



AMCHP ISSUE BRIEF

The Affordable Care Act and Children and Youth with Autism Spectrum Disorder and Other Developmental Disabilities

AMCHP'S ROLE

The Association of Maternal & Child Health Programs (AMCHP) supports state maternal and child health (MCH) programs and provides national leadership on issues affecting women and children. We work with partners at the national, state and local levels to expand medical homes; provide and promote family-centered, community-based, coordinated care for children with special health care needs; and facilitate the development of community-based systems of services for children and their families.

The AMCHP State Public Health Autism Resource Center (SPHARC) is a comprehensive resource center for state Title V programs and others interested in improving systems for children, youth, and families with autism spectrum disorders and other developmental disabilities.

INTRODUCTION

Children and youth with autism spectrum disorder and other developmental disabilities (ASD/DD) are a subpopulation of children and youth with special health care needs (CYSHCN). As with all CYSHCN, they require a comprehensive array of medical, behavioral and developmental health services that are often inadequately covered under the current system of health coverage. This leaves children at risk for missed or delayed care and their families with significant financial burdens. The *Patient Protection and Affordable Care Act* (ACA) is designed to increase health coverage, improve benefits, and provide important new insurance protections for all Americans. Many of the law's provisions will impact children, including those with ASD/DD, and will be implemented over time. This report, developed by The Catalyst Center at the Boston University School of Public Health, offers a brief description of selected provisions in the ACA that have implications for CYSHCN with ASD/DD. It also describes how state Title V maternal and child health (MCH) programs can maximize opportunities under the ACA to develop and strengthen systems of care for CYSHCN with ASD/DD.

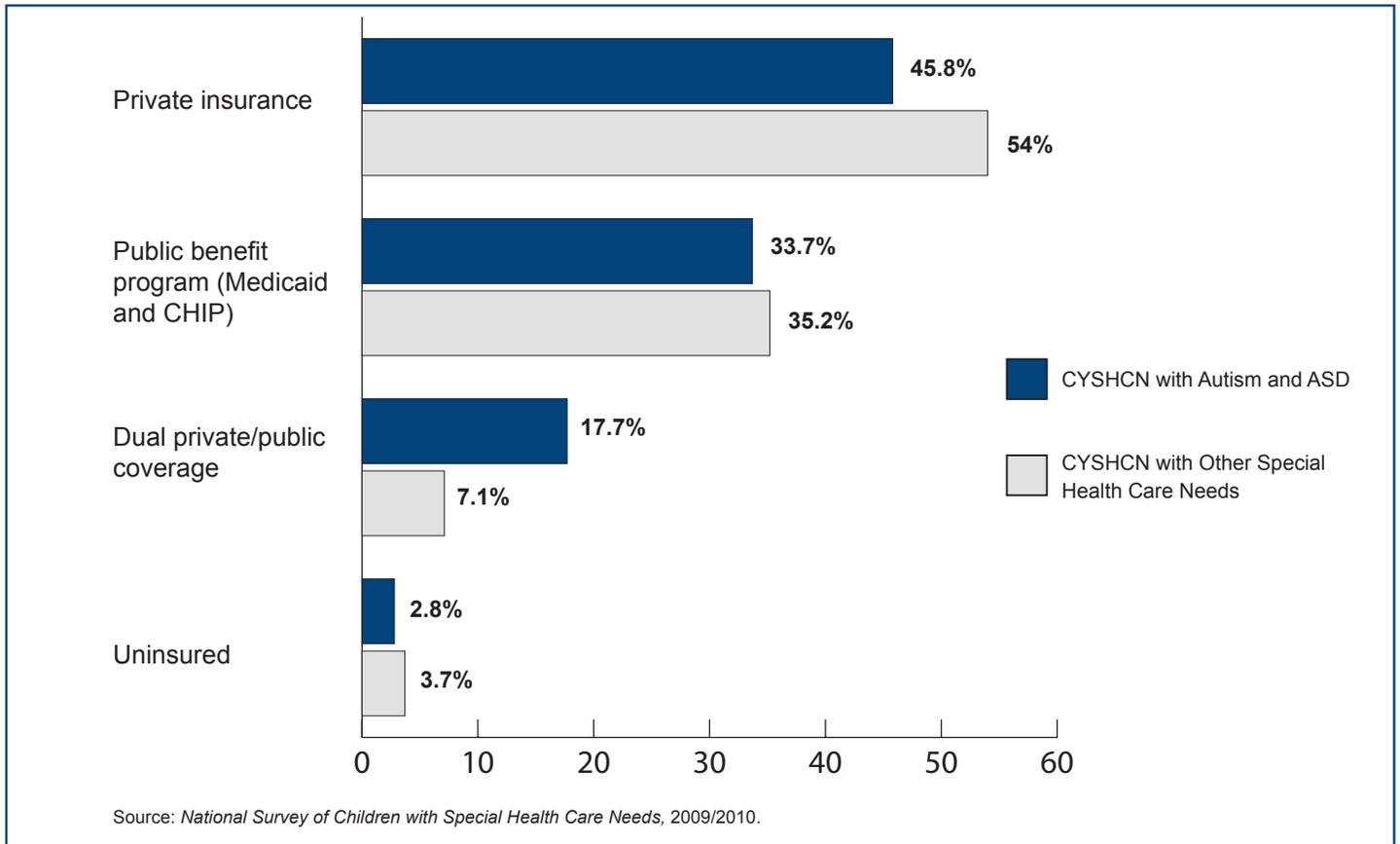
BACKGROUND

All children need health care coverage that is universal and continuous, adequate to meet their needs, and affordable. However, CYSHCN with ASD/DD face more serious gaps in coverage or benefits than other children, even when compared with CYSHCN with other special health care needs.¹

Some of these gaps in coverage can delay the diagnosis of ASD/DD. This can have a negative impact on the effectiveness of treatment. In addition to their developmental and behavioral care needs, CYSHCN with ASD/DD often have other important health concerns. According to the 2009/10 National Survey of Children with Special Health Care Needs (National Survey), over 90% of the approximately 839,275 CYSHCN with ASD/DD living in the United States² have four or more coexisting health conditions.³ As a result, their health care needs extend beyond well child care and treatment for ASD/DD to include a wide range of medical, behavioral and developmental services. When it comes to health insurance coverage for CYSHCN with ASD/DD, three key factors are critical to ensuring the best health outcomes: health care coverage that is universal and continuous, adequate and affordable. Following is a more detailed analysis of these three factors and their impact on children with ASD/DD.



FIGURE 1. Distribution of Insurance Coverage for CYSHCN with ASD/DD Compared with Other CYSHCN



UNIVERSAL AND CONTINUOUS COVERAGE

Children and youth with special health care needs known to have ASD/DD face many gaps in access to universal and continuous health insurance coverage. Nearly half of CYSHCN with ASD/DD are covered by private insurance, 33.7 percent are covered by Medicaid or the state-based Children’s Health Insurance Program (CHIP), and 17.7 percent have dual public and private coverage. A relatively small proportion (2.8 percent) are uninsured (See Figure 1).⁴

While a total of 96.5 percent have health care coverage, it is often not enough to meet their myriad and complex needs. Prior to passage of the ACA, preexisting condition exclusions created a significant barrier to accessible, adequate private health insurance. According to the American Health Insurance Plan’s Center for Policy and Research, in 2008, over 20,000 children were denied individual health insurance policies based on a preexisting condition and over 18,000 additional children had individual policies issued but restrictions were placed on their covered benefits.⁵ From the data, we do not know the specific diagnoses of the children who were impacted. However, given the cost associated with screening, diagnosis and treatment of ASD/DD, it is reasonable to assume that they are well represented in these statistics. In other cases, children who received coverage through their parents’ employers experienced gaps when their parents lost or changed jobs.

