disparities; its ultimate impact is determined by its efficacy (including adverse effects) as well as by social patterns of diffusion. Therefore, new or improved technologies for children with disabilities may or may not reduce disparities in disabilities or their impact on the daily lives of affected children. Rather, close examination of the interactions between the technologies, the distribution of need, and access will always be required.

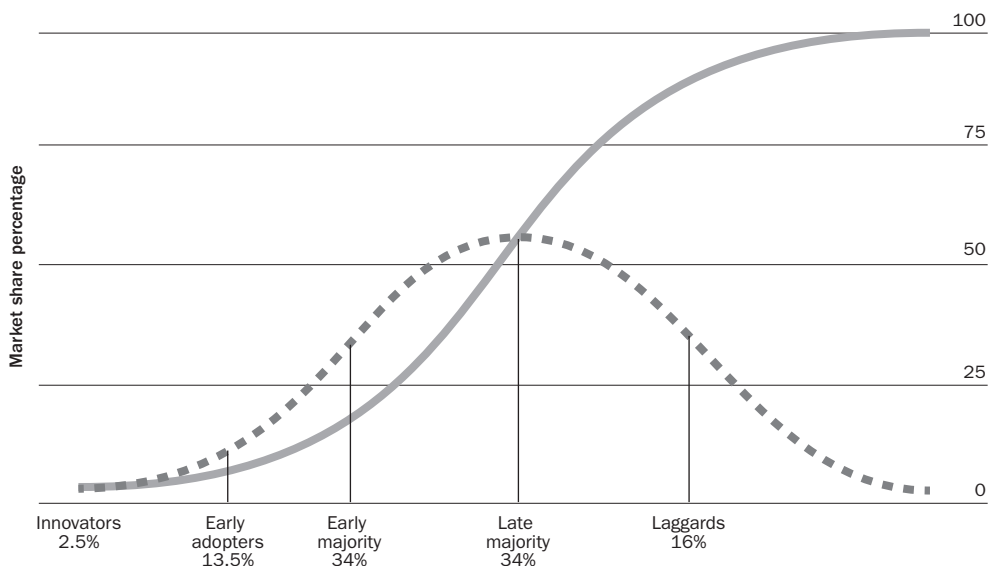
Diffusion Science and Disparity Creation

If technological innovation enhances efficacy, then factors that shape the diffusion of this new technology throughout a delivery system can be of crucial importance to health disparities. The diffusion of technical innovations has been studied since the late nineteenth century, but it became the focus of modern analysis after the publication in 1962 of the *Diffusion of Innovations* by Everett Rogers.⁶⁰ Rogers defined diffusion as the process through which an innovation is communicated through certain channels over time among members of a social system, his point being that diffusion occurs through social systems.

The Social Determinants of Technology Diffusion

A variety of studies have demonstrated that diffusion generally occurs in an S-shaped curve over time, depicted as the solid line in figure 1. This shape represents a nonlinear pattern of adoption, reflecting different affinities for adoption in a population. Rogers categorized these different affinity groups as early adopters, majority adopters, and those who are ungenerously labeled laggards. These categories are illustrated in figure 1

Figure 1. Innovation Adoption Pattern in a Social System



Source: Adapted from E. Rogers, *Diffusion of Innovations*, 5th ed. (Free Press: New York, 2003), figures 1-2 and 7-3.
 Note: The solid line represents the cumulative percentage of adoption or market share over time. The dotted line represents the distribution of adoption around a mean. Each adopter category is delineated by the multiple of the standard deviation around the mean.

as sections under the dotted line representing the distribution of adopters around the mean. A large body of work now documents the mechanisms that determine diffusion patterns. Not unexpectedly, much of this literature is focused on how best to optimize diffusion either to expand product market share or to alter patterns of practice.

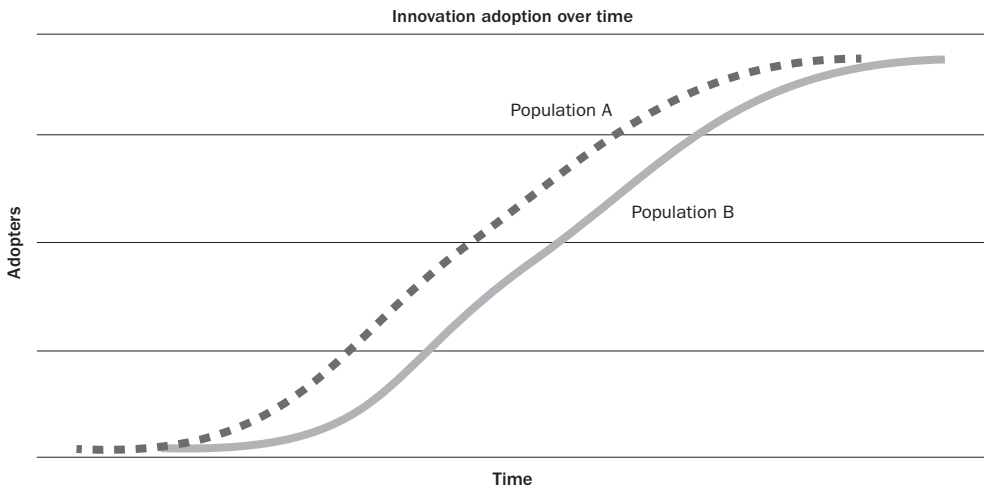
For children with disabilities, the nature of the technical innovation and the practical delivery system are both crucial and highly interactive. The characteristics of innovations likely to move quickly through the S-curve include perceived utility, low cost (not only in dollars but also in ease of use), and good aesthetics. In addition, innovations that depend on a complex infrastructure for use may be more sensitive to the capacity of delivery systems for widespread adoption. For example, amniocentesis for prenatal diagnosis is highly dependent on a fairly

sophisticated delivery system for its use. It should not be surprising, therefore, that in a socially stratified delivery system, social disparities in the use of amniocentesis are greater than those for other, less complex, prenatal screening technologies.⁶¹ Systems heavily dependent upon standardized payers, such as insurance plans, may prolong early adopter phases until the payer authorizes expenditures for mainstream adoption. In this manner, the innovation diffusion patterns are sensitive to the interaction of innovation and system characteristics.

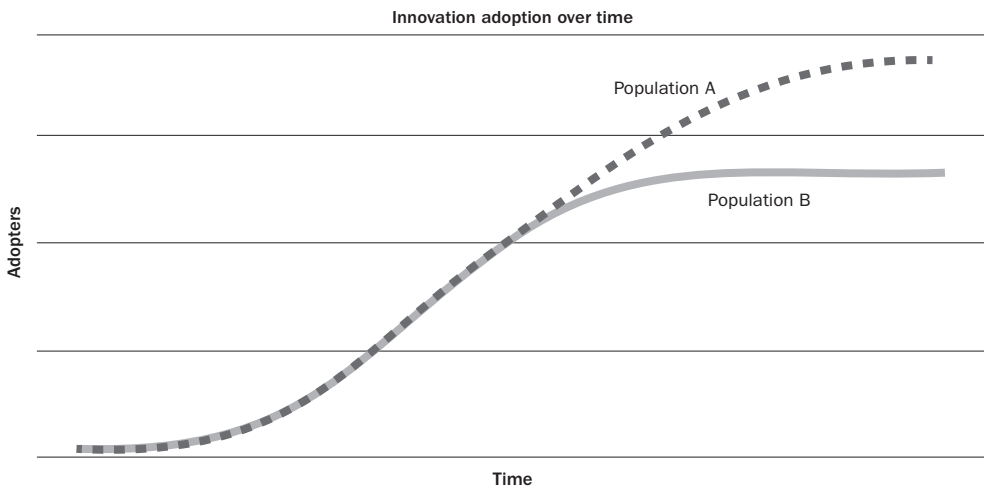
The concern is that these potential interactions may create social differences in the diffusion patterns of highly efficacious innovations. For example, stratified delivery systems can delay adoption and have the effect of shifting the S-curve to the right along the time axis (figure 2A). In this manner, two populations may exhibit the same

Figure 2. Variations in Innovation Adoption over Time-Delayed and Arrested Adoption Curves

A. Delayed adoption curve



B. Arrested adoption curve



Source: See figure 1.

