State Health Care Financing Strategies for Children with Intellectual and Developmental Disabilities

Sara S. Bachman, Margaret Comeau, Carol Tobias, Deborah Allen, Susan Epstein, Kathryn Jantz, and Lynda Honberg

Abstract
We provide the first descriptive summary of selected programs developed to help expand the scope of coverage, mitigate family financial hardship, and provide health and support services that children with intellectual and developmental disabilities need to maximize their functional status and quality of life. State financing initiatives were identified through interviews with family advocacy, Title V, and Medicaid organizational representatives. Results showed that states use myriad strategies to pay for care and maximize supports, including benefits counseling, consumer- and family-directed care, flexible funding, mandated benefits, Medicaid buy-in programs, and Tax Equity and Fiscal Responsibility Act of 1982 funding. Although health reform may reduce variation among states, its impact on families of children with intellectual and developmental disabilities is not yet clear. As health reform is implemented, state strategies to ameliorate financial hardship among families of children with intellectual and developmental disabilities show promise for immediate use. However, further analysis and evaluation are required to understand their impact on family and child well-being.

Key Words: health care financing policy; children with intellectual and developmental disabilities; family financial hardship

Over the past 2 decades, increasing numbers of children with intellectual and developmental disabilities (IDD) have gained health care insurance coverage (Braddock, Hemp, & Rizzolo, 2008). Although about half of families of children with IDD are covered by private employer-sponsored health care coverage (Child and Adolescent Health Measurement Initiative, 2005–2006), families may also receive benefits from multiple public programs to supplement the breadth and depth of coverage. Each of these programs has its own specific eligibility criteria linked to financial status, diagnosis, or functional level. In fact, increased coverage from public programs has been a major factor in the health insurance coverage gains among children with IDD (Honberg, Kogan, Allen, Strickland, & Newacheck, 2009).

Some of the key state public programs that are available to cover services for children with IDD include the Title V Children with Special Health Care Needs (CSHCN) program, Medicaid, or the state-based Children’s Health Insurance Program (CHIP) and sometimes other state or county agencies. Although children and young adults with IDD who are in transition may also be eligible for Medicare benefits, most public coverage is through state-sponsored programs; hence, state programs are our focus in this article.

The Title V program was first authorized under the Social Security Act of 1935 and is funded to support state efforts to extend and improve health and welfare services for mothers and children. Federal Title V funds support maternal and child health and CSHCN programs in each state. These programs may provide direct care but generally focus on provision of wrap-around and population-based services (e.g., immunization) and on ensuring capacity for maternal and child health care. Title V is administered nationally by the Maternal and Child Health Bureau, which defines CSHCN 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” (U.S. Department of Health and Human Services, 2011). Children with IDD are a subpopulation of CSHCN and therefore a group that Title V is mandated to serve. Although the methods states use to provide services to CSHCN and their families vary, all state Title V programs are expected to facilitate the development of comprehensive, family-centered, community-based, culturally competent, coordinated systems of care for CSHCN (U.S. Department of Health and Human Services, 2011).

A second program that funds services for children with IDD is the Medicaid program. The Medicaid program is a joint state and federal program that is administered within each state according to federal guidelines and is available to children and families that meet financial or functional status criteria. According to the National Survey of Children with Special Health Care Needs (NS-CSHCN), approximately 30% of children with IDD younger than age 17 are enrolled in the Supplemental Security Income program, which in most states confers automatic eligibility for Medicaid coverage. The federal government sets the floor for income and benefit limits, although states can expand on these minimum criteria. States also have the flexibility to ask for waivers of federal regulations and use these waivers to develop home- and community-based programs or test new financing strategies. Thus, although states must meet the federal floor for benefits and eligibility, states vary considerably in the population of children with IDD that may enroll in Medicaid and the services they are eligible to receive once they are enrolled. For example, children ages 6–19 in Kansas must meet family income eligibility criteria equal to 100% of the federal poverty level, whereas children in the same age category who live in Minnesota are eligible if their family income is 275% of the federal poverty level (Kaiser Family Foundation, 2011).