ADEQUACY OF COVERAGE

In addition to problems getting and keeping health care coverage, CYSHCN with ASD/DD can experience problems with the health benefits that their plan offers. Approximately half of insured CYSHCN with ASD/DD (49.4 percent) have families who report that their child’s health insurance coverage is inadequate to meet their needs (See Figure 2).

Many insurance plans may either not cover certain essential health services (e.g. speech, language and occupational therapies) or place a cap on and limit important benefits like mental and behavioral health care, rehabilitative and habilitative therapies (e.g. speech, language), and prescription drugs. These limits can result in many families struggling to cover the cost of their child’s necessary medical, behavioral and developmental care and services themselves. In the worst case scenario, a child does not receive the care he or she needs. Forty-three percent of CYSHCN with ASD/DD have families who say their child’s health condition has caused financial problems for the family – almost double the number of other families of CYSHCN who report financial problems (19.6 percent).⁶ Over half had families (57.1 percent) who reported that a family member cut back on or stopped working to care for a child with ASD/DD – again a much higher percentage than among other families of CYSHCN generally (21.6 percent).

AFFORDABILITY OF COVERAGE

Affordability of coverage is a key issue for CYSHCN with ASD/DD. Expensive premiums make coverage elusive for many families. Out-of-pocket costs for care, such as high deductibles and frequent co-pays, often require families to make hard choices between medical care and other necessities such as housing, food and utilities.⁷ High cost sharing (e.g. co-pays, premiums) can mean that some CYSHCN with ASD/DD may have limited or no access to needed health care services and supports.

In summary, gaps in all three domains of coverage (universal/continuous, adequate and affordable) currently cause significant problems for CYSHCN with ASD/DD in obtaining needed health care services and supports. These caps often result in considerable financial hardship for their families. The ACA provides several opportunities to improve and strengthen access to coverage by expanding coverage under Medicaid, preserving the Children’s Health Insurance Program (CHIP), and creating a new mechanism for purchasing health insurance coverage through an “Exchange.” (See page 7 for further explanation.) The ACA also created broad health insurance reforms, which have significant benefit for CYSHCN, including those with ASD/DD. Taken together, these provisions provide significant potential for state efforts to improve the coverage and financing of care for CYSHCN. Figure 3 details the timeline for implementation of ACA provisions. The following section highlights these key provisions and their implications for CYSHCN with ASD/DD.

FIGURE 2. Adequacy of Coverage

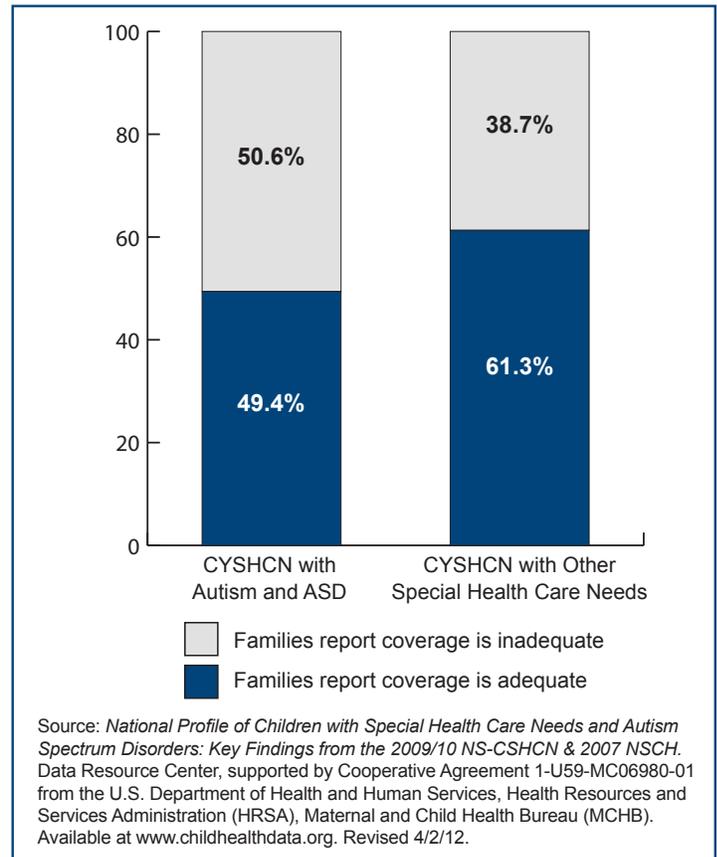
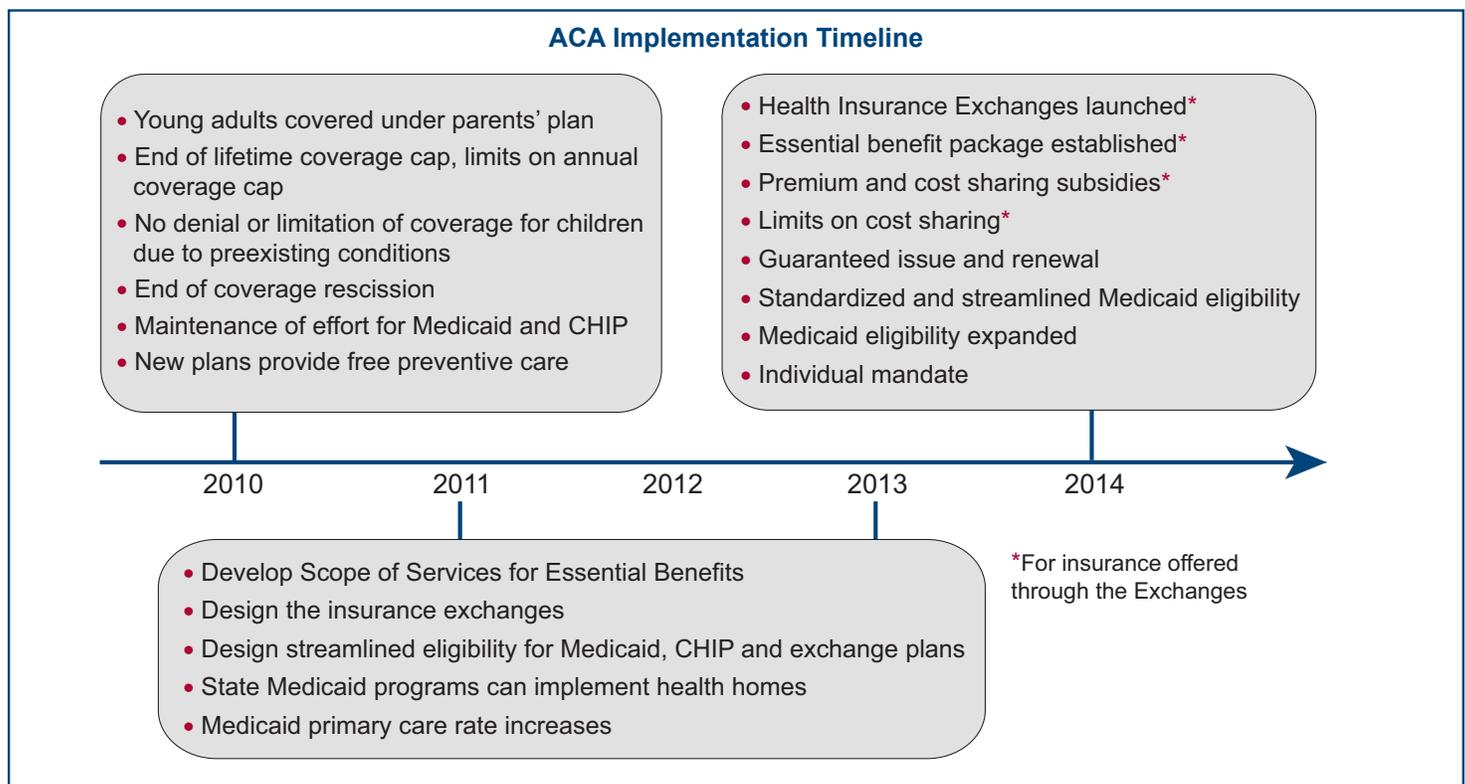