Note: In panel A, the S-shaped curve of adoption occurs first in one population (Pop A) relative to another population (Pop B), and so a disparity in adoption will be observed until the innovation is completely adopted by both groups. In panel B, adoption is similar for both populations until an adoption plateau is reached in one population (Pop B); in this case a disparity in adoption emerges midway through the diffusion process.

adoption pattern but with highly dissimilar time frames, which could create disparities in outcomes for any efficacious intervention for lengthy periods of time. Alternatively, socially disparate characteristics of the delivery system could arrest diffusion at some

level of adoption along the S-curve (figure 2B). Adoption could slow, for example, if it required a certain level of base resources (say, for an intensive care unit) that may not be sufficiently available across the whole system serving a socially defined population.

Whenever efficacious interventions exist, differences in the diffusion of and access to these interventions are thus likely to play a major role in shaping disparities in health outcomes. General populations (including adults) show some signs of significant social disparities in access to assistive technologies.⁶² These disparities appear to be particularly large for expensive devices, such as powered wheelchairs.⁶³ Significant variation in coverage policies among private insurance plans and public programs such as Medicaid have made it difficult, however, to fully gauge access disparities to important assistive technologies for children with disabilities.

Technology Design, Markets, and the Burden of Provision

While the inherent interaction between the characteristics of an innovation and the nature of the system dedicated to its functional delivery must be recognized, the forces shaping the design of the technology most relevant to children who are disabled should also be considered. Assistive technology has been generally considered, particularly by the health and human service community, as inherently compensatory or accommodative in nature. Basically, this technology is viewed as being directed at a selected population of disabled users who would benefit from the technology's ability to address a specific functional impairment. Under this approach, assistive technology often represents a specialized adaptation of broader technologies and is distinguished from technology in general on the basis of the rarity of a specific human need. In this setting, one would expect that the design and manufacture of this specialized assistive technology would be dominated by a set of relatively small, niche manufacturers, a phenomenon that traditionally has been very much the case.

An alternative approach perceives the design of technology for the disabled as part of the essential design of any technological innovation. Generally referred to as "universal design," this approach guides "the design of all products and environments to be usable by people of all ages and abilities to the greatest extent possible."⁶⁴ This approach does not depend upon the delayed reconfiguration of a general technology to meet the specific requirements of the disabled. Rather, it attempts to design from the start innovations that are accessible to all.

Universal design responds to conceptual frameworks developed to create highly inclusive disability theory and law.⁶⁵ It has proven most crucial in influencing the design of new digital technologies, particularly those mediating social communications through the Internet. The reasons have been twofold. First, designing computer software and hardware for universal use should be easier and less costly than designing many other general technologies for such use. Second, and more important, universal design may be most critical in settings of extremely rapid innovation. Adaptive designs, even when developed and implemented relatively rapidly, are not likely to keep up with a highly dynamic technology environment. This lag can lead to the chronic exclusion of disabled people from mainstream technology use. Although relatively little evidence is available regarding the impact of universal design on the activity and participation of children with disabilities, the importance of rapidly advancing digital technologies to the lives of all children, and particularly to disabled children, may underscore the importance of research in this area. In addition, the impact of universal design may prove particularly important in a setting of constrained public financing for health care services. The reduction or elimination of Medicaid support

for the acquisition of assistive or adaptive technologies may only strengthen the utility of universal design strategies.

The potential utility of universal design is also closely related to the concern that small niche markets for adaptive technologies do not provide sufficient financial incentives to support the development of highly innovative products. Drugs or technologies for small markets, often termed “orphan” technologies, may be required to supplement broader, universal approaches.⁶⁶ The record on the actual effectiveness and pricing of orphan medications and technologies has been mixed, however, and new strategies may be required to ensure the robust development of new interventions for relatively rare disorders. In addition, universal design may prove more practical for technologies used by large populations of disabled persons, such as the elderly—technologies that may or may not relate directly to the needs of much smaller groups, like disabled children.

An enhanced reliance on universal design, particularly given the persistence of social inequalities in access to computer and Internet-based technology (the well-known digital divide), will nevertheless require specific mechanisms that ensure universal access to the technology in question.⁶⁷ This imperative highlights the potential need for specified, focused programs directed at affording access to disabled children and their families even if such programs are concerned with technology designed for and used by a general population. More broadly, rapid innovation in health-related technologies may blur distinctions between universal and orphan interventions. For example, advances in genetic testing technologies have generated hopes for

individualized risk assessments and therapeutic plans, a new strategy of “personalized medicine.”⁶⁸ Such visions transcend traditional boundaries between universal and orphan approaches and underscore just how dynamic the interaction between technologic innovation and systems of dissemination can be.

Conclusion

Childhood disability cannot be fully understood without a clear appreciation for the power and machinery of technical innovation in the modern world. Technical progress in both preventive and therapeutic interventions is constantly reshaping the character and prevalence of childhood disability and therefore its essential challenge to both the health and education communities. Yet technical innovation is also generating remarkable new prospects for enhancing the capacities of affected children and optimizing their quality of life. Indeed, the nature and cadence of technical innovation are likely to set in motion profound changes in the meaning of disability for affected children and their families, particularly as the use of technology becomes more deeply integrated into the common tasks and routines of daily life for everyone.

As technical capacity expands, so too does the burden on society to provide this capacity to all children in need. Here, the essential challenge to practitioners and policy makers is the link between technical innovation and equitable provision, without which technological innovation will likely expand disparities in child outcomes rather than reduce them. While transforming human capability and disability, technical innovation also constantly reshapes our collective commitment to equality and social justice, and, in so doing, to the aspirations and promise of childhood.

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Prevention of Disability in Children: Elevating the Role of Environment

Stephen A. Rauch and Bruce P. Lanphear

Summary

Much public attention and many resources are focused on medical research to identify risk factors and mitigate symptoms of disability for individual children. But this focus will inevitably fail to *prevent* disabilities. Stephen Rauch and Bruce Lanphear argue for a broader focus on environmental influences that put entire populations at risk. They argue that identifying and eliminating or controlling environmental risk factors that incrementally increase the prevalence of disability is the key to preventing many disorders.

Rauch and Lanphear examine emerging evidence that many disabilities of childhood have their roots in the environment—from toxins in air, water, and soil, to the stressors of poverty, to marketing practices that encourage unhealthy choices or discourage healthy ones. They review research on well-known environmental causes of disability, such as exposures to lead, cigarette smoke, and industrial air pollution. They point to new evidence suggesting that chemicals found in commonly used plastics may have subtle but serious effects on child development, and that many disabilities spring from the complex interplay of environmental risk factors and genetic susceptibility.

Rauch and Lanphear make a case for turning our attention to societal or population-level interventions that would rely less on medical and genetic technology and more on policies and regulations that would reduce children's exposure to ubiquitous environmental risks. Examples include required testing of new chemicals for developmental toxicity before they are put on the market; zoning regulations that separate residential communities from industrial areas; and restrictions on advertising of unhealthy products, such as tobacco, alcohol, and junk foods, to children. Rauch and Lanphear outline and assess the effectiveness of interventions that could be adopted, and suggest what a healthy modern community might look like. Such interventions, they acknowledge, are likely to be highly controversial, require both long-term investments and shifts in societal thinking, and produce less well-defined outcomes than individual medical treatments. But in the long run, the authors contend, such interventions could prevent many of the disabilities that now afflict millions of children and adults.

