

# Health Insurance and Children with Disabilities

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## Summary

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

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

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

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

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

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

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

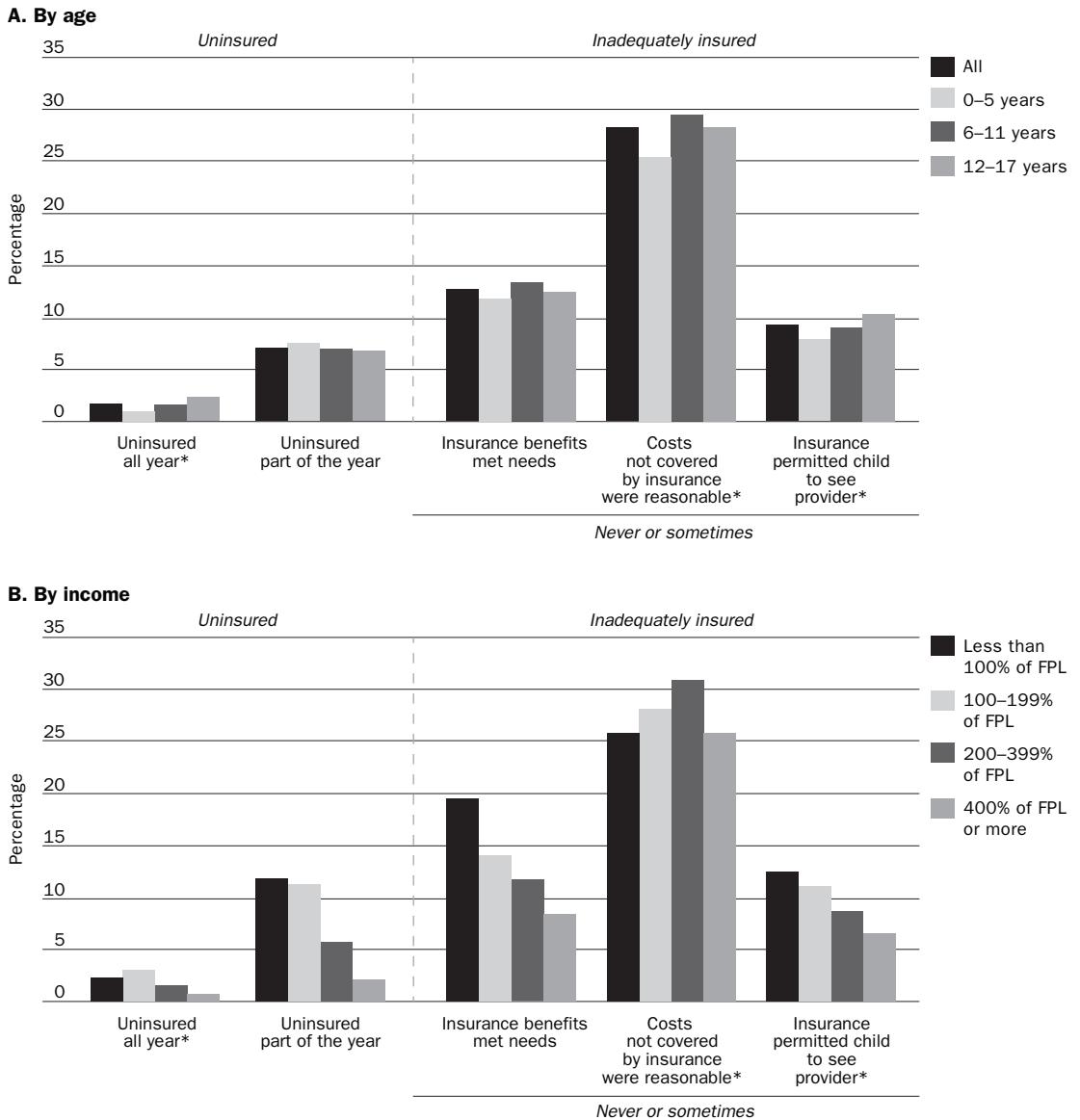
## **Current Patterns and Recent Trends in Health Insurance**

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

### **Adequacy of Health Insurance Coverage**

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

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



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

FPL = federal poverty level.