FIGURE 3. Implementation of Key Provisions in the Patient Protection and Affordable Care Act Timeline



KEY PROVISIONS OF THE *PATIENT PROTECTION AND AFFORDABLE CARE ACT*

INSURANCE REFORMS

Prohibits Private Insurance Companies from Denying Coverage Based on Preexisting Conditions

A preexisting condition is a health care need that was present before a person was issued a particular private insurance policy. Prior to Sept. 23, 2010, insurance companies could legally deny coverage of claims to a preexisting condition or could refuse it outright to issue a policy to a person with a preexisting condition. For families of children and youth with special health care needs, including those with ASD/DD, this can make it difficult to find affordable and adequate coverage for their child's health care needs, exacerbate job loss or job changes if they have their health insurance through their employer, placing families at risk for financial hardship and debt.

Under the ACA, insurance companies are now prohibited from using the preexisting conditions to deny health insurance coverage. This provision went into effect for children under age 19 on Sept. 23, 2010. It begins for adults over age 19 on Jan. 1, 2014 and includes a ban on denial of coverage for claims related to a preexisting condition. This requirement is for both new and existing insurance policies, except for "grandfathered" individual policies (policies purchased on or before Mar. 23, 2010 directly from the insurer, not through an employer).

Allows Coverage of Young Adults on Their Parent's Policy

Young adults currently have the highest rate of uninsurance among all age groups.⁸ For those just starting careers and families, the cost of employer-sponsored health insurance can be prohibitive, assuming it is even available to them. In some states, young adults have been able to stay on their parent's health plan but only as long as they are full-time students, single or receive financial support from their parents. Under the ACA provision, otherwise independent young adults can receive health care coverage through their parent's plan up until the age of 26. Here are some of the details regarding eligibility for young adults:

- The parent's plan must offer dependent coverage and the parent must enroll in a family or dependent plan
- Parents must be allowed to enroll in whatever family or dependent coverage is available to them or switch coverage options if they are currently insured

- Parents can enroll their married adult children under their plan, but not their child's spouse or dependent children
- This provision applies to individual and group market plans, and includes self-insured plans
- For grandfathered plans (those group or individual health plans in existence on Mar. 23, 2010), the young adult must not have access to their own employer-sponsored insurance (until Jan. 1, 2014; then anyone under age 26 regardless of access to their own insurance can be covered under their parent's plan)

This provision holds potential for assuring access to coverage for children and youth with ASD/DD who reach age 18, are not eligible for Medicaid and are no longer considered dependents. The limitation of this provision is that it will not help young adults whose parents' insurance continues to deny policies or limit benefits based on a preexisting condition between now and 2014, when the ban on denial of coverage for preexisting conditions goes into effect for adults. While access to simple coverage is affected by this provision, the depth of the benefit package is not. This provision allows an adolescent or young adult to join their parent's plan, but if the parent only has access to relatively thin coverage that does not pay for all the services and supports his or her child needs, it will not get better as a result of this provision.

End of Lifetime Coverage Cap, Limits on Annual Coverage Cap

Insurance companies can no longer impose any lifetime benefit caps on coverage and annual benefit caps will gradually be phased out for all self-funded plans. As of Sept. 23, 2010, insurance companies cannot impose lifetime benefits caps on either new or current employer-based plans or a restrictive annual benefit limit on new individual plans. In 2014, insurance companies will not be able to impose any annual benefit cap. Individuals who were previously dropped from a plan because they reached their lifetime limit will be allowed to reenroll if they are still eligible for the coverage. Removing limits on the total dollar amount associated with benefits is an important step toward improving access to health care services for children with ASD/DD who need a level and frequency of services beyond that generally required of children or CYSHCN. However, insurers can still cap individual benefits, such as limiting the number of physical therapy sessions or mental health visits in a calendar year.

End of Coverage Rescission for Health Reasons

Prior to passage of the ACA, the advent of high-cost claims for a particular person prompted many insurance

companies to find ways to drop an individual's insurance coverage. Insurance companies typically did this by finding a mistake or inadvertent omission on the original application for coverage – a practice called “rescission.” Not only could an individual be left with bills for a specific episode of care, the rescission could be made retroactive to the beginning of coverage. This practice created major financial hardships for individuals and families who had already used extensive health care services. Under the ACA, rescission is prohibited and insurance companies cannot drop coverage because of a mistake or inadvertent omission on an application, except in cases of proven fraud. This provision applies to all health plans, including grandfathered plans.

Guaranteed Issue and Guaranteed Renewal

This provision requires that a new policy must be issued and an existing policy must be renewed for anyone who meets the criteria for coverage, regardless of health status, age or gender (except in cases of fraud). This prohibits denial of coverage or non-renewal of coverage for health status or high utilization of health care services, both important issues for children with ASD/DD. Grandfathered individual and group plans are exempt from this provision. (See text box.)

New Plans Must Cover Preventive Care

New health insurance plans or insurance policies beginning on or after Sept. 23, 2010, must cover certain preventive services without charging a co-payment/co-insurance or a deductible (grandfathered plans are exempt). This provision may be especially important to children and youth with ASD/DD because it removes cost as a potential barrier to early diagnosis, which is critical to effective treatment.⁹

The preventive services under this provision include the following:

- Comprehensive guidelines for infants, children, and adolescents supported by the U.S. Department of Health and Human Services, including: the Periodicity Schedule of the Bright Futures Recommendations for Pediatric Preventive Health Care (brightfutures.aap.org/index.html) and the Uniform Panel of the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (hrsa.gov/advisorycommittees/mchbadvisory/heritabledisorders/recommendedpanel/index.html). The Bright Futures Initiative recommends regular developmental surveillance and screening, as well as screening specifically for ASD/DD at ages 18 and 24 months
- Additional preventive care/screening based on the recommendations for children and adolescents by the U.S. Preventive Services Task Force (ahrq.gov/clinic/tfchildcat.htm)

- Immunizations recommended by the Centers for Disease Control and Prevention (cdc.gov/vaccines/pubs/ACIP-list.htm)

Special Considerations for Private Health Insurance Plans

It is important to note that many of the reforms described above **do not apply** to two types of private health insurance plans: **grandfathered plans and certain employer-sponsored plans**, which are plans that were in effect on the day ACA was signed into law (Mar. 23, 2010), are exempt from many of the health care reform law provisions as long as they keep their grandfathered status. A plan can lose its grandfathered status by making major changes, such as significantly raising premiums or reducing benefits, but this process may take several years. **Employer-sponsored coverage** that companies fund themselves, sometimes known as **ERISA** plans, are also exempt from some important ACA provisions. Because half of children and youth with ASD/DD have employer-sponsored insurance (a substantial proportion of which is grandfathered or self-insured) many of the ACA reforms will not apply to them. It is important to understand which existing ACA provisions are beneficial to children and youth with ASD/DD and which provisions have exemptions, in order to provide accurate benefits counseling to these families.