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Americans have an unwavering belief that advances in biomedical technology and medical care will solve their health problems. With few exceptions, however, the best these can achieve is enhanced treatment of existing diseases or disabilities. It would be far better to *prevent* disabilities from developing in the first place. For most clinicians, “prevention” usually occurs in a clinical setting and seeks to identify signs, symptoms, or risk factors for a disability in an individual child. In contrast, a strategy that focused on prevention would concentrate on reducing environmental influences that put entire populations at risk. Identifying, and either eliminating or controlling, widespread exposures to modifiable environmental risk factors that incrementally increase the prevalence of disability in a population is the key to preventing many disorders in children and adults.

For the most common childhood conditions, primary prevention may best be achieved through universal and nonmedical interventions.

In this article, we examine the emerging evidence showing that many prevalent disabilities of childhood have their roots in environmental influences, and we make a case for devoting more attention to societal or population-level interventions. These interventions would rely less on medical and

genetic technology and more on recommendations, policies, and regulations that would reduce children’s exposure to ubiquitous environmental risks. Such interventions are likely to be highly controversial, require long-term investments as well as shifts in societal thinking, and have less well-defined outcomes than individual medical treatments. But in the long run, they could prevent many of the disabilities that currently afflict millions of children and adults.

Primary versus Secondary Prevention

Prevention occurs at three levels. Primary prevention seeks to keep disabilities from developing in the first place. Secondary prevention consists of methods of screening and early detection to identify problems early, before they can do too much damage (the “nip it in the bud” approach). Tertiary prevention deals with restoring health and function to people who have already developed a disability. Secondary and tertiary prevention efforts—which are the focus of clinic-based prevention—typically involve screening or treatment. Screening and treatments are beneficial for individuals who are sick, but primary prevention is essential to reduce the prevalence of disability in a population.

The medical community is currently devoting considerable attention and resources to personalized predictive medicine—the identification of genetic markers that make a particular individual susceptible to a specific illness or disability, with the ultimate goal of tailoring therapies to individual patients. These efforts have led to early identification and some promising treatments for specific conditions such as cystic fibrosis.¹ Useful clinical applications have thus far been few in number, however. Overreliance on gene discovery and personalized predictive medicine

may disproportionately benefit those in the best position to take advantage of the new innovations and exacerbate the already gaping socioeconomic disparities in health by draining resources away from underfunded population-level interventions that benefit everyone (see also the article by Paul Wise in this volume).²

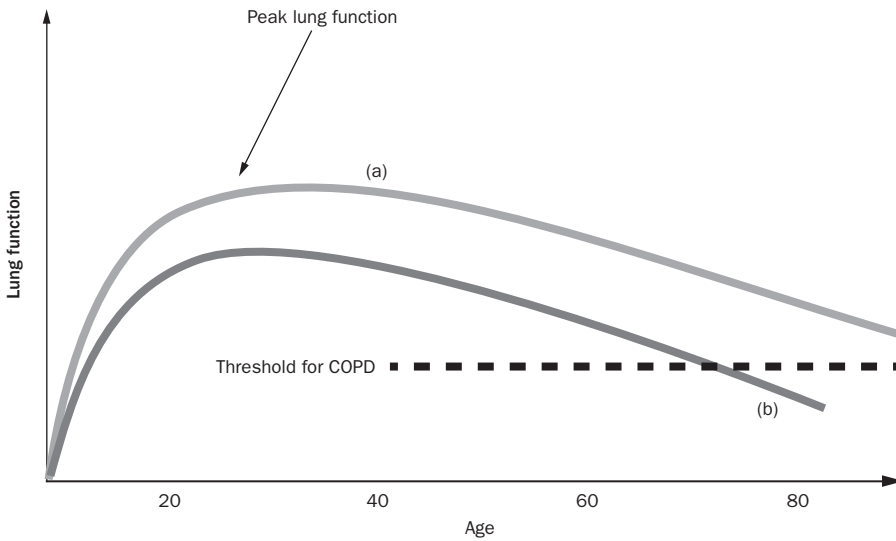
Moreover, the causes of many disabilities in childhood are complex and result from the interplay of environmental risk factors and genetic susceptibility; purely genetic or purely environmental disabilities exist but are rare.³ For the most common childhood conditions, primary prevention may best be achieved through universal and nonmedical interventions. As Geoffrey Rose, a pioneer in the science of prevention, wrote provocatively, “If causes can be removed, susceptibility ceases to matter.”⁴

A key example of Rose’s dictum is the dramatic decline in infant and child mortality and the subsequent rise in life expectancy in the United States over the past century. One explanation for this shift, often touted to support investments in biomedical research, credits the development of vaccines, antibiotics, and other advances in medical technology. The greatest progress in reducing deaths from many infectious diseases and extending life expectancy, however, occurred decades before the discovery or introduction of effective medical treatments.⁵ John and Sonja McKinlay, among others, have shown that clean water, sanitation, and changes in living conditions led to the initial improvements in public health. Especially in cramped and unsanitary urban slums, which spawned epidemics of typhoid, cholera, and tuberculosis, it was social reform and environmental engineering, not medical advances, that reduced poor health and increased life

expectancy. Thus, while vaccines, antibiotics, and the development of neonatal intensive care have played a significant role in the continuing decline in infant and child mortality, the overall decline has had more to do with establishing a clean water supply than with any “medical” factor.⁶

Notably, few of the early “sanitarians” or bacteriologists understood the exact mechanisms by which disease was transmitted. Rather, they drew conclusions after observing the patterns of disease, which gave them sufficient information to act, even in the absence of conclusive knowledge of a mechanism. Knowing the mechanism through which environmental influences cause disease can enhance prevention and public health, however, and genetic research can be helpful in this regard.⁷ For example, being the victim of maltreatment (or child abuse) has been shown to be a risk factor for antisocial behavior, but questions about the causal relationship persisted because the underlying mechanism was unclear.⁸ One study found that males who were maltreated in childhood were more likely to exhibit violent or antisocial behavior in adolescence and young adulthood. But the risk was primarily observed in men who had a particular variant of the gene coding for monoamine oxidase A (MAOA), an enzyme that breaks down neurotransmitters.⁹ While several studies have confirmed the role of MAOA in conferring susceptibility, there already was, of course, sufficient evidence of the adverse consequences of maltreatment to prevent it *without* understanding the mechanism. Similarly, while it might be desirable and useful to understand the exact way that exposure to recognized hazards such as air pollution leads to disease and disability before regulating that exposure, it is not essential.

Figure 1. Schematic Curve of Lung Function over a Person's Lifetime, with Normal and Impaired Growth



Source: Adapted from Lei Wang and Kent E. Pinkerton, "Detrimental Effects of Tobacco Smoke Exposure during Development on Postnatal Lung Function and Asthma," *Birth Defects Research (Part C)* 84 (2008): 54–60.

Note: Curve (a) represents normal growth and decline in lung function. Curve (b) represents a person with impaired growth caused by exposure to environmental pollutants such as prenatal tobacco smoke or airborne fine particulates. This person has a lower peak lung function, leading to an earlier onset of chronic obstructive pulmonary disease symptoms in old age.

Why Focus on Preventing Disabilities in Children?

