

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

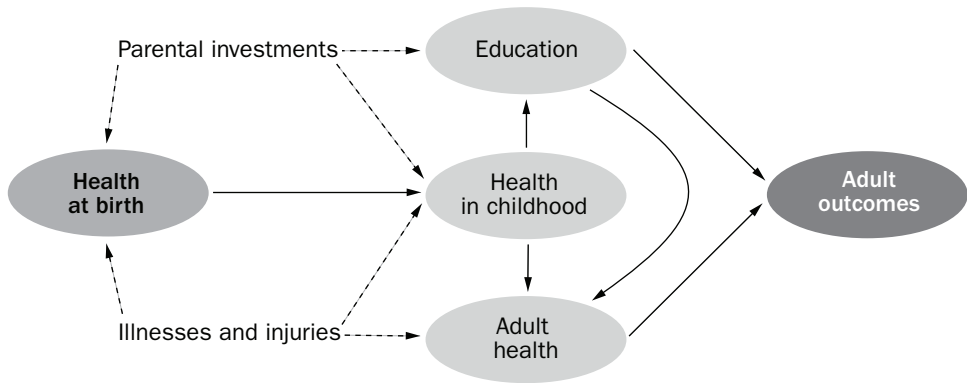
only at the most recent contributions.² We also discuss the benefits of various empirical approaches and remaining empirical challenges.

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.

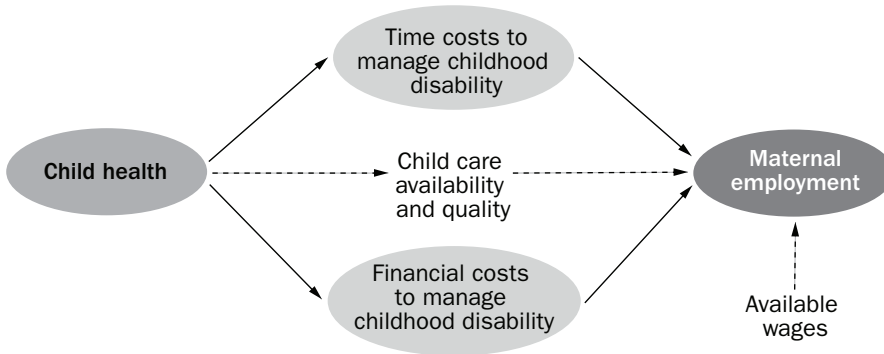
James Heckman describes the notion of “dynamic complementarity” in the case of human capital accumulation as arising when “stocks of capabilities acquired in the previous period make investment in the [current] period more productive. Such complementarity explains why returns to educational investments 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

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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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10. Gary Becker and H. Gregg Lewis, "On the Interaction between the Quantity and Quality of Children," *Journal of Political Economy* 81 (1973): S279–88.
11. Nancy Reichman, Hope Corman, and Kelly Noonan, "Effects of Child Health on Parents' Relationship Status," *Demography* 41, no. 3 (2004): 569–84.
12. Neal Halfon and others, "The Changing Landscape of Disability in Childhood," *Future of Children* vol. 22, no. 1 (2012).
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,

- “Financial Burden in Families of Children with Special Health Care Needs: Variability among States,” *Pediatrics* 122 (2008): 13–18.
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.
 16. Anderson and others, “The Personal Costs of Caring for a Child with a Disability” (see note 2).
 17. Barbara Dobson and Sue Middleton, *Paying to Care: The Cost of Childhood Disability* (York, U.K.: YPS Joseph Rowntree Foundation, 1998).
 18. Philip Jacobs and Suzanne McDermott, “Family Caregiver Costs of Chronically Ill and Handicapped Children: Method and Literature Review,” *Public Health Reports* 104 (1989): 158–63.
 19. Shattuck and Parish, “Financial Burden in Families of Children with Special Health Care Needs” (see note 13).
 20. Lisa C. Lindley and Barbara A. Mark, “Children with Special Health Care Needs: Impact of Health Care Expenditures on Family Financial Burden,” *Journal of Child and Family Studies* 19 (2010): 79–89. The authors report health expenditures in six categories, so this estimate is calculated by combining the midpoint of each range with the proportion reporting an amount in that range.
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