LIST OF ACRONYMS

- **ABA** – Applied Behavioral Analysis
- **ACA** – Affordable Care Act
- **ASD** – Autism Spectrum Disorder
- **ASD/DD** – Autism Spectrum Disorder/developmental disability
- **CHIP** – Children's Health Insurance Program (formerly SCHIP, the State Children's Health Insurance Program)
- **CMS** – Centers for Medicare and Medicaid Services
- **CSHCN/CYSHCN** – Children with Special Health Care Needs/Children and Youth with Special Health Care Needs
- **EPSDT** – Early, Periodic Screening, Diagnosis and Treatment
- **FPL** – Federal Poverty Level
- **HIT** – Health Information Technology
- **MAGI** – Modified Adjusted Gross Income
- **MCH** – Maternal and Child Health
- **MOE** – Maintenance of Effort
- **SPA** – State Plan Amendment (Medicaid)

COVERAGE AND BENEFITS

Medicaid Eligibility Expanded

In 2014, Medicaid eligibility will be expanded to anyone whose income is less than 133 percent of the Federal Poverty Level (FPL), including low-income youth with ASD/DD as they transition to young adulthood, regardless of family or disability status. Children in families with income less than 133 percent of FPL who are enrolled in CHIP will switch to Medicaid coverage. In states where CHIP is operated separately from Medicaid, children and youth with ASD/DD who become eligible for Medicaid under this expansion will gain access to coverage under the Medicaid Early Periodic Screening, Diagnosis, and Treatment (EPSDT) benefit for children. EPSDT is considered by many advocates to be more generous and comprehensive set of benefits than those typically provided by many private health insurance plans.

Medicaid Eligibility Continued for Children Aging Out of the Foster Care System

Beginning in 2014, states must continue providing Medicaid coverage to children who have aged out of the foster care system but who are under age 26. This will be an important benefit for children with ASD/DD in the foster care system transitioning from pediatric to adult health care systems.

Children's Health Insurance Program (CHIP)

The Affordable Care Act requires states to maintain income eligibility levels for CHIP through Sept. 30, 2019. From fiscal year 2014 to 2019, states will receive a 23-percentage point increase in the federal CHIP match rate, subject to a cap of 100 percent. CHIP-eligible children who cannot enroll in CHIP due to federal allotment caps will be eligible for tax credits in the state Exchange.

National Standard for Medicaid Eligibility Determination

Today, each state sets its own income eligibility limits for Medicaid and CHIP, subject to overall federal regulations.¹⁰ Many states make adjustments when considering individual income by disregarding certain expenses or not counting some sources of income. Some states are more generous than others in making these adjustments. Some pathways to Medicaid coverage (such as buy-in and waiver programs) include disability, as well as or instead of income, as the foundation for eligibility. As a result, there is wide variability across states regarding actual income eligibility for Medicaid coverage. In 2014, these existing, state-specific criteria will be replaced with a national standard, called Modified Adjusted Gross Income (MAGI). Under MAGI, 5 percent of

individual or family income will be disregarded, an amount that also varies widely from state to state now. The MAGI will also be used to determine eligibility for subsidized coverage in the Exchanges. This will create uniform income eligibility across states for public coverage, and will facilitate transitions between Medicaid, CHIP and the Exchange plans. Some children with disabilities (including ASD/DD) who receive Supplemental Security Income benefits, as well as those who are served by the foster care system, are exempt from MAGI. However, since many children and youth with ASD/DD are eligible for Medicaid based on criteria other than income (e.g. through an autism waiver, buy-in program, spend-down) states will need to ensure that as Medicaid eligibility is streamlined through income-based standards that these other pathways are also considered and factored into any system changes.

Design Streamlined Eligibility Processes

Over the next three years, states will work to develop a single, simplified form for determining eligibility for Medicaid and CHIP and for premium tax credits on plans offered through the Health Insurance Exchanges. This provision is important because children's eligibility for different programs may fluctuate due to changes in their parents' income and employment status. To date, it is not clear whether disability determination will be part of this streamlined enrollment process but, if it is, it could benefit children and youth with ASD/DD since disability is a pathway to many public benefit programs. If disability determination is not a part of these processes, determination of eligibility for public programs may be slowed down or decisions may be made in error, increasing the administrative burden on families and potentially limiting access to coverage for children and youth with ASD/DD.

Maintenance of Effort (MOE) for Medicaid and CHIP

Under the ACA, states must maintain the Medicaid and CHIP eligibility criteria and enrollment/renewal processes (i.e. Maintenance of Effort) that they had in place when ACA was signed into law (Mar. 23, 2010) through Sept. 20, 2019. Under the MOE provision, states cannot reduce the income eligibility for these programs, nor can they make it more difficult for families to enroll their eligible children. They can, however, raise the income eligibility thus allowing more children to be eligible for the program and/or make enrollment easier.

In spite of this progress, many states experience increasing pressure to reduce health care costs overall and their Medicaid spending in particular. As a result, several states have indicated that they want to reduce Medicaid eligibility but cannot do so under the ACA Maintenance of Effort provision. Under ACA, states can apply to the Centers for Medicare and Medicaid Services (CMS) for an exemption from the MOE requirement. However, such an exemption only applies to coverage of adults in optional categories; the MOE provision still applies to children, pregnant women and people with disabilities – populations that

comprise a significant majority of Medicaid enrollees. As a result, many states are pressing for an outright repeal of this ACA provision. If repealed, many children and youth with ASD/DD may be at risk of losing their Medicaid or CHIP coverage entirely as the result of cuts in eligibility.

However, there are other mechanisms states can use to reduce public benefit program spending that may have implications for children and youth with ASD/DD. States can reduce provider payment rates, which may in turn limit access to primary or specialty care. They can also increase cost sharing for families as long as they stay within the current rules. If this happens, families of children and youth with ASD/DD may experience greater financial burden with their children losing access to essential care and services.