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

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

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

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

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

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

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

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

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

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

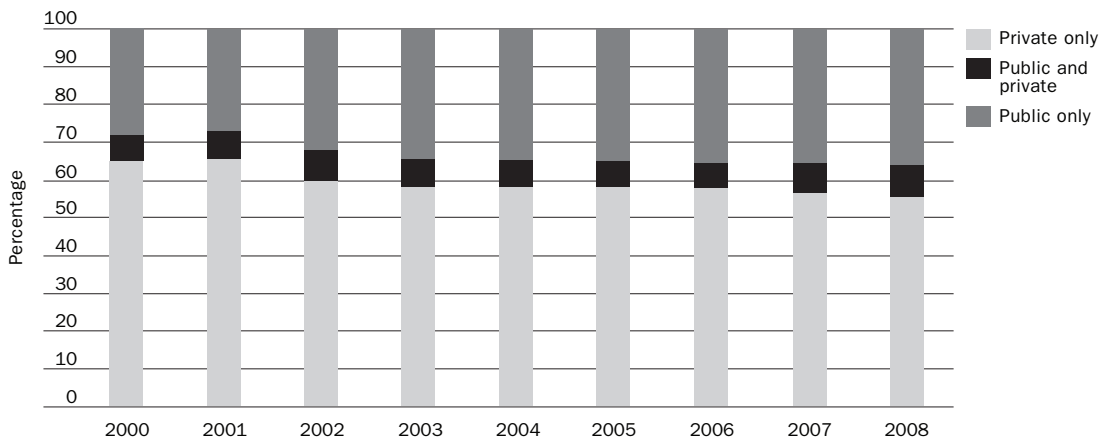
### Recent Trends in Types of Coverage

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

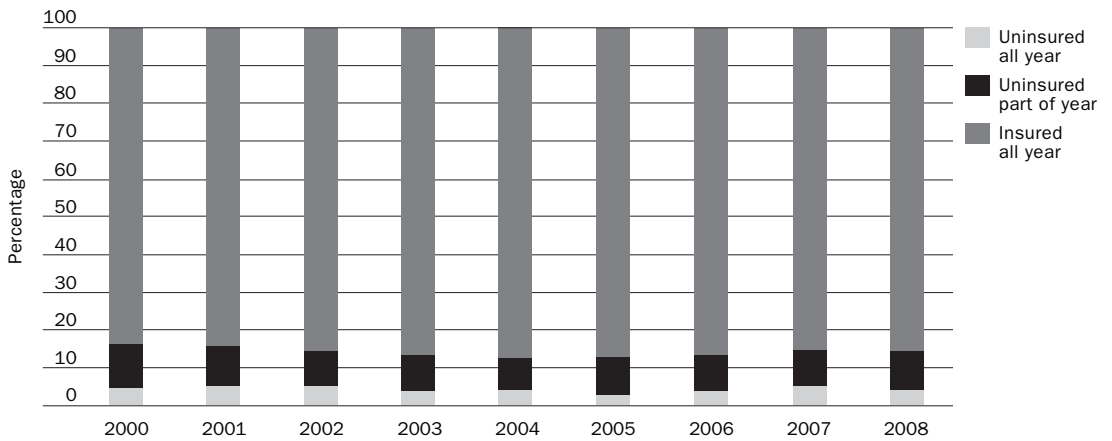
The result has been an overall decline in uninsured rates among children in general and a slight decline among children with disabilities. The Medical Expenditure Panel Survey for each year since 2000, the first year

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

**A. Type of coverage among those covered**



**B. Levels of insurance coverage throughout the year**



Source: 2000–08 Medical Expenditure Panel Survey.

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

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

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

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

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

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

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

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

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

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

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

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

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## Coverage for Specific Services

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

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

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

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

### Special Public Programs for Children with Disabilities

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

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

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

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

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

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

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

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

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

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

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

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

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

### Health Care Reform 2010 and State Programs

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



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

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

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

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

### **Impact of Health Insurance on Children with Disabilities**

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

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

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

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

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

## Health Insurance and Access to Appropriate Health Services

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

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

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

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

### Health Insurance and Use of Care

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

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

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

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

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

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

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

### Health Insurance and Quality of Care among Children with Disabilities

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

### **Insurance and Health Outcomes**

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

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

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

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

### **Impact of Various Types of Insurance**

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

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

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

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

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

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

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

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

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

### **The Future: Improving Health Insurance for Children with Disabilities**

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

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

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

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

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

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

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



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

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

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

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

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

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

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

important step to track this population and monitor care.

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

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

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

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

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

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

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

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

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