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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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VOL. 22 / NO. 1 / SPRING 2012 13

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)

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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

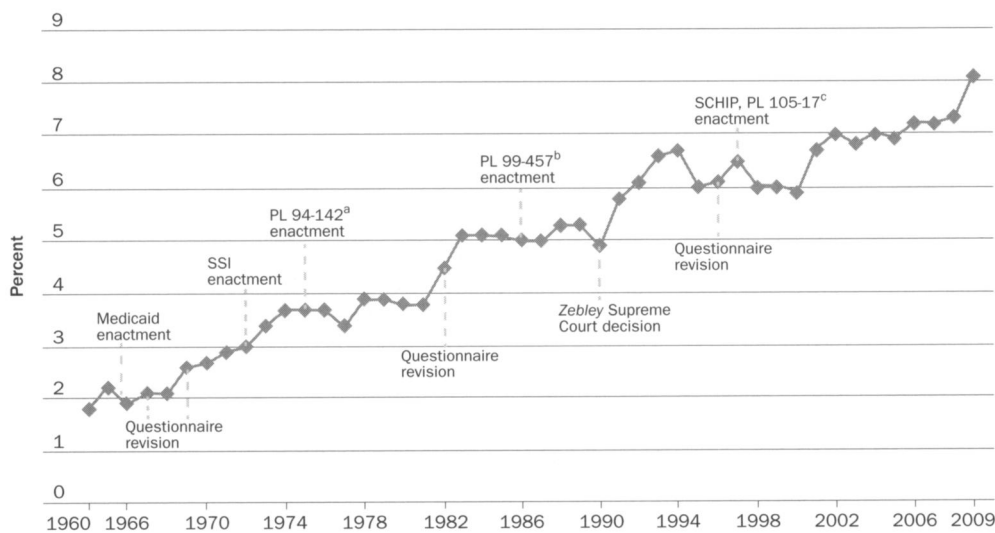
As indicated earlier, the leading conditions associated with activity limitations in 2008–09 were largely developmental, emotional, and behavioral in nature. Comparison with earlier time periods is made difficult by changes in the way condition data are collected and coded in the NHIS. Before 1996 respondents 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. Nonparalyticorthopedic impairment	6. Nonparalyticorthopedic 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 neurodevelopmental 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

The country appears to have made no progress in reducing socioeconomic disparities in disability over the past half century.

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.

Endnotes

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

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