Health Insurance Exchanges

Exchanges are entities that will be set up in states to create an organized and competitive market for health insurance. Exchanges are expected to offer consumers a choice of qualified health plans and establish common rules regarding the offering and pricing of insurance. Additionally, consumers will have access to help in understanding and comparing the benefits and out-of-pocket costs of each Exchange plan, as well as whatever tax credits or subsidies that they might be eligible for in order to help them afford the plan they choose. States must establish Exchanges by Jan. 1, 2014. If the secretary of the U.S. Department of Health and Human Services (HHS) determines that a state will not have an Exchange operational by 2014, the secretary must establish and operate the exchange in that state. According to the Kaiser Family Foundation, by July 2011, more than one third of states had begun laying the foundations for Exchanges that meet the requirements outlined by the ACA.

Develop the Scope of Services for Essential Benefits

The ACA includes a provision that health plans offered through the Exchanges must cover a set of Essential Benefits, many of which are vitally important to children and youth with ASD/DD. Some of these benefits are not currently covered in many private sector plans.

The list of categories under the Essential Benefits includes:

- Ambulatory services
- Emergency services
- Hospitalization
- Laboratory services
- Maternity and newborn care
- Mental health and substance abuse services, including behavioral health treatment
- Pediatric services, including oral and vision care

- Prescription drugs
- Preventative and wellness services, and chronic disease management
- Rehabilitative and habilitative services and devices

The exact definition, duration and scope of benefits under each of these broad categories was originally to be determined by HHS between 2011 and 2013. However, on Dec. 16, 2011, HHS issued a bulletin that calls for a benchmark approach, similar to the one used when the Children Health Insurance Program (CHIP) began. Instead of a national standard determined by HHS, states will be able to choose from one of four kinds of plans to serve as their essential health benefits. They are:

- One of the three largest small group plans in the state by enrollment
- One of the three largest state employee health plans by enrollment
- One of the three largest federal employee health plan options by enrollment
- The largest HMO plan offered in the state's commercial market by enrollment

The broad benefit categories described above remain the same but the requirement under ACA that the essential health benefits be balanced across all 10 categories and look like the "typical employer-sponsored benefit package" remains concerning to those who want as comprehensive an array of services as possible, since the majority of "typical" plans do not include every category of service required under the essential health benefits. If a service category is missing from the benchmark plan chosen by an individual state, it must be added using what is offered through one of the other benchmark plans. However, this does not address benefit categories that are traditionally not covered by these plans. The final outcome of this process will be very important to children and youth with ASD/DD, particularly in the areas of habilitative therapies, prescription drugs and mental and behavioral health services. It is important to note that all grandfathered plans (where the majority of children and youth with ASD/DD get their coverage) will be exempt from this provision, although any of them that are not self funded will still be subject to existing ASD/DD-related state mandated benefit laws. There are currently 29 states that mandate some level of coverage for services to individuals with ASD/DD.

Disagreement between insurers, providers and families about whether a particular ASD/DD-related service should be covered has been common heretofore. This debate has resulted in many states requiring private insurance companies to cover ASD/DD screening, diagnosis and/or treatment. Private insurers, as well as Medicaid and CHIP programs, have used medical necessity as the standard by which to determine coverage of services. The specific definition of medical necessity varies from insurer to insurer and between private and public insurance coverage but in general, it includes a requirement that a service be needed to diagnose or treat a health-related problem, that it be delivered by accredited health care providers, be evidence based (proven

to work) and cost effective. Medical necessity will be used by plans that must include the Essential Benefits. However, while mental and behavioral health treatment is specifically identified under the list of categories of services, just how it will be defined and operationalized and its implications for children and youth with ASD/DD is as yet unknown. In addition, because the HHS bulletin did not address medical necessity, the application and scope of the definition of medical necessity are still unclear under the ACA.

Premium and Cost-Sharing Subsidies Available on a Sliding Fee Scale

In 2014, exchanges will be launched to help small businesses and individuals who are without affordable employer-sponsored coverage purchase health insurance. The Exchanges will offer four categories of coverage, including platinum, gold, silver and bronze. These levels refer to the different degrees of cost sharing in each plan, not the level of benefits included. The cost of the premiums will vary by the level of the plan, being more costly at the platinum level than the bronze. The tax credits and

other cost-sharing subsidies described below will be offered only on coverage purchased at the silver level. The Exchanges will provide information to help people compare the benefits and cost of coverage across these plans, and determine the value of any individual credits or subsidies for which they might be eligible.

Premium subsidies will be implemented in the form of a tax credit to offset the cost of buying insurance. Families with incomes up to 400 percent of the FPL will be eligible for premium tax credits on a sliding fee scale when they purchase coverage through the Exchanges. For example, a three-person family making \$24,000/year (just over 133 percent of the FPL) might buy an insurance policy costing \$11,500. Their tax credit would be \$10,768, making the cost of the policy \$732, or 3 percent of their income (Figure 4 provides an overview of the Federal Poverty Guidelines).

Families with incomes under 250 percent of FPL will be eligible for cost-sharing subsidies that reduce the cost of co-payments, co-insurance and deductibles on a sliding-fee scale. Families must purchase a silver category of coverage, meaning that the