The state and federal governments also jointly sponsor CHIP, a program that also has considerable cross-state variability. For example, the CHIP program may or may not be closely affiliated with the Medicaid program in any given state, depending on how it is implemented in that state. A child who is covered by a separate CHIP program does not have access to the Early, Periodic Screening, Diagnosis, and Treatment Program, a provision that requires coverage of medically necessary services for Medicaid-enrolled children and youths younger than age 21. Because the Early, Periodic Screening, Diagnosis, and Treatment Program is designed to ensure preventive treatment and to promote early diagnosis and treatment of identified health needs, it is particularly important to CSHCN. Thus, in some states with separate CHIP programs the benefits are not as robust as those in Medicaid and so do not provide coverage that is as comprehensive (Marcus, Rosenbaum, & Cyprien, 2004). In addition, although CHIP income eligibility guidelines may be higher than those for the Medicaid program and so may expand insurance coverage, families must be uninsured to enroll in CHIP. As a result, families may not enroll in CHIP to gain access to wrap-around services that may promote more robust coverage for children with IDD.

Children with IDD may also be eligible for services provided by other state agencies such as departments of mental retardation, intellectual or developmental disabilities, mental health, or others. Each of these departments is likely to have specific eligibility criteria and benefit options. For children who meet agency eligibility criteria, the benefits provided are another valuable source of support. However, little coordination is likely to be found among these service systems, and families may need to navigate a complex web of eligibility requirements, benefit options, and potentially conflicting policies and programs.

Regrettably, the gains in insurance enrollment and coverage from public programs such as those we have described do not always translate into adequate coverage for children with special health care needs, including children with IDD (Kogan et al., 2010). Although intended to assist families by mitigating the financial hardship associated with raising a child with IDD (Lukemeyer, Meyers, & Smeeding, 2000), state-sponsored programs do not necessarily lift families out of financial distress. In particular, eligibility guidelines for these programs limit the income adults in the families can earn and retain benefits (Meyers, Lukemeyer, & Smeeding, 1998). Thus, some families make a rational choice to forgo work or enhanced employment opportunities to keep earnings low enough so that their children can receive essential Medicaid benefits (Meyers et al., 1998). According to the NS-CSHCN, 54.5% of U.S. families of children with IDD have reported cutting back on or stopping
work, and 34.6% of all families of children with IDD have reported having financial problems as a result of their child’s condition (Child and Adolescent Health Measurement Initiative, 2005–2006).

In addition to public program limitations with respect to income eligibility, families who do become eligible for public programs such as Medicaid may not have access to the full range of program benefits. For example, Medicaid programs can offer home- and community-based services waiver programs, which may include children with IDD in the target population. However, these programs often have a limited number of slots and so are not available to all eligible children. States develop waiting lists for waiver slots, and some states have waiting lists that extend to thousands of names, suggesting that a child with IDD in such a state will never have access to these services (Kaiser Family Foundation, 2011). Moreover, public program benefits are not typically offered in a systematic, coordinated way, and so families may be caught between differing program guidelines, rules, and benefits.

With the passage of the federal Patient Protection and Affordable Care Act of 2010, some private insurance industry practices that negatively affect children with IDD and their families are now banned, including denial or rescission of coverage for children with preexisting conditions or lifetime benefit caps. Health reform also extends coverage in ways that are especially meaningful for families of children with IDD, such as the provision that children can remain covered by a parent’s policy until age 26. However, many of the aspects of the health care reform law that hold promise for alleviating financial hardship among families raising children with IDD (particularly in the area of underinsurance) will not be operationalized for some time, and the protections that are offered will be built on the existing foundation of employersponsored private health insurance. As a result, many children with IDD will continue to receive health care coverage through a parent’s or guardian’s employer-based policy. Existing underinsurance problems resulting from limitations in the amount or scope of private benefits will continue to disproportionately affect children with IDD because most of this group have greater health care needs.

For example, much has been made of the “essential benefits” required under Section 1302 of the Affordable Care Act, which requires provision of many services that are currently optional for private insurance policies. However, the essential benefits will apply only to coverage issued through new individual and small group plans, as well as the state-based exchanges; large group plans, under which most privately insured children with IDD are covered, are exempt. As attention is focused on implementing health care reform, there may be additional pressure to limit the scope of benefits to make universal coverage more affordable for the general U.S. population. It will thus be even more imperative to focus efforts on addressing the gaps in coverage for the nearly 40% of families of children with IDD who are underinsured (Child and Adolescent Health Measurement Initiative, 2005–2006).