Children are particularly vulnerable to environmental stressors; they pass through several delicate developmental stages and, pound for pound, they eat and breathe more environmental contaminants than adults.¹⁰ An exposure that is innocuous in adults can have a dramatic effect when it occurs during fetal development or early childhood. For example, in the mid-1900s thalidomide was prescribed to treat morning sickness in thousands of pregnant women, at doses that were nontoxic for adults. But the drug had devastating effects on their fetuses, especially when administered between twenty-seven and forty days after conception, when limb development occurs. While thalidomide causes gross deformities, many other environmental exposures that occur during fetal

development and childhood can have substantial lifelong implications among a population of children, even if the effects are subtle for an individual child. Unfortunately, these effects are much less likely to be recognized and addressed; David Rall, former director of the National Institute of Environmental Health Sciences, once remarked, "If thalidomide had caused a ten-point loss of IQ instead of obvious birth defects of the limbs, it would probably still be on the market."¹¹

Exposures that occur during fetal development or early childhood can obstruct or retard normal function. Children's lungs, for example, continue to develop from birth throughout adolescence, and lung function increases throughout childhood, reaching a peak in the late teens or early twenties (figure 1). Then it plateaus for several years before it begins to gradually decline in older

adulthood. Several recognized risk factors can alter lung function over the life span. One risk is prenatal exposure to tobacco smoke, which lowers lung function in childhood as well as peak lung function.¹² Similarly, exposure to air pollution has been associated with reduced lung function.¹³ Children who face multiple risk factors that diminish their lung function are at higher risk of meeting a threshold associated with chronic respiratory disease. Put another way, insults in early development can impair or obstruct function throughout the life span, leading to diminished function and accelerated disability at older ages. This relationship between early-life insults and later disability occurs in other chronic conditions, such as lead-associated cognitive deficits and dementia, or lower bone mineral density and earlier-onset osteoporosis associated with calcium-deficient diets.¹⁴

Although Americans' life expectancy has increased, so have the years many of them live with a disability or chronic disease.¹⁵ Many factors undoubtedly account for this increase in disability, but environmentally induced conditions incurred during childhood can compound throughout a person's lifetime and express themselves as chronic diseases in adulthood or old age. Today's increases in childhood obesity will lead to tomorrow's epidemics of diabetes in young adults and to cardiovascular disease in middle-aged or older adults.¹⁶ The emerging evidence thus suggests that preventing the development of chronic disease in adults requires improving the health of children. That, in turn, will require dramatic shifts of resources for a country that spends the vast majority of its health care dollars for medical treatment of the elderly.¹⁷

Another reason to focus on prevention in children is because disabilities in children

are on the rise (see the article in this volume by Neal Halfon and others).¹⁸ The definition of disability varies depending on the survey used, but the number of children diagnosed with an activity limitation stemming from a chronic health condition rose from 1.8 percent in 1960 to 7.3 percent in 2006, while the prevalence of diagnosed developmental disabilities rose from 12.8 percent in 1997–99 to 15 percent in 2006–08.¹⁹ Many of the most common disabilities, including asthma, premature birth, autism, attention-deficit/hyperactivity disorder (ADHD), and obesity, appear to be on the rise.²⁰

A shift to prevention of disabilities should be attractive to policy makers because prevention reduces health care and societal costs, as well as alleviating human suffering. For example, lead in house paint is known to be associated with lower IQ and ADHD in children and with criminal behavior in adulthood.²¹ Policy makers may balk at requiring homeowners, landlords, and others to undergo the expense and effort of removing the hazard, yet a cost-benefit analysis concluded that every \$1 spent to reduce lead hazards in housing would produce between \$17 and \$221 in benefits by reducing expenditures on screening and treatment for lead toxicity, ADHD treatment, and special education; increasing income and tax revenue; and reducing crime. The analysis estimated a total potential net savings from the elimination of lead hazards of \$118 billion to \$269 billion.²² Another study estimated the cost of disease from exposure to pollutants linked with asthma, cancer, and neurobehavioral disorders at \$76.6 billion in a single year (2008).²³

The Epidemiologic Transition and the Emergence of the New Morbidities

To understand the causes of the “new morbidities,” or disabilities, of childhood, it is

useful to examine trends in patterns of disease and disability over the past century. As noted, in the early 1900s public health concerns were dominated by epidemics of infectious disease, overt nutritional deficiencies, and infant mortality associated with poor urban living conditions. With the advent of public water and sanitation systems, pasteurization of milk, and housing safety codes, death rates fell sharply, especially among infants and children, and life expectancy in the United States increased from forty-seven years in 1900 to sixty-eight years by 1950, and to seventy-eight years in 2007.²⁴ Moreover, the pattern of mortality and morbidity shifted from infectious diseases to chronic conditions such as cardiovascular disease and cancer, a shift commonly known as the epidemiologic transition.²⁵ In recent years, a similar transition has been taking place for children, as the burden of illness and disability shifts from infectious disease to chronic conditions including asthma, obesity, and mental health and neurobehavioral problems such as autism and ADHD.

Risk Factors for Disabilities in Children

Many harmful exposures, from toxic exposures to marketing practices to social inequities, have been recognized as contributing to the rise in child disability.

Poverty

Poverty is one of the most significant risk factors for disabilities and is especially troubling because one-fifth of all children in the United States were living in poverty in 2010.²⁶ Linking disability with poverty is hardly new, but the relationship is just as powerful with chronic conditions as with infectious disease.²⁷ Poverty affects health on several levels: directly, through the psychological stress and social stigmatization that accompany

living in poverty, and indirectly, through increased exposure to a wide range of environmental stressors such as pollution, crime, and lack of access to healthful food.²⁸ People living in poor neighborhoods, especially racial or ethnic minorities, also face disproportionately high exposures to toxic and hazardous wastes, air pollution, contaminated water, and unsafe housing.²⁹

Even without the deprivations of poverty, people may still suffer from being on the lower rungs of the social ladder. Michael Marmot described the phenomenon of a “social gradient,” a direct, linear relationship between health and position in the social hierarchy, while examining members of the British civil service.³⁰ These effects have been found elsewhere, including among children; moreover, the gradient appears to grow sharper (that is, the health of rich and poor diverges further) as children age, and “the adverse health effects of lower income accumulate over children’s lives.”³¹

In addition to the harmful effects of poverty, it has been argued that the overall *level* of inequality in a society also affects health. Richard Wilkinson and Kate Pickett have shown that countries with greater social inequities experience poorer health than more egalitarian countries on almost all available measures, including life expectancy, infant mortality and child health, obesity, and mental health; the United States, with its wide gaps between rich and poor, fares worse than most other developed countries, a difference that persists even when only wealthy individuals are considered.³² In other words, poor Americans fare much worse than wealthy Americans, but even wealthy Americans fare worse than wealthy (and even middle-class) residents of many other countries.³³

Eliminating poverty would likely dramatically improve the overall health of the nation's population, but the changes in the structure of society required to significantly reduce poverty appear to be beyond the typical range of public policies. Indeed, efforts in the United States to address poverty on a national scale have stalled or lost ground in recent decades. Another approach to mitigating the negative health effects of poverty would ask *how* being poor leads to worse health (toxic exposures, psychological stress, lack of medical care) and then develop interventions that address those specific risks.