FIGURE 4. 2012 Poverty Guidelines

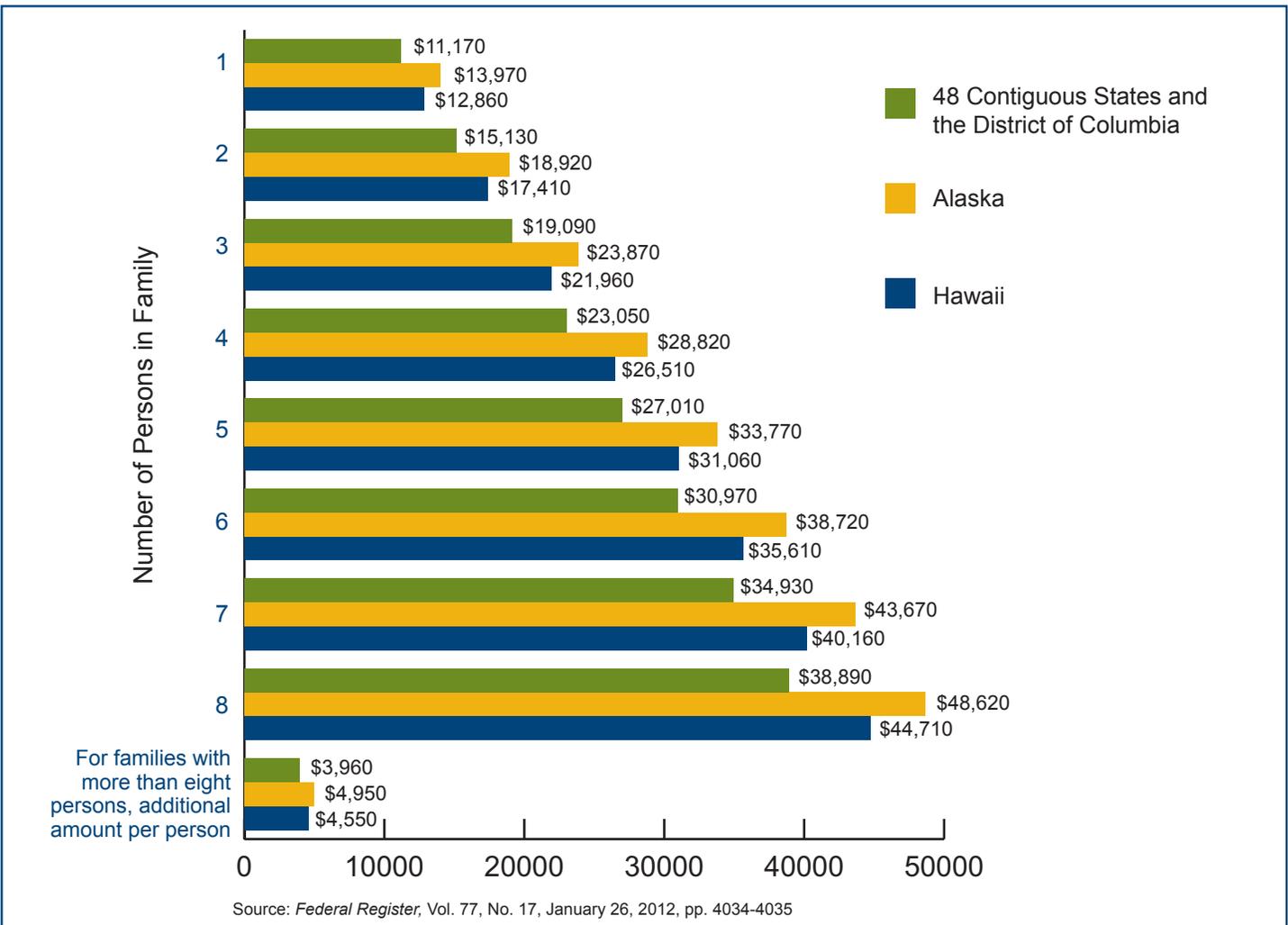


FIGURE 5. Percent of Expenses Covered by the Plan

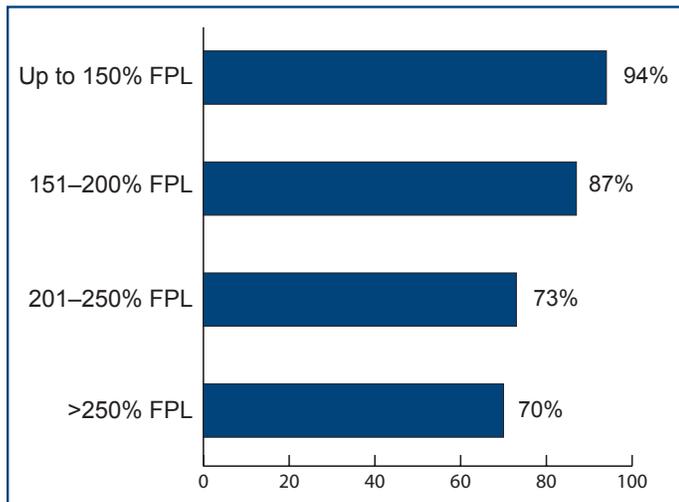
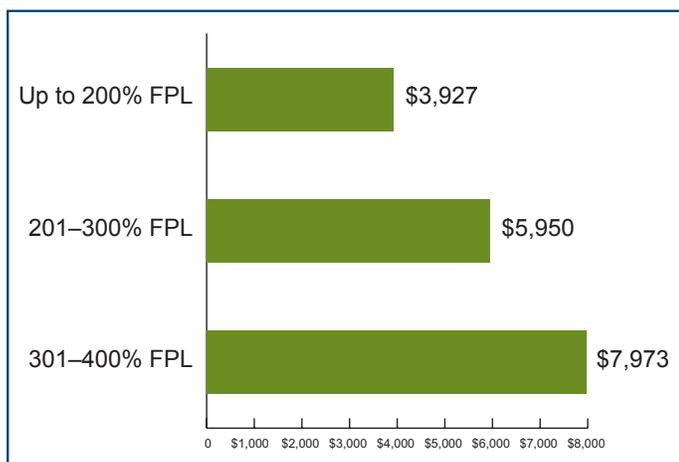


FIGURE 6. Out-of-Pocket Limits in Silver Exchange Plans



Source for Figures 5 and 6: *The Affordable Care Act and Children with Special Health Care Needs: An Analysis and Steps for State Policymakers*, January 2011. The National Academy for State Health Policy for the Catalyst Center. Retrieved 4/13/11 from hdwg.org/sites/default/files/ACAandCSHCNpaper.pdf

plan covers, on average, 70 percent of the costs of care and the member pays the rest. Figure 5 shows what percent of all cost sharing will be covered by the plan at different family income levels.

In addition to the cost sharing subsidies described above, out-of-pocket expenditures will be limited to \$11,900 in 2010 dollars (subject to change each year) for family coverage, regardless of family income. Families with incomes under 400 percent of FPL who purchase silver plans under the Exchanges will have additional limits on their out-of-pocket expenditures. Grandfathered plans are exempt from this provision (see Figure 6).

SYSTEMS IMPROVEMENTS

State Medicaid Programs Can Implement Health Homes

Under Section 2703 of ACA, the Medicaid Health Home State

Plan Option states have the option to allow adult and child Medicaid beneficiaries with “at least two chronic conditions, one chronic condition and the risk of developing a second, or one serious and persistent mental health condition” to select a specific provider as their health home to help coordinate their treatments. Services under the health home as defined by CMS are: comprehensive care management, care coordination and health promotion, comprehensive transitional care from inpatient to other settings, individual and family support, referral to community and social support services, and the use of health information technology (HIT), such as electronic medical records. Participating states get an enhanced federal matching rate of 90 percent for the first eight quarters that the option is in effect. Other health care services for program participants will continue to be matched at the state regular matching rate. CMS released its initial guidance on Section 2703 to states in a November 2010 state medicaid director letter along with a draft template for states to use in designing and developing health home State Plan Amendments (SPAs). Several states are currently working on developing Section 2703 SPAs that include children with chronic conditions, as well as adult enrollees. These plans are preliminary at the time of publication but details will be disseminated to the MCH community as they are released by states.

Expansion of Home and Community-based Services for Medicaid Enrollees: Community First Choice Option

Beginning Oct. 1, 2011, states can choose to provide Medicaid home- and community-based personal care services and supports under a 1915(k) plan. Unlike services provided under

COST SHARING

Cost sharing refers to the amount of money an individual spends when they actually use health care services (as compared to their premium payment, which refers to the cost of buying insurance). Cost sharing includes:

- **Co-payments** – a set fee that is paid every time a service is used. For example, a \$15 co-pay for a physician visit or a \$30 co-pay for a mental health visit
- **Co-insurance** – instead of a set fee, a percentage of the cost of each service is required. For example, some plans require enrollees to pay 20 percent of all outpatient service costs within their specific network and 40 percent of all outpatient costs outside the network
- **Deductibles** – a flat fee paid out of pocket each year before the plan starts paying for covered benefits, for example, having a \$500 deductible means you must pay \$500 of your own money before the insurance company will start paying their share of a claim

a waiver, states taking up this option must make services available statewide, with no caps or waiting lists. Limiting eligibility by age or severity of disability is not allowed. Services must be provided in the most integrated setting appropriate for an individual's needs. States that take up this option will receive a 6 percent increase in their federal match for the costs associated with this program, a potentially attractive incentive for doing so.