Although much of health reform will occur as a federal initiative, many provisions are optional, and thus systems of care for CSHCN, including children with IDD, will continue to be implemented at the state level. Even before health reform, states had begun the process of developing strategies for addressing financial hardship of families caring for a child with special needs. In this article, we provide the first descriptive summary of a range of programs that have been developed to help expand the scope of coverage, mitigate family financial hardship, and provide health and support services that children with IDD need to maximize their functional status and quality of life.

**Method**

Data for this descriptive study were gathered through structured interviews with or written surveys of agency representatives of the Title V CSHCN and Medicaid programs in the states and with representatives of Family Voices, a family information and advocacy organization with chapters in each state. The mission of Family Voices is to achieve family-centered care for all children and youths with special health care needs or disabilities, including those with IDD (see http://www.familyvoices.org/about?id=0003). All 50 states, the District of Columbia, and Puerto Rico were included in the original sample. Data were initially gathered in 2007–2008 with a second round of structured interviews and surveys conducted in 2010–2011. To recruit respondents, a letter was sent to the director of each of the three agencies or programs in every state, Puerto Rico,
and the District of Columbia. The letter was followed up by a telephone call and e-mail correspondence. In the 2010–2011 survey, 48 states were represented in the responses, including 47 Title V directors or their designees (90% response rate), 35 Medicaid directors or their designees (67% response rate), and 22 Family Voices representatives (42% response rate).

The structured data-gathering instrument focused on strategies targeting the general population of CSHCN as defined by the Maternal and Child Health Bureau, which includes children with IDD. Specific, open-ended questions were aimed at identifying strategies states use to finance health and support services for the target population. Examples of the strategies that were discussed include home- and community-based waivers, Medicaid buy-in programs, care coordination, and medical homes. State representatives were also asked to describe other strategies being implemented in their state that they considered effective.

From the responses we gathered, and working in consultation with parent leaders, including the director of the federally funded center on financing care for CSHCN, we identified strategies that had the potential to promote comprehensive coverage and mitigate family financial hardship. The initiatives highlighted here describe programs that either target CSHCN, including children with IDD, or target a larger population of CSHCN but have specific applications for children with IDD. The programs that are highlighted are presented as selected options, not as an exhaustive list of current state practices.

Results
The respondents identified a range of policy and program solutions already in use at the state level. Here we discuss seven selected practices that are relevant for children with IDD and their families, including benefits counseling, financing of care coordination, consumer- and family-directed care, flexible funding, mandated benefits, Medicaid buy-in programs, specialized medical day care and respite and day camps, and use of the Tax Equity and Fiscal Responsibility Act of 1982 (TEFRA) Medicaid eligibility option for children. Although our discussion offers ideas for how these strategies might be useful, we do not attempt to evaluate the outcomes of their implementation, especially from the perspective of the enrolled families, nor do we offer data from families apart from those who represent the family advocacy organization in their state.

Benefits Counseling
Providing benefits counseling to families is one strategy that Title V programs, advocacy organizations, and health plans, among others, use to address underinsurance, maximize benefits, and reduce financial hardship. In benefits counseling programs, a health care coverage expert works closely with a family to help them navigate the complex world of health insurance, often providing direct advocacy for families in negotiating benefits with the state Medicaid program or with private insurance plans. Benefits counseling programs assist families in identifying and enrolling in the programs that will offer benefits that most effectively meet their child’s needs. For example, the Illinois Title V program has hired former staff of health insurance companies who travel to regional public health offices and work with care coordinators, showing them how to help people maximize their private benefits and advocate with Medicaid to pay for needed services. In Vermont, Title V staff work directly with privately insured families to advocate for coverage of services that are prescribed by a physician or referrals to out-of-network providers that were initially rejected by the insurer.

Making the Case for Coverage (Epstein, Glauber, Tellis, & Turnbull, 2007), a publication developed by a health care policy organization in Massachusetts, has described health plan decision-making processes and identified strategies for providers in addressing medical necessity. This document is used by families and health care providers to document the need for services that might be denied by a private health plan, to maximize coverage for medically necessary services.

