

The Affordable Care Act & CYSHCN

Coverage & Benefits for Autism Spectrum Disorder & Other Developmental Disabilities

The AMCHP Role

AMCHP supports state maternal and child health 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.

AMCHP's National Center for Health Reform Implementation provides state maternal and child health (MCH) leaders and their partners with the information, tools and resources to optimize the opportunities presented by the Patient Protection and Affordable Care Act (ACA) for improving services, systems, and health outcomes for MCH populations.

Introduction

Overview

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. Children with ASD/DD often have inadequate insurance coverage, putting them at risk for missed or delayed care and leaving their families with significant financial burdens. The 2010 *Patient Protection and Affordable Care Act* (ACA) is designed to increase health coverage, improve the level of benefits, and provide important new insurance protections for all Americans. Many of the law's provisions impact children, including those with ASD/DD. This issue brief describes selected provisions in the ACA that have implications for CYSHCN with ASD/DD. It also describes how state Title V MCH programs can maximize opportunities under the ACA to develop and strengthen systems of care for CYSHCN with ASD/DD.

Background

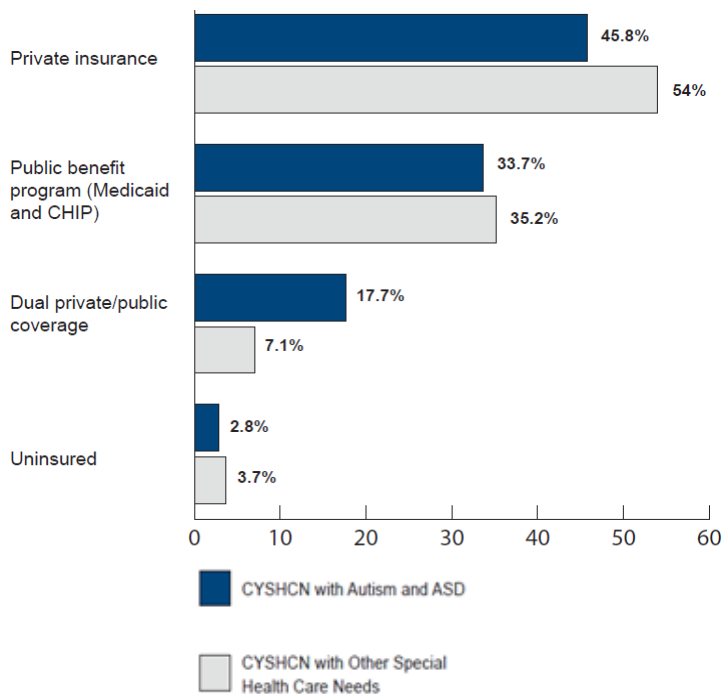
CYSHCN with ASD/DD face more serious gaps in coverage and benefits than other children, even when compared with CYSHCN with other special health care needs.¹ Some of these gaps in coverage can have a negative impact on the effectiveness of treatment. In addition to their developmental and behavioral health care needs, CYSHCN with ASD/DD often have other important health concerns. According to the 2009/2010 National Survey of Children with Special Health Care Needs (National Survey), more than 90 percent of the approximately 840,000 CYSHCN with ASD/DD living in the United States² have four or more co-existing health conditions.³ As a result, their health care needs extend beyond well child care and treatment for ASD/DD, and include a wide range of medical, behavioral and developmental services. As with all children, three factors are critical for health insurance that ensures the best health outcomes for CYSHCN with ASD/DD: coverage must be universal and continuous, adequate and affordable.



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. According to 2009–2010 National Survey data, approximately half of CYSHCN with ASD/DD are covered by private insurance, 34 percent are covered by Medicaid or the state-based Children’s Health Insurance Program (CHIP), and 18 percent have dual public and private coverage. A relatively small proportion (3 percent) is uninsured (see Figure 1). Although nearly all children with ASD/DD have health care coverage, it is often not enough to meet their myriad and complex needs, given the cost associated with screening, diagnosis and treatment of ASD/DD.