IMPLICATIONS FOR STATE TITLE V MCH AND CYSHCN PROGRAM LEADERS

State Title V MCH and CYSHCN programs provide leadership in ensuring the health and well-being of mothers and children, including those with special health care needs, and improving the system of care that serves them. Doing so for children and youth with ASD/DD can be particularly challenging because of the specific issues associated with this population of CYSHCN. The increasing prevalence and incidence rates of ASD/DD in children, as well as the high cost of the care and services they require, is placing greater pressure on a public system already strained by budget cuts and workforce reductions. Many gaps and issues in the current health care system, particularly in the areas of the scope and duration of health care coverage, and the ongoing issue of states' definitions of medical necessity, have not yet been addressed by state or federal health care reform efforts. Title V MCH and CYSHCN program leaders will need to strengthen their work with other state agencies, particularly Medicaid and CHIP, at a time when these agencies face a deluge of new ACA-related regulations and deadlines that potentially limit their capacity to tackle new initiatives targeted at specific populations. Finally, the critical importance of early, and often times intensive, interventions in improving health outcomes for children with ASD/DD adds an additional layer of urgency on top of these challenges.¹²

While these factors create complex work conditions for Title V MCH and CYSHCN program leaders, their direction and expertise is critical to developing comprehensive and coordinated systems of care for children and youth with ASD/DD. These include:

- Medical home development and implementation
- Provision and payment for care coordination
- Benefits counseling
- Engaging family leaders in developing and improving comprehensive systems of care
- Partnering with Medicaid and other child-serving state agencies, nonprofit organizations, etc.
- Data collection, use, tracking and monitoring for quality improvement

- Promoting a comprehensive, coordinated system of care for children and youth with ASD/DD and ensuring systems address the six MCHB critical indicators for CYSHCN (family-professional partnerships, early and continuous screening, medical home, insurance and financing, transition to adulthood, and easy-to-use services)¹³

Title V leaders have many roles to play in the successful implementation of the ACA and improving the system of care. Children and youth with ASD/DD have overlapping medical, behavioral and mental health needs. States typically place responsibility for addressing these components under individual state agencies. Title V, with its mandate to serve the broad spectrum of CYSHCN, includes at its foundation an understanding of the importance of considering the needs of children and youth from a holistic standpoint rather than a diagnosis-specific standpoint. Quality services for children and youth with ASD/DD, and their families, needs to be coordinated and comprehensive rather than fragmented across systems. Title V programs have a long history of experience in collaborating across and coordinating between programs to ensure that the needs of CYSHCN, including children and youth with ASD/DD, are addressed in the overall system of care. Historically, Title V has also served a critically important role in building consensus among constituencies with competing interests, ensuring that a balance is considered between the needs of CYSHCN in general and those of specific targeted populations in equitable policymaking and resource allocation. Finally, Title V programs have been instrumental in supporting the roles of families in developing and strengthening systems of care. All of these roles are critical to implementing the ACA provisions in a manner that ensures the needs of children and youth with ASD/DD are met.

Identifying opportunities and implementing ways to apply Title V expertise in the areas described above will be an ongoing challenge in this time of economic retrenchment but also an opportunity to form and strengthen the Title V role in building systems of care for children and youth with ASD/DD and all CYSHCN.

CONCLUSION

Unique, historic opportunities for improving access to care for children and youth with ASD/DD are contained within the ACA. The work in ensuring that children and youth with ASD/DD have access to coverage that is universal and continuous, adequate and affordable will be ongoing. Several provisions, particularly in the area of consumer protections, hold significant potential for meeting these goals. There are also some limitations, primarily in the exemption of large-group, grandfathered and self-funded plans – where nearly half of children and youth with ASD/DD get their coverage – from the Essential Health Benefits requirement. Moreover, it is still yet to be determined as to the full impact of the ACA on reducing underinsurance and improving systems of care for children and youth with ASD/DD.

As the federal regulations, guidance and clarifications to the ACA are being developed, state agency staff and policymakers, child health advocates, clinicians, families, and others interested in the health

and well-being of children and youth with ASD/DD in particular, and children and youth in general, must be well informed about the details of the various provisions and the opportunities and limitations of each. Only then can state MCH leaders and other child advocates be best prepared to effectively ensure that children and youth with ASD/DD have access to the coverage they need for the care they deserve so that they can grow to their fullest potential. Leadership from state Title V MCH and CYSHCN programs in ensuring that the needs of children and youth with ASD/DD are recognized and considered will be essential.

APPENDIX

- **Association of Maternal & Child Health Programs (AMCHP)** – The AMCHP National Center for Health Reform Implementation provides state MCH leaders and their partners with the information, tools and resources they need to optimize the opportunities presented by the ACA for improving services, systems and health outcomes for MCH populations. Additional information covering key aspects of the ACA that pertain to promoting medical homes, improving the health and well-being of adolescents, along with CYSHCN, is available at: amchp.org/Advocacy/health-reform/Pages/default.aspx.
- **AMCHP State Public Health Autism Resource Center (SPHARC)** – SPHARC is a comprehensive resource center for state Title V agencies and others interested in improving systems for children, youth and families with autism spectrum disorders. SPHARC offers bi-monthly technical assistance calls to its grantees and a comprehensive list of resources on its website, including best practices, state initiatives, links to education and training materials, media highlights, announcements of events, and more at amchp.org/spharc.
- **The Patient Protection and Affordable Care Act of 2010 (Public Law 111-148)** – This link will bring you to the full text of the ACA legislation from the U.S. Government Printing Office: gpo.gov/fdsys/pkg/PLAW-111publ148/pdf/PLAW-111publ148.pdf.
- **The Catalyst Center at the Boston University School of Public Health** – The Catalyst Center is funded by the federal Maternal and Child Health Bureau/Health Resources and Services Administration/Department of Health and Human Services to serve as the national center on improving financing of care for CYSHCN. They create publications and products, answer technical assistance questions, research innovative state-based financing strategies, guide stakeholders to outside resources, and connect those interested in working together to address complex health care financing issues. See their health care reform section at hdwg.org/catalyst/publications/aca for more resources, including:
 - **Policy Paper: *The Affordable Care Act and Children with Special Health Care Needs: An Analysis and Steps for State Policymakers*** [PDF] (A publication by the National Academy for State Health Policy (NASHP, nashp.org) for the Catalyst Center) (Jan. 2011)

- In addition to these materials, the **Catalyst Center Week in Review** offers a compilation of media items related to coverage and financing of care for CYSHCN in general and ACA news in particular. Their quarterly e-newsletter, *Catalyst Center Coverage*, includes more in-depth news and analysis, links to resources and original articles on related topics of interest. Sign up to automatically receive both by providing your e-mail in the field in the upper right corner of their homepage at: catalystctr.org.

Understanding Title V

State Title V maternal and child health (MCH) programs have a 75-year history of building comprehensive, integrated systems to ensure the health and well-being of women, children, including children with special health care needs, and their families. All states and U.S. territories receive funds from the Title V Maternal and Child Health Services Block Grant program (Title V Block Grant) to build a comprehensive system of programs, services and supports for these populations. This federal program provides critical funds to states for programs, services, supports and leadership in areas including improving infant and child health outcomes, reducing infant and maternal mortality rates and providing prenatal care to low-income pregnant women. By federal law, at least 30 percent of federal Title V Block Grant funding has to play a key leadership role in promoting and fostering systems integration at the state and local level through initiatives, such as the State Early Childhood Comprehensive Systems Initiative (SECCS).