Airborne and Other Environmental Pollutants

Just as the deplorable conditions of Victorian-era slums led to insights into the causes and control of infectious disease, environmental disasters and epidemics over the past century have linked exposures to industrial pollutants and environmental chemicals with overt toxicity. In Queensland, Australia, an epidemic of childhood lead poisoning in the early 1900s was traced to lead in house paint, establishing the link that still haunts residents of older housing in many countries around the world.³⁴ In December 1952, a dense fog of sulfurous particles from burning coal enveloped London for five days, leading to an estimated 12,000 deaths, mostly from respiratory or cardiovascular disease; children and older adults were especially vulnerable to the sulfur-laden coal smoke.³⁵ This disaster—and a similar one in Donora, Pennsylvania, in 1957—began to focus people's attention on the harmful effects of air pollution, ultimately spurring the development of environmental regulations regarding levels of particulate matter. In the 1950s and 1960s, cases of severe congenital defects in the Japanese town of Minamata Bay were traced to mercury emissions from a local plastics factory.³⁶

Scientists also have taken advantage of other “natural experiments” to test associations between health and air pollution. In the late 1980s, for example, C. Arden Pope and his colleagues showed that the closing of a Utah steel mill led to lower levels of airborne particles and lower mortality and hospitalizations.³⁷ In 1996 the summer Olympic Games in Atlanta reduced traffic there, which led to lower air pollution and fewer hospitalizations.³⁸ More recently, the introduction of E-ZPass, an electronic highway toll collection method, reduced traffic congestion and lowered the incidence of preterm birth and low birth weight by an estimated 6 to 9 percent among babies living within two kilometers of toll plazas along three major roadways in New Jersey and Pennsylvania.³⁹

Airborne pollutants are known to contribute to other debilitating illnesses in both children and adults, including asthma. The most common childhood chronic condition in the United States, asthma affected an estimated 9.7 percent of American children in 2009.⁴⁰ The disease, which is characterized by airway inflammation, difficulty breathing, and reduced respiratory function, takes a heavy physical and psychological toll on those affected. Its prevalence has risen steadily in most Western countries since the 1980s, although it seems to have leveled off in the past decade.⁴¹ The reasons for this pattern are not entirely clear, but airborne particles smaller than 2.5 microns (also called PM 2.5 or fine particles) have been associated with impaired lung function and asthma exacerbations.⁴² Exposure to prenatal smoking and secondhand smoke is also associated with impaired lung development, reduced lung function, and asthma, and other studies have linked airborne pollutants to preterm birth and lower birth weight as well as to chronic cough and bronchitis.⁴³

These harmful effects of air pollution on respiratory function are well established. More recent studies are now finding links between exposure to air pollutants and reduced cognitive development. Black carbon (an airborne product of combustion from fossil fuels and other sources) has been associated with lower verbal and nonverbal intelligence and poorer memory performance in a Boston-based birth cohort of children aged eight to eleven.⁴⁴ Frederica Perera and others, using polycyclic aromatic hydrocarbons (PAHs) as a biomarker, found that children with higher exposures to combustion products had diminished cognitive abilities.⁴⁵ These links between airborne toxins and cognitive performance are less established, but they fit a larger pattern of toxic exposures interfering with brain development in young children.

The use of exposure biomarkers, which measure the amount or internal dose of a pollutant in the body, has allowed scientists to directly quantify the effects of exposures encountered by the general population.⁴⁶ The increasing use of biomarkers is showing that industrial pollutants and environmental chemicals are not only harmful at the higher levels of exposure but at lower concentrations as well. For example, lead has long been associated with poorer intellectual development in children, but more recently exceedingly low blood lead levels (fewer than five micrograms a deciliter) have been linked with lower IQ scores. Even more troubling, the observed decrements in intellectual abilities are proportionately greater at the lowest blood lead levels, indicating that there is no “safe” level of exposure.⁴⁷ Similarly, pregnant women are at risk of giving birth prematurely not only if they are smokers but if they are exposed to secondhand tobacco smoke.⁴⁸ Scientists looking for “safe” levels of fine particles in air pollution found a steady relationship with

While some of the rise was explained by changes in diagnostic practices and an increased awareness of autism, these factors alone did not account for the dramatic rise in autism.

adult mortality down to the lowest detectable levels.⁴⁹ Thus, for some of the most established pollutants, increasing evidence of toxicity is appearing even at the lowest levels of exposure. Moreover, while it was once thought that only workers and urban dwellers were exposed to these industrial pollutants, it is now realized that these contaminants are ubiquitous: virtually no one is unexposed.⁵⁰

The Rise of Autism: More Questions than Answers

The incidence of autism, one of the most disabling conditions of childhood, has increased dramatically in recent years, although it remains rare in comparison to conditions such as ADHD. An exhaustive study of California’s birth and medical-service records reported an increase in the rate of autism diagnosis before the age of five from 6.2 per 10,000 births in 1990 to 42.5 in 2001. While some of this rise was explained by changes in diagnostic practices and an increased awareness of autism, these factors alone did not account for the dramatic increase in autism.⁵¹

Very little is known about risk factors for autism or autistic behaviors. While autism is believed to have a genetic component, such a rapid increase in prevalence points to an

increase in one or more environmental risk factors. The little evidence available suggests the risk increases for mothers who live near a freeway during the third trimester of pregnancy and decreases for mothers who take prenatal vitamins in the period around conception.⁵² Other suspected causes of autism, such as mercury in childhood vaccines, have not been supported by the evidence.⁵³ Autism may be a “test case” for the ubiquity and variety of man-made chemicals, many of which have never been tested for their health effects in humans, especially children.⁵⁴ While any links between environmental chemicals and autism are speculative, it would not be surprising if a chemical (or combination of chemicals acting synergistically) were contributing to this heightened autism prevalence. It is worth asking whether a revision of the regulatory framework for environmental chemicals might begin to control the autism epidemic, even before the responsible toxicant(s) is identified.

Linking Environmental Toxicants to Psychopathology

Researchers are increasingly finding links between exposures to environmental toxicants and neurobehavioral disorders, one of the most rapidly rising categories of disabilities in children; one such disorder is ADHD, which affects almost one in ten children.⁵⁵ Using a nationally representative sample, for example, Tanya Froehlich and her colleagues estimated that children with blood lead concentrations in the highest tertile—above 1.3 micrograms per deciliter ($\mu\text{g}/\text{dl}$)—were two and a half times as likely as children with the lowest blood lead concentrations (less than 0.8 $\mu\text{g}/\text{dl}$) to meet criteria for ADHD.⁵⁶ This finding is particularly disturbing because blood lead levels above 1.3 micrograms per deciliter are far below the current “level of concern” of 10 $\mu\text{g}/\text{dl}$.

Similarly, children who were prenatally exposed to tobacco were nearly two and a half times more likely to meet criteria for ADHD than children whose mother did not smoke during pregnancy. Furthermore, lead and tobacco exposures interacted synergistically; children in the highest lead category who were also prenatally exposed to tobacco smoke were eight times as likely to meet diagnostic criteria for ADHD as children with neither exposure. Several other lines of evidence link lead exposure with neurobehavioral disorders. Neuroimaging studies, for example, have associated lead exposure with reduction in gray matter volume in the prefrontal cortex, a key area of the brain necessary for executive functions, impulse control, and decision making.⁵⁷ Another study cites declining blood lead levels as the primary reason for the decline in homicides and other criminal behaviors over the past thirty years.⁵⁸

Although the evidence is less definitive, other chemicals, such as organophosphate pesticides, mercury, and polychlorinated biphenyls (PCBs), have also been linked to the development of ADHD.⁵⁹ While the use of biomarkers has allowed scientists to connect environmental exposures to disabilities in children, the long latency between exposure and disability makes it difficult to establish these links with certainty. Still, these studies raise serious questions about the need to revise the existing regulatory framework—which essentially allows children to be exposed to suspected toxicants or chemicals until there is definitive proof of their toxicity.