Care Coordination
Care coordination is a critically needed service for children with IDD because they often have complex health care conditions that require services from multiple providers and specialty types (Council on Children with Disabilities, 2005). According to the NS-CSHCN, 43.2% of children...
with IDD have four or more coexisting health conditions. In addition to their general parenting and direct caregiving responsibilities, families must often take on the task of linking the various services and supports their child needs. This process can be exceedingly difficult because of the complexity of provider and payment systems. Through care coordination, families receive professional assistance and supports in navigating this complex web. Thus, the family not only receives needed supports but the effective and efficient use of resources is also promoted while ensuring access to care and services for children. Supported by most Title V CSHCN programs, these services can play a significant role in helping families gain adequate coverage by helping them to connect to supportive services or benefits. However, access to care coordination through Title V (as well as through other state agencies) is often limited by the availability of federal or state funds. Several states have expanded the availability of care coordination for CSHCN by combining state Title V and Medicaid funding or by blending Title V and private insurance funding.

For example, Arizona blends funding from the Title V program and the Governor’s Council on Traumatic Brain Injury and Spinal Cord Injury, using statewide vendors to provide care coordination to these specific populations. Michigan, Utah, New Mexico, and West Virginia use state funds for CSHCN to provide the state match to draw down federal Medicaid funds for care coordination for Medicaid-eligible CSHCN, which allows these states to provide care coordination services for many more children than Title V funding alone would permit. New Hampshire’s Partners in Chronic Care program works with the Title V program, Family Voices, and private payers such as Anthem Blue Cross Blue Shield to promote a team approach that includes care coordination and family support.

**Consumer- and Family-directed Care**

Some state Medicaid programs have introduced consumer- or family-directed care, providing families with broader latitude for choice and control of the services they receive and how they are delivered. These programs tend to support community-based long-term care. Consumer-directed care models, also called family-directed care models, allow an individual with disabilities or his or her family to decide how limited funds, services, or other resources are used and to hire or direct personal care staff. Thus, families have the flexibility to design and implement service plans that meet their specific needs rather than enroll in programs that offer a service that, although useful, may not best address the particular gaps that a family is experiencing.

A few states have implemented programs that allow families wide-ranging choice in the selection and direction of long-term support services for their child using a variety of mechanisms available to state programs. Florida operates a consumer-directed long-term care waiver that includes children with IDD who are eligible for the Medicaid waiver. Massachusetts covers consumer-directed personal assistance as a Medicaid state plan service and makes these services available for children with disabilities. Virginia uses a home- and community-based services waiver to cover consumer-directed personal assistance services to adults and children with disabilities. Ohio’s Department of Education created an Autism Scholarship program that allows parents to put together their own education program using state funds to purchase educational and health-related services from private providers.

**Flexible Funding: Trust and Relief Funds**

Although many state Title V programs function as the payer of last resort for children who meet their clinical and income eligibility guidelines, the funding for these services is limited by the size of the state’s Title V funding allocation or the state budget. Several states provide flexible funding through trust or relief funds, sometimes called catastrophic relief funds, that expand the availability of this last-resort coverage. Parents can use this flexible funding to pay for services not typically covered by health insurance, such as home or vehicle modifications, or the cost of accompanying a child to a tertiary care center. When established at the state level, catastrophic relief funds are usually administered by independent commissions or Title V programs and receive funding through a variety of public and private sources such as a state assessment on hospitalizations, a bequest, or private donations (Catalyst Center, 2007). The term catastrophic refers not to the condition for which the expense is incurred but rather to the impact on a family’s finances. State-operated relief funds include Colorado’s Traumatic Brain Injury Trust Fund, Georgia’s Brain and Spinal Injury Trust
Fund, Kansas Relief Fund, Michigan’s Special Needs Fund, and New Jersey’s and Massachusetts’ Catastrophic Illness in Children Relief Funds.