Figure 1: Percent of CYSHCN with ASD/DD with Insurance by Type



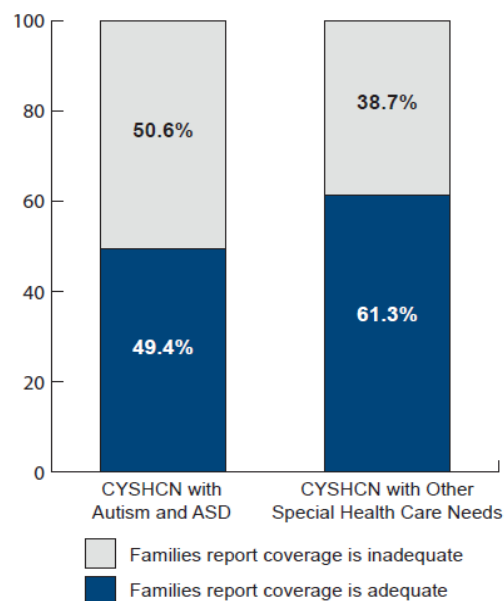
National Profile of CYSHCN and Autism Spectrum Disorder 2009/10

Adequacy

In addition to problems accessing and maintaining health care coverage, CYSHCN with ASD/DD can experience problems with the health benefits offered by their health plans. Half of insured CYSHCN with ASD/DD have families who report that their child’s health insurance coverage is inadequate to meet their needs (see Figure 2). Many insurance plans limit important benefits like

mental and behavioral health care, rehabilitative and habilitative therapies (e.g. speech, language) and prescription drugs. With these limits, many families struggle to cover the cost of their child’s necessary medical, behavioral and developmental care and services. 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 that report financial problems (19.6 percent).⁴ More than half (57.1 percent) had families 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 other CYSHCN (21.6 percent).

Figure 2: Percent of Families Reporting Inadequate Insurance



National Profile of CYSHCN and Autism Spectrum Disorder 2009/10

Affordability

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.⁵ High cost-sharing (e.g. co-pays, deductibles and co-insurance) can mean that some CYSHCN with

ASD/DD may have limited or no access to necessary health care services and supports.

In summary, gaps in all three domains of coverage (universal/continuous, adequate and affordable) cause significant problems for CYSHCN with ASD/DD in obtaining needed health care services and supports. These gaps 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 CHIP, and creating a new mechanism for purchasing health insurance coverage through the Health Insurance Marketplace (Marketplace). The ACA also created broad health insurance reforms with significant benefits 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 with ASD/DD.

ASD/DD Provisions in the *Patient Protection and Affordable Care Act*

INSURANCE REFORMS

Prohibition on Denial of Coverage Based on Pre-existing Conditions

A pre-existing condition is a health care need that was present before a person was issued a particular private insurance policy. Prior to passage of the ACA, insurance companies could legally deny coverage of claims related to a pre-existing condition, or they could refuse to issue a policy to a person with a pre-existing condition. Under the ACA, insurance companies are now prohibited from using a pre-existing condition as grounds for denying claims or issuing health insurance policies. This requirement is for both new and existing insurance policies, except for “grandfathered” individual policies (policies purchased on or before March 23, 2010, directly from the insurer, not through an employer). Over time, all plans must comply with this provision.

Coverage of Adult Children on Parent’s Health Insurance Plan

Prior to 2010, most young adults lost dependent coverage between the ages of 18 and 22. Through

a provision in the ACA, otherwise independent young adults can receive health care coverage through their parent’s plan up until the age of 26. This provision holds potential for ensuring access to coverage for young adults with ASD/DD, who are not otherwise eligible for Medicaid.

Details regarding young adult eligibility for parental coverage are as follows:

- All health plans—employer-sponsored, as well as individual policies purchased in or out of the (Marketplace)—must offer coverage to adult children up to age 26.
- 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.
- Coverage is available regardless of an adult child’s employment or marital status. Coverage does not extend to the child’s spouse or dependent children.

End of Lifetime and Annual Coverage Caps

Insurance companies can no longer impose lifetime or annual benefit caps on 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 faced 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

Under this provision, insurance companies must issue a new policy, and must renew an existing policy for anyone who meets the criteria for coverage, regardless of health status, age or gender (except in cases of fraud). The provision 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.

Mandatory Coverage of Preventive Services

Non-grandfathered health insurance plans must cover certain preventive services without charging a co-payment, co-insurance or a deductible. This provision may be especially important to CYSHCN with ASD/DD because it removes cost as a potential barrier to early diagnosis, which is critical to effective treatment.

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* and the [Recommended Uniform Panel of the Advisory Committee on Heritable Disorders in Newborns and Children](#). *Bright Futures* recommends regular developmental surveillance and screening, as well as specific screening 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](#)
- Immunizations recommended by the [Centers for Disease Control and Prevention](#)

Special Considerations for Health Plans:

Note that many of the insurance reforms described above do not apply to two types of private health insurance plans: grandfathered plans and certain employer-sponsored plans. Grandfathered plans are those that were in effect on the day ACA was signed into law (March 23, 2010). These plans are exempt from many ACA 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 coverage, is also exempt from certain ACA provisions. 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.