The Emergence of Endocrine Disruptors

One emerging area of concern is a class of chemicals known as “endocrine disruptors” because of their ability to mimic natural hormones.⁶⁰ Evidence from several recent studies has linked prenatal exposure to

phthalates and bisphenol A (BPA)—ubiquitous, estrogenic-mimicking chemicals found in plastics—with endocrine-sensitive outcomes such as decreased anogenital distance (a condition linked to infertility), decreased “masculine” play in boys, and externalizing behavioral problems in girls; this link suggests that endocrine disruptors can alter neurological development.⁶¹ While most evidence on the effects of endocrine disruptors concerns sex hormones or the thyroid, some endocrine disruptors (known as “obesogens”) may mimic other hormones, including those involved in the development of obesity. The role of obesogens in the obesity epidemic is still speculative, but a chemical called tributyltin has been identified as a possible obesogen in some animal studies.⁶² In addition, one national cross-sectional study found associations between body mass index—a measure of obesity—and phthalates in adolescent girls.⁶³

The Rise of Obesity and Diabetes

Americans have become steadily heavier over the past thirty years. In a nationally representative sample taken in 2007–08, almost 17 percent of children and adolescents aged two to nineteen were classified as obese, up from 5 percent in 1971–74 and 10 percent in 1988–94.⁶⁴ Obese children are more likely to become obese adults, who are at heightened risk for type II diabetes, cardiovascular disease, and some cancers.⁶⁵ Diabetes is also on the rise in young people, where it can have especially serious health consequences (compared with a later onset).⁶⁶ Being obese can also have profound psychosocial effects on children; one study found that obese children fared as badly or worse on several measures of psychological functioning and stress as children who had cancer.⁶⁷

For conditions such as obesity and diabetes, the dialogue surrounding prevention typically

focuses on individual “lifestyle choices.”⁶⁸ It is easy to blame a person for eating too much, getting too little exercise, or smoking cigarettes. But lifestyle choices depend to a large extent on social context, a point that is too often unacknowledged. For children, whose preferences are still developing and who are open to a wide range of influences, it is easy to see how their “choices” may be manipulated by outside factors.

Marketing and advertising are staples of modern life, affecting how each of us views and interacts with the world. This is especially true for children. Children see an average of fifteen television commercials for food every day (in addition to ads on billboards, online, and elsewhere), the vast majority of which feature foods high in sugar, fat, or sodium.⁶⁹ Food and beverage companies spend upward of \$10 billion annually marketing to children, and several experimental and cross-sectional studies support the thesis that advertising alters children’s taste preferences as well as the amount they eat.⁷⁰ In one study, children given identical food in either a plain bag or a McDonald’s bag rated the food in the branded bag as better tasting; the effect was stronger in children who had more TV sets in their home and who ate at McDonald’s more often.⁷¹ In another study, children who watched cartoons interspersed with food ads ate more than children who watched cartoons with other kinds of commercials.⁷² The increase in consumption was greater for overweight children than for those of normal weight, and greater still in obese children, suggesting that some individuals may be more susceptible than others to these influences.⁷³

Skeptics may dismiss the notion of advertising as “mind control,” but repeated exposure at a very young age can have a profound

effect on a child's later actions, even into adulthood. Children are thought to be capable of some "defense" against persuasion by marketing by age eight, at which point most children are able to recognize advertisements and evaluate their claims accordingly. But there is little evidence that children above age eight are any more resistant to the effects of advertising than younger children.⁷⁴ Ads do not simply make factual claims about their product; they are designed to create emotional associations, often at an unconscious level, and to bypass the "rational" parts of the brain.⁷⁵ Nor is the effect of advertising limited to food and obesity. Repeated studies have linked tobacco marketing to teenagers' decision to start smoking, and several cross-sectional and longitudinal studies have linked exposure to alcohol marketing to adolescents' being more likely to start drinking and to drink more frequently.⁷⁶

The built environment, the physical design of the areas around children's homes, can play a powerful role in determining children's "lifestyle choices." Many children live in neighborhoods with few (if any) sidewalks, bike lanes, parks, and green spaces that encourage exercise. Urban (or suburban) sprawl has created dependence on cars by placing destinations farther apart, while parents' concerns about crime may further reduce the amount of time children spend outside. Conversely, neighborhoods designed to be "walkable" encourage exercise and physical activity.

At the same time, over the past several decades schools faced with budget cuts have been dropping physical education programs to save money, while installing soda machines to raise badly needed sponsorship funds.⁷⁷ Recently, many schools have improved children's nutrition by regulating the offerings in vending machines and providing more

nutritional items in school cafeterias, but such actions have largely taken place on a school-by-school or district-by-district basis.⁷⁸ Several lines of evidence link features of the built environment with obesity or overweight in children and adults.⁷⁹ There is less agreement about the most effective interventions, largely because changing the physical structures of neighborhoods and cities is difficult and costly. But the evidence does suggest that tackling the obesity epidemic will require attention to the built environment as well as to individual behavioral change.

Consumption of healthful or unhealthful foods is typically discussed in terms of lifestyle choices. However, eating a healthful diet is highly dependent on having markets nearby that sell affordable fresh fruits and vegetables, and such places may be scarce or nonexistent in poor neighborhoods, while cheap, highly processed fast food is plentiful—even if, as some have argued, home-cooked food is actually less expensive (in terms of raw ingredients) than the fast-food equivalent.⁸⁰

Tools for Preventing Harmful Exposures

Policy makers and other public health advocates can take several approaches to preventing disabilities that result from harmful environmental exposures. These are often classified into "the Three Es": education, enforcement, and engineering. Education involves giving people information on health risks in an effort to change their behavior. Enforcement uses legislation and regulations to reduce or curtail harmful behaviors. Engineering involves manipulating the environment to passively reduce exposures to a hazard. For example, to prevent childhood obesity or type II diabetes, children might be given lectures or promotional materials about the risks of a diet high in saturated fat and

the benefits of eating more fruits and vegetables (education); fast-food advertising aimed at children might be restricted (enforcement); and neighborhoods might be designed to encourage walking and other physical activity or making healthful snacks and water more easily available to school children than unhealthy ones (engineering).

All three methods have strengths and weaknesses. Education is the least invasive, but changing behavior through education is notoriously difficult and often ineffective (smoking-cessation programs and campaigns aimed at increasing fruit and vegetable consumption tend to have low success rates), especially when modifying one's behavior requires acting differently from friends, family, or the larger society. In contrast with education-only efforts, enforcing certain behaviors, by restricting the sales of tobacco products and alcohol to minors, for example, has been more effective. Enforcement can be quite contentious when it involves regulating industries or people's behavior and often leads to accusations of paternalism or heavy-handedness, although paternalism may be more acceptable where children are concerned. From a population-wide perspective, the engineering approach has the greatest potential to improve health: by making more healthful lifestyles the "path of least resistance," it bypasses the difficult process of persuading people to change their behavior. Engineering the environment, such as treating water to reduce diarrheal diseases, phasing out the use of leaded gasoline to prevent lead poisoning, or instituting zoning codes to limit proximity of residential dwellings to industries emitting toxic material, have all proved to be highly effective ways of preventing disease and disability. At the same time, engineering solutions can be costly to implement. This approach also requires the

involvement of professionals outside the typical conception of "health"—engineers and city planners, as well as political leaders—in addition to physicians and public health scientists. Still, as noted, some of the largest increases in life expectancy over the past century have resulted primarily from population-wide engineering solutions.⁸¹

Population-wide approaches to prevention can be effective because they are capable of "shifting the curve." Disabilities exist on a continuum. Thus, a small increase in risk for a common disease or disability affects population health more than a large increase in a rare condition.⁸² For example, children's capacity for attention, hyperactivity, and impulse control varies across a wide spectrum, and it is only to simplify the diagnosis and treatment that health care providers create a clear division between "normal" children and those who have ADHD. Geoffrey Rose used the idea of "shifting the curve" to describe the relationship between individual- and population-level risks. He showed that many diseases or disabilities exist on a continuum; the number of people in the "high-risk" group (in this case, those corresponding to the clinical criteria for ADHD) is closely tied to the overall state of the population as a whole.⁸³ In other words, the number of children diagnosed with ADHD in a population can often be predicted from the average behavioral profile of children in the population. Depending on the shape of the distribution, small shifts in behaviors or exposures associated with ADHD can have a dramatic effect on the number of children who meet clinical criteria for ADHD. And in practice, with the exception of immunizations, population-wide interventions to prevent disabilities are largely limited to modifying environmental risk factors.