The federal Title V Block Grant also includes important requirements for coordination between state Title V and Medicaid programs. By federal law, state Title V programs are required to:

- Assist with coordination of Medicaid EPSDT
- Establish coordination agreements with their State Medicaid programs
- Provide a toll-free number for families seeking Title V or Medicaid providers
- Provide outreach and facilitate enrollment of Medicaid eligible children and pregnant women
- Share data collection responsibilities
- Provide services for CSHCN not covered by Medicaid

Sources: Understanding Title V of the Social Security Act, Health Resources and Services Administration, Maternal and Child Health Bureau, Accessed on 4/11/11 at: mchb.hrsa.gov/about/understandingtitlev.pdf; EPSDT and Title V Collaboration to Improve Child Health, Health Resources and Services Administration, Maternal and Child Health Bureau, Accessed on 4/11/11 at mchb.hrsa.gov/epsdt.

ACKNOWLEDGEMENTS

On behalf of the Association of Maternal & Child Health Programs, we wish to thank the Catalyst Center team at the Boston University School of Public Health for their time and dedication in writing this paper and for providing the analysis of the Affordable Care Act specific to children and youth with autism spectrum disorders and other developmental disabilities.

The Catalyst Center offers its thanks to Catherine Hess, Kathleen Farrell, Diane Justice and Jennifer Dolatshahi with the National Academy for State Health Policy (NASHP) and Sarah DeLeone, formerly with NASHP and now with the Centers for Medicare and Medicaid Services (CMS) for the work in developing much of the original content for this brief, published in the policy paper: *The Affordable Care Act and Children with Special Health Care Needs: An Analysis and Steps for State Policymakers* (A publication by the National Academy for State Health Policy (NASHP) for the Catalyst Center) (January 2011), available for download at aca.catalystctr.org.

We are equally grateful for the thoughtful review and helpful comments made by Maria Nardella, Children with Special Health Care Needs Section Manager, Washington State Department of Health; Stuart Spielman, Senior Policy Advisor and Counsel, Autism Speaks; Shelley Barnes, Family Consultant, Oregon Health and Science University; Tamara Bakewell, parent leader, Portland, Oregon and the State Public Health Autism Resource Center (SPHARC) grantees.

AMCHP STAFF CONTACT INFORMATION

For more information, please visit the AMCHP website at: amchp.org and/or contact the AMCHP staff listed below. All AMCHP staff can be reached by phone at (202) 775-0436.

Karen VanLandeghem

Senior Adviser, National Center for Health Reform Implementation
kvan@amchp.org

Treeby Brown

Senior Program Manager, Children and Youth with Special Health Care Needs
tbrown@amchp.org

This publication was supported by cooperative agreement U01MC11069 from the Maternal and Child Health Bureau (MCHB). Its contents are solely the responsibility of the author and do not necessarily represent the official views of MCHB.

END NOTES

¹ Child and Adolescent Health Measurement Initiative (2012). *National Profile of Children with Special Health Care Needs and Autism Spectrum Disorders: Key Findings from the 2009/10 NS-CSHCN & 2007 NSCH*. Data Resource Center, supported by Cooperative Agreement 1-U59-MC06980-01 from the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Available at childhealthdata.org. Revised 4/2/12.

² This prevalence number is different from the 730,000 children with autism and ASD/DD estimated by the U.S. Centers for Disease Control and Prevention and that readers may expect to see. However, we use the National Survey of Children with Special Health Care Needs (2009/2010) number because it allows us to correlate autism prevalence data with health care financing and insurance information. Using the National Survey of Children with Special Health Care Needs data also allows us to make accurate comparisons between CYSHCN with autism and ASD/DD and children with other special health care needs from data collected at the same point in time, in the same way. In addition to autism and ASD/DD, the list of specific co-existing health care conditions the National Survey collects data on includes Asthma, Attention Deficit Disorder (ADD) or Attention Deficit Hyperactive Disorder (ADHD), Down Syndrome, intellectual or developmental delay, depression, anxiety, an eating disorder, or other emotional problems, diabetes, heart problems, blood problems, Cystic Fibrosis, Cerebral Palsy, Muscular Dystrophy, Epilepsy or other seizure disorder, migraine or frequent headaches, Arthritis or other joint problems and allergies, including food allergies.

³ Child and Adolescent Health Measurement Initiative (2012). *National Profile of Children with Special Health Care Needs and Autism Spectrum Disorders: Key Findings from the 2009/10 NS-CSHCN & 2007 NSCH*. Data Resource Center, supported by Cooperative Agreement 1-U59-MC06980-01 from the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Available at childhealthdata.org. Revised 4/2/12.

⁴ *National Survey of Children with Special Health Care Needs, 2009/2010*. Child and Adolescent Health Measurement Initiative, Data Resource Center on Child and Adolescent Health website.

⁵ America's Health Insurance Plans' Center for Policy and Research. *Individual Health Insurance, 2009: A Comprehensive Survey of Premiums, Availability and Benefits*. Washington, DC, October 2009. Retrieved online 2/2/11 from ahipresearch.org/pdfs/2009IndividualMarketSurveyFinalReport.pdf.

⁶ Child and Adolescent Health Measurement Initiative (2012). *National Profile of Children with Special Health Care Needs and Autism Spectrum Disorders: Key Findings from the 2009/10 NS-CSHCN & 2007 NSCH*. Data Resource Center, supported by Cooperative Agreement 1-U59-MC06980-01 from the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Available at childhealthdata.org. Revised 4/2/12.

⁷ Parish, S., Rose, R., Grinstein-Weiss, M., Richman, E. & Andrews, M. (2008), Material hardship in US families raising children with disabilities, *Exceptional Children*, 75(1), 71-92.

⁸ U.S. Department of Labor, Bureau of Labor Statistics, *Current Population Survey 2008*.

⁹ Dawson, G., Rogers, S, Munson, J., Smith, M., Winter, J., Greenson, J., Donaldson, A., and Varley, J. (2010), Randomized, Controlled Trial of an Intervention for Toddlers With Autism: The Early Start Denver Model. *Pediatrics* January 2010; 125:1 e17-e23; published ahead of print November 30, 2009, doi:10.1542/peds.2009-0958.

¹⁰ For details, see the Kaiser Family Foundation's chart: *Income Eligibility Limits for Children's Regular Medicaid and Children's CHIP-funded Medicaid Expansions as a Percent of Federal Poverty Level (FPL)*, January 2011 on their website at statehealthfacts.org/comparereport.jsp?rep=76&cat=4.

¹¹ Autism Speaks (2011). *State Autism Insurance Reform Initiatives*. Retrieved online 11/28/11 from autismvotes.org/site/c.frkNI3PCImE/b.3909861/k.B9DF/State_Initiatives.htm.

¹² Association of Maternal & Child Health Programs, State Public Health Autism Resource Center, *Roles for State Title V Programs in Building Systems of Care for Children and Youth with Autism Spectrum Disorder and Other Developmental Disabilities*, Washington, DC, 2011.

¹³ Maternal and Child Health Bureau, *Achieving and Measuring Success: A National Agenda for Children with Special Health Care Needs*, mchb.hrsa.gov/programs/specialneeds/measuresuccess.htm.