Mandated Benefits for Specialized Services

Mandated benefits are one way to promote more robust private coverage; they require health insurance carriers to cover selected benefits and specifically counteract variation in private health insurance benefits packages. Moreover, mandated benefits may be an effective strategy to address trends in the declining depth of health care benefits. State legislatures across the country have passed mandated benefit laws, ensuring that people who are covered by private insurance have access to selected benefits. Often, these benefits are preventive services such as screenings, which have the potential to reduce costs for the system as a whole by identifying children with conditions before they become severe and possibly more costly to treat. In some cases, mandated benefits are designed to meet the needs of particular populations at high risk, including children with IDD. These benefits may be needed by small numbers of children who would be at extreme risk if services or treatment were not provided, such as children with phenylketonuria who require special diets to prevent intellectual disability or death, or for services that affect larger populations. Examples of benefits deemed essential for public health by some states include mandated coverage for early intervention and developmental services for children from birth to age 3 (Massachusetts, Rhode Island, Connecticut, New Hampshire, Virginia, Missouri, New Mexico, New York, Indiana) and the use of telemedicine (Hawaii). The mandates ensure that children with private coverage have access to these critical services.

In recent years, the trend has been toward mandated benefits or insurance reform targeting autism (Autism Speaks, 2011; Boudet, Spielman, & Mandell, 2009). As with many other children with IDD, health care expenditures for children with autism are greater than those for typically developing children (Croen, Najjar, Ray, Lotspeich, & Bernal, 2006). However, the increased rate of diagnosis of children with autism and the higher costs associated with their specialized care has brought this population to the attention of state policymakers. In 26 states, such as Pennsylvania and Maryland, for example, private insurance companies are required to cover autism services, including applied behavioral analysis (Autism Speaks, 2011).

Mandated benefits typically apply to private or employer-sponsored health care coverage. An important exemption from state benefit mandates applies to companies that self-insure. Instead of purchasing health insurance coverage for their employees, self-insured companies pay for employees’ health care costs directly, often using a health plan to administer the benefits. Self-insured employers are exempt from all state mandates under the provisions of the federal Employee Retirement Income Security Act of 1974 (Jensen & Morrisey, 1999).

Medicaid Buy-In Programs

Medicaid has been shown to provide significant financial support to families raising a child with a disability (Lukemeyer et al., 2000). Traditional Medicaid, however, places limits on family income for people to be eligible for benefits. Medicaid buy-in programs promote a blend of public Medicaid and private employer-sponsored coverage and allow families of children who are over the maximum income for Medicaid to purchase Medicaid benefits, even if they have private insurance coverage. In most cases, the child must meet disability-related eligibility criteria. Several states have implemented Medicaid buy-in programs for low-income children or children with disabilities. With the passage of the Family Opportunity Act of 2005, these buy-in programs may serve as models for other states that want to expand coverage or benefits for children with IDD.

Medicaid buy-in programs are particularly important for underinsured children because they allow families to purchase Medicaid benefits specifically to cover services that are either not covered at all or are covered inadequately by employer-sponsored insurance plans. In addition to promoting more comprehensive health care coverage, Medicaid buy-in programs allow parents to continue to work and to maintain both earnings up to a limit and employer-sponsored private coverage. Illinois, Iowa, Louisiana, Massachusetts, North Dakota, Pennsylvania, Texas, and Vermont have all passed legislation or implemented programs that allow families to purchase Medicaid benefits for their children, either as full coverage if the child is uninsured or as supplemental coverage if the child
has private insurance. Most apply a premium based on a sliding scale, some limit the buy-in option on the basis of disability criteria, and others use income criteria to limit eligibility. Note that although some states allow families to buy in to CHIP if a child is uninsured, families must be uninsured to enroll in CHIP and thus cannot buy in to CHIP to supplement existing private coverage.

Specialized Medical Day Care and Respite and Day Camps
Providing specialized medical day care, respite care, or access to summer programs can allow families to maintain or return to employment knowing their children are receiving needed services during parent work hours. Several states, including Georgia, Maryland, South Carolina, and Rhode Island, use Medicaid funds to pay for health care services that assist children with IDD to participate in day care, after-school programs, or summer camps. For example, California’s Pediatric Day Health Care Facilities, developed under Medicaid’s Early, Periodic Screening, Diagnosis, and Treatment Program authority, provide individualized, family-centered services to children who are younger than age 21 and who have a medically complex condition that requires skilled nursing and therapeutic intervention for part of the day (less than 24 hours).