Taking the Precautionary Principle with Children's Toxic Exposures

How much evidence is needed before action is taken? The dangers of tobacco and lead were understood for decades before prevention became a priority. Today, however, for a variety of reasons, policy makers are reluctant to act on a hazard unless the precise way that it causes disease or disability is known.⁸⁴ The sanitarians of the early twentieth century understood that demonstrating a pattern of disease was sufficient to take action, often decades before the bacterial causes were discovered. One way to apply that lesson is by reforming the way industrial chemicals are tested and allowed onto the market.

Currently, industrial chemicals are “innocent until proven guilty.” They can be introduced without being fully tested for toxicity: indeed, of more than 200 industrial chemicals known to have neurotoxic effects in adults, only a handful have been tested for neurotoxicity at lower (subclinical) doses.⁸⁵ Moreover, a chemical is taken off the market or a pollutant regulated only when harmful effects are proven definitively; by convention, this means that a chemical has to be proven toxic in laboratory experiments and then in a series of epidemiologic studies, which usually take decades to complete.⁸⁶ In the interim, millions of people, including children and pregnant women, will have been exposed and possibly harmed. Thousands of chemicals are currently in the environment, making it difficult to attribute disability or disease to any one particular chemical. For those chemicals that persist indefinitely in the environment, even when harmful effects are identified, stemming the tide of exposure may be the most that can be accomplished. Although the insecticide DDT was banned in the United States in the early 1970s, one recent study estimated that its metabolite DDE can be

detected in 95 percent of Americans.⁸⁷ It has been linked with diabetes, spontaneous abortion, and impaired neurodevelopment.⁸⁸ PCBs, which have been linked to reduced IQ and immune system and thyroid dysfunction, have been banned for decades; however, they are routinely detected in newborns and children around the world; exposure is nearly universal.⁸⁹

The experience with lead, tobacco, PCBs, mercury, and other toxicants indicates that the United States should adopt the precautionary principle and identify toxicants before they are marketed and widely disseminated in the environment. Other governments have already taken such a step. In 2007 the European Union instituted the REACH Program, which requires manufacturers to prove that chemicals are safe before they are marketed.⁹⁰

Setting Priorities: Population Attributable Fractions

How do we prioritize what environmental influences or risk factors to target? From a prevention perspective, efforts should focus on common and modifiable risk factors associated with high-prevalence disabilities and potentially debilitating conditions, such as ADHD, obesity, or asthma. A tool known as population attributable fraction, a measure of the proportion of disability or disease in a population that can be attributed to a particular risk factor, can help quantify priorities.⁹¹ The population attributable fraction takes into account both the risk posed by an exposure and the frequencies of exposure and disease in the population.

Tanya Froehlich and her coworkers estimated that exposure to higher levels of lead and prenatal tobacco each accounted for 500,000 additional cases of ADHD in U.S. children;

Table 1. Population Attributable Fractions (PAF) and Number of Attributable Cases for Select Environmental Risk Factors and Childhood Disabilities

Condition	Exposure	PAF (%)	Number of cases
ADHD	Prenatal tobacco smoke	22	510,000
	Blood lead in top tertile	25	598,000
	Prenatal smoke or blood lead	38	900,000
Conduct disorder	Environmental tobacco smoke (cotinine in top quintile)	39.2 ^a	—
	Blood lead in top quartile	38.9 ^a	—
Preterm birth	Maternal smoking during pregnancy	5.3–7.7	—
Low birth weight		13.1–19.0	—
Asthma	Residential exposures (secondhand smoke, pets, allergies)		
	age 0–5	39	533,000
	age 6–16	44	2,000,000
At risk for overweight (85th–95th percentile) ^b	Never breast fed in first 6 months, age 3–5	20.2 ^a	—
Overweight (95th percentile ^b and above)	Breast feeding (mostly formula vs. mostly breast fed), age 9–14	9.2 ^a	—
Metabolic syndrome	Smoking (age 12–19)	27.5	—

Sources: Tanya E. Froehlich and others, "Association of Tobacco and Lead Exposures with Attention-Deficit/Hyperactivity Disorder," *Pediatrics* 124 (2009): e1054–e1063; Joe M. Braun and others, "Association of Environmental Toxicants and Conduct Disorder in U.S. Children: NHANES 2001–2004," *Environmental Health Perspectives* 116, no. 7 (2008): 956–62; Patricia M. Dietz and others, "Infant Morbidity and Mortality Attributable to Prenatal Smoking in the U.S.," *American Journal of Preventive Medicine* 39, no. 1 (2010): 45–52; Bruce P. Lanphear and others, "Residential Exposures Associated with Asthma in U.S. Children," *Pediatrics* 107, no. 3 (2001): 505–11; Bruce P. Lanphear and others, "Contribution of Residential Exposures to Asthma in U.S. Children and Adolescents," *Pediatrics* 107, no. 6 (2001): e98, DOI: 10.1542/peds.107.6.e98; Mary L. Hediger and others, "Association between Infant Breastfeeding and Overweight in Young Children," *Journal of the American Medical Association* 285 (2001): 2453–60; Matthew W. Gillman and others, "Risk of Overweight among Adolescents Who Were Breastfed as Infants," *Journal of the American Medical Association* 285 (2001): 2461–67; Michael Weitzman and others, "Tobacco Smoke Exposure Is Associated with the Metabolic Syndrome in Adolescents," *Circulation* 112 (2005): 862–69.

Notes: PAFs for exposures are not additive, and may sum to over 100 percent.

a. We calculated PAF estimates from figures in paper and using the formula $\frac{\text{exposed cases}}{\text{total cases}} \times \frac{(RR-1)}{RR}$, where RR stands for relative risk.

b. Percentiles are weight-for-height, compared to sex- and age-specific distributions.

— Estimate of attributable cases not given.

using the population attributable fraction, they estimated that 38 percent of cases of ADHD could be prevented if childhood lead exposure and smoking in pregnant women were eliminated.⁹² They also showed that, because lead and tobacco interact synergistically, children who had high blood lead and exposure to prenatal tobacco constituted only 7.7 percent of the population, but they represented nearly 25 percent of the total cases of ADHD.⁹³ It is worth noting that both blood lead levels in children and smoking among pregnant women have decreased significantly in the last few decades, so they cannot explain the increase in ADHD

prevalence.⁹⁴ However, the prevalence of ADHD would undoubtedly be higher if these two environmental factors had not been reduced. There are now several other toxicants, as well as other risk factors, suspected of contributing to the development of ADHD.⁹⁵ However, the current health care system continues to focus almost entirely on identification and treatment of children for ADHD rather than on further reductions in toxicants demonstrated or suspected of elevating the risk for the disorder.

Calculating population attributable estimates for prevalent disabilities is not always feasible

—it requires a representative sample, an estimate of the prevalence of exposure, and a measure of risk—but estimates do exist for several notable risk factors for prevalent childhood disabilities (table 1). Bruce Lanphear and others estimated, for example, that residential exposures—including exposure to secondhand smoke, the presence of pets, use of a gas stove, and allergies to dust mites or cockroaches—accounted for approximately 533,000 cases of asthma (39 percent of all cases) in children under six and 2 million cases (44 percent of the total) in children aged six to sixteen.⁹⁶

Healthy Communities: Challenges and Successes

We have a remarkable opportunity to protect the health of children and prevent the development of disability. While it is not yet definitive, a growing body of evidence shows that prenatal or early-life exposure to chemicals or malnutrition can have severe effects on physical and mental development that persist over the life span and that effects are found at increasingly lower levels of exposure.

Children are routinely exposed to thousands of man-made chemicals, most of which have not been tested for safety, from an early age, and often even before they are born. From a very young age, children are inundated with marketing for fast-food restaurants, sugary cereals, tobacco, and alcohol; these exposures can shape their developing behaviors, food preferences, and decisions to smoke or drink alcohol. While the task may seem daunting, these exposures are all modifiable if we have the will to do so, and taking action would produce considerable benefits.

Reducing toxic exposures is not impossible. C. Arden Pope and his colleagues estimated that as much as 15 percent of the increase in life expectancy from 1980 to 2000 in many

U.S. cities was attributable to environmental regulations that reduced air pollution.⁹⁷ Further reductions in allowable levels of airborne pollutants are likely to result in even greater benefits.⁹⁸ Another promising finding is a reduction in asthma rates brought about by smoking bans. In Scotland and Kentucky, recent bans on smoking in public places have each led to an 18 percent reduction in child asthma hospitalizations and emergency-room visits in the areas affected by the bans.⁹⁹ Through coordinated public health campaigns, social attitudes about smoking are changing, and tobacco use has declined.¹⁰⁰ Regulations lowering the allowable levels of lead in gasoline, paints, and other consumer products led to an 84 percent reduction in children with elevated blood lead (more than 10 micrograms per deciliter) in the United States between 1988–91 and 1998–2004.¹⁰¹ And while efforts to curb childhood obesity have, thus far, been unsuccessful at the societal level, a few school-based programs have had some success in lowering the body mass index for some children or increasing their physical activity.¹⁰²

These success stories demonstrate the potential benefits that could result from wide-scale prevention of disability in children. But it is not enough to address *this* chemical or *that* risk factor when thousands more have not been tested and new ones are introduced every day. Many of the best-known environmental risk factors have been decreasing in recent decades, yet the prevalence of childhood disability is rising. If the established pollutants are not responsible for the increase in disability, those other exposures that are responsible must be identified. If we want to make meaningful progress in preventing disability and promoting health, we must be willing to make fundamental changes to our environment. We must ask ourselves: What

kind of world do we want to live in? What would a healthy city or community really look like?

Many interventions aimed at mothers with small children have been shown to be effective in giving children a healthy base for development. Breast feeding is known to lower risks of such wide-ranging conditions as asthma, obesity, and diabetes, and it is associated with greater mental development in preterm infants.¹⁰³ Increasing rates of breast feeding will require not only educational campaigns but the removal of structural and institutional barriers for breast-feeding mothers; new federal legislation requiring employers to provide space and break time for mothers provides some support in states without previous legislation, although barriers to acceptance still remain.¹⁰⁴

Another intervention that has gained support is the practice of nurses' visits to low-income first-time mothers in their home to promote care of healthy infants and injury prevention. Evidence for the effectiveness of this intervention is mixed, but randomized trials have shown that one program, the Nurse Family Partnership, which has been tested around the country and now operates in thirty-two states, reduces maltreatment and behavioral problems and increases cognitive performance in children.¹⁰⁵ These successes provide ideas for changes that would work at a larger level, but investments in these interventions must be long term to be effective; it takes years for the benefits to accrue. Such programs are thus often deemphasized in favor of medical treatments that produce more immediate results for the individual but few long-lasting benefits for society.

By their physical design, cities and towns can lend themselves either to a healthy population

or to one with high levels of disability and disease. One aspect of cities that has received much attention is the built environment. As noted, the built environment is linked with obesity, but just as environments can be "obesogenic," they can also promote physical activity and healthful eating. By designing cities with efficient public transportation, greater urban density, mixed land use, and easy access to fresh produce, more healthful choices would become easier to make. As with any engineering solution, however, these large-scale changes will require great effort, leadership, expense, and collective will.

Increased public transportation, in particular, would make cities more healthful on several fronts. Fewer cars on the road, particularly if a greater share of them emitted fewer pollutants, would reduce air pollution levels, which would lead to lower rates of asthma and cardiovascular disease and to longer life expectancy.¹⁰⁶ Greater use of public transportation could also lower levels of obesity; one study found that users of public transit in Atlanta were more than twice as likely to meet the recommended levels of physical activity.¹⁰⁷ Another study after the addition of light rail transit in Charlotte, North Carolina, found that transit users lost weight compared with those who did not use it.¹⁰⁸

Environments are social, as well as physical. It is virtually impossible to shield a child from the marketing that surrounds her at every stage of her life, and research is making it increasingly clear that the repetitive exposures leave a mark. One way to improve children's health would be to restrict certain types of advertising. Tobacco ads are already banned from television, but depictions of smoking in movies still influence children's decisions about whether (or when) to begin smoking. Similar arguments can be made for alcohol

and fast food: one study estimated that a ban on fast-food advertising aimed at children and adolescents would reduce rates of overweight children by 18 percent for children aged three to eleven, and 14 percent for those aged twelve to eighteen.¹⁰⁹ Increasing children's media literacy might also give children some "resistance" against marketing and a healthy suspicion of advertisers' claims. While such media savvy may help counter the most harmful effects of the consumer culture, the only widely effective solution is likely to be regulation of marketing to children. The British government has banned junk food advertisements in programs aimed at children under sixteen; it remains to be seen whether other countries will follow with similar regulations.¹¹⁰

Finally, virtually every health measure available is connected with socioeconomic status. Efforts to reduce poverty will require a high level of coordination and political determination and may require realigning a nation's collective priorities. Some programs, such as instituting a living wage, have sought to address specific aspects of poverty. Limited evidence is available about the feasibility and effectiveness of a living wage, but few would argue that a family's basic needs, such as housing, food, clothing, and health care, should go unmet.

What would a healthy community look like? In many ways, Vancouver, on the west coast of Canada's British Columbia, fits this description. The city has low levels of air pollution and relatively low rates of smoking (15.1 percent of people over age fifteen, lower than the rest of Canada or the United States).¹¹¹ The city is built to encourage walking, bicycling, and use of public transit; the number of major highways that cut through the heart of the city is minimal. And its

inhabitants seem to live longer, healthier lives. In 2005–09, Vancouver's life expectancy at birth was 82.6 years, which—if it were a country—would rank second only to Japan.¹¹² In addition, Vancouver has begun an initiative to become the world's greenest city by 2020, an effort that includes sustainable industries, low levels of air pollution, and a citywide goal of walking, cycling, or using public transportation for at least half of all trips taken.¹¹³ This vision is in stark contrast with cities of the past that aspired to attract industry, only to end up with high levels of air pollution and widespread sprawl centered around cars and highways. One might imagine policies influencing other aspects of life that affect children's health: low-density billboards and restrictions on marketing unhealthy products would create a more healthful media environment. Cities could institute a living wage for workers, following the example of more than 100 U.S. cities, or commit to providing health care for its uninsured residents, as San Francisco has done.¹¹⁴

A nation that committed itself could take actions that would prevent childhood disabilities by greatly reducing exposures to environmental hazards, at a great savings in human capital and health care costs. A strategy for the prevention of disability must prioritize and target prevalent environmental exposures across populations, rather than continue to focus primarily on the treatment of high-risk or susceptible children. Preventing disabilities will require us to change the way we live—how we build our communities, travel, regulate pollutants, and invest our resources. We now have the evidence and tools to profoundly improve the health and functioning of children, but implementing a preventive strategy will take a concerted effort involving parents, pediatricians, public health officials, policy makers, and society at large.

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