TEFRA Medicaid Eligibility Option for Children
The TEFRA Medicaid state plan option was introduced through federal legislation and was modeled after an existing home- and community-based waiver called the Katie Beckett Waiver. Through these programs, children younger than age 19 who meet hospital or institutional level-of-care needs owing to the complexity of their condition are eligible to receive comprehensive community-based services at home. Thus, through the TEFRA option, children with complex disabilities can remain at home instead of being admitted to an institution even if family income exceeds state Medicaid eligibility limits. The goal of this option is to promote family-centered care at home as well as promote cost savings and efficiencies through avoided hospitalizations or institutional placements. As of 2011, 19 states had adopted the TEFRA state plan option (Catalyst Center, 2012).

Conclusion
Data from the NS-CSHCN have indicated that current efforts to finance health care for children with IDD do not provide enough coverage to meet their needs. Of children with IDD, 10% did not have health insurance coverage at some point during the year of the survey, and 39.4% of families reported that their insurance was inadequate to meet their needs. More than half of families of a child with IDD reduced or quit work to care for their child (Child and Adolescent Health Measurement Initiative, 2005–2006). These findings suggest that families continue to experience significant challenges in accessing the range of benefits and health care coverage that their child needs. Because nearly one-fifth of all U.S. children experience a developmental delay, the financial hardship of parenting a child with IDD is significant and widespread (Centers for Disease Control and Prevention, 2000).

For some families, the impact of inadequate health care coverage is experienced economically: They must make hard choices about how to spend limited salaries and then make substantial sacrifices in family budgets to ensure they can access the services their children need. For other families, however, the resources to pay for health care are simply not there: Children and youths who are uninsured or whose insurance does not pay for critical components of care may experience adverse outcomes in relation to health, development, and capacity to function because their families just cannot afford to pay for care.

With federal health care reform a reality, there is promise that the most devastating financial consequences for families of children with IDD may be addressed through the consumer protection, universal coverage, individual mandate, and expansion of Medicaid eligibility health reform provisions. However, significant legal challenges to the reform law continue. In addition, most children will continue to receive health care coverage through a parent’s or guardian’s employer-based policy. Limitations in the amount or scope of private benefits disproportionately affect children with IDD because they have higher-than-average health care needs. Even with national health care reform, pressure to limit the scope of benefits covered to make coverage universal and affordable may be strong, which means that focusing efforts on addressing the gaps in coverage for the nearly 40%
of children with IDD who are underinsured will be even more imperative (Child and Adolescent Health Measurement Initiative, 2005–2006).

However, many of the policy initiatives that result in improvements to the current system used by children with IDD are also likely to be implemented through existing state systems. Each state has a unique health insurance and delivery marketplace and a specific context for implementing federal policy. Although the individual state-based Medicaid and Title V Children with Special Health Care Needs programs both have their legislative basis in the federal Social Security Act, these programs vary much at the state level in how policies are implemented and programs are designed. CHIP similarly varies across states. State policymakers and other stakeholders influence the structure and operations of these and other federally authorized programs, as well as shape critical state policy on private insurance coverage.

As a result, states have had a great deal of room for discretion, creativity, and experimentation, and families caring for children with IDD experience very different financing and support systems from state to state. The knowledge garnered by individual states through implementation of programs such as those described earlier can be used to help close insurance and health care financing gaps for families caring for children with IDD across the nation. State public health programs and community-based service providers must be challenged to address sources of financial hardship that fall outside the purview of traditional health insurance. These solutions should include adopting flexible financing programs that can assist families with higher routine costs of living and provide supports such as specialized day care that can help families minimize loss of employment income. Although these strategies do not address all the issues families face, such as limited public benefits and fragmented systems of care, they do provide hope for families as the intricacies of health reform are sorted out at the state and federal levels. Further analysis and evaluation are required to provide evidence about the impact of these state initiatives on family and child well-being. With results from rigorous evaluation, states and families will have access to an evidence base to help guide decision making about which strategies will provide the maximum gains for all stakeholder groups.

References


Received 7/29/10, first decision 12/22/10, accepted 8/3/11.

Editor-in-Charge: Marji Erickson Warfield

Authors:

Sara Bachman (e-mail: sbachman@bu.edu), School of Social Work, Boston University, Boston, MA 02215, USA; Margaret Comeau, Boston University School of Public Health; Carol Tobias, Boston University; Deborah Allen, Boston Public Health Commission; Susan Epstein, New England SERVE; Kathryn Jantz, Boston University School of Public Health; Lynda Honberg, U.S. Department of Health and Human Services.