COVERAGE AND BENEFITS

Expansion of Medicaid Eligibility

The ACA expansion of the Medicaid program for adults earning income less than 138 percent of the Federal Poverty Level (FPL) is a state option, as a result of the Supreme Court's ruling in *National Federation of Independent Business v. Sebelius*. As of November 2015, 31 states, including the District of Columbia, have adopted the Medicaid expansion.⁶ Low-income youth with ASD/DD residing in expansion states are likely to benefit from the change in Medicaid eligibility. As they transition to young adulthood, these youth will be eligible for ongoing health care services, regardless of family or disability status.

The ACA has raised the Medicaid eligibility level for all children under the age of 18 to 138 percent of the FPL. Children living in families with incomes below 138 percent of the FPL who are enrolled in CHIP are now covered by Medicaid. 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. Many advocates

consider EPSDT to be a more generous and comprehensive set of benefits than those typically provided by many private health insurance plans.

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

States must continue to provide Medicaid coverage to children who have aged out of the foster care system but who are under age 26. This is an important benefit for children with ASD/DD in the foster care system, as they transition from the pediatric to the adult health care system. Currently, former foster care youth can receive extended Medicaid coverage only in the state where they aged out of the foster care system. Legislative action is required for former foster care youth to receive full Medicaid benefits if they move to a different state.

Children's Health Insurance Program

The ACA requires states to maintain CHIP income eligibility levels that were in place in March 2010 through September 30, 2019. From fiscal years 2014 through 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 health insurance exchange. While the ACA has authorized the program through 2019, the Medicare Access and CHIP Reauthorization Act (MACRA) of 2015 extended CHIP through September 30, 2017⁷. To fund CHIP past September 2017, legislative action is required.

National Standard for Medicaid Eligibility Determination

Each state sets its own income eligibility limits for Medicaid and CHIP, subject to the new ACA regulations.⁸ However, states must use a single, simplified form for determining eligibility for Medicaid and CHIP and for premium tax credits on plans offered through the Marketplace. In addition, all states must use Modified Adjusted Gross Income (MAGI), the new income eligibility standard. MAGI is gross income, adjusted for deductions, with no asset test. Under MAGI, 5 percent of individual or family income is disregarded. These new regulations create uniform income eligibility across states for public coverage, and facilitate transitions between Medicaid, CHIP and

Marketplace plans. This provision is important because children's eligibility for different programs may fluctuate due to changes in their parents' income and employment status.

Some children with disabilities (including ASD/DD) who receive Supplemental Security Income (SSI) benefits, as well as those who are served by the foster care system, are exempt from MAGI. However, because 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, or spend-down), states need to ensure that as Medicaid eligibility is streamlined through income-based standards, these other pathways are also considered and factored into any system changes.

Medicaid Disability-Related Coverage Determination

Medicaid eligibility determinations for disability-related coverage groups continue to be based on pre-existing rules and are not affected by the ACA's 2014 eligibility and enrollment changes. However, states can opt to apply their streamlined renewal and reconsideration procedures for poverty-related coverage groups to disability-related coverage groups as well. In states where disability determination is not a part of the new Medicaid enrollment processes, determination of eligibility for public programs may take longer 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. In Medicaid expansion states, more people with disabilities may qualify for Medicaid based solely on their low-income status, which enables them to enroll in coverage as quickly as possible, without waiting for a disability determination.

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 the ACA was signed into law (March 23, 2010) through September 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 expressed their desire to reduce Medicaid eligibility, but they cannot do so under the ACA MOE provision.

Under the ACA, states can apply to the Centers for Medicare & Medicaid Services (CMS) for an exemption from the MOE requirement. However, this type of 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 it is repealed, many children and youth with ASD/DD may be at risk of losing their Medicaid or CHIP coverage entirely.

However, states can use other mechanisms 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 burdens, and their children may lose access to some essential care and services.

Health Insurance Marketplace

The Marketplace facilitates the purchase of health insurance by individuals and small businesses. The Marketplace in each state offers consumers a way to compare and shop for private health insurance plans. Subsidies are available to individuals with a household income between 100 and 400 percent of the FPL.

The Marketplace also screens individuals for eligibility for Medicaid and CHIP coverage, ensuring that individuals experience “no wrong door” to health coverage. Additionally, consumers have access to Navigators and other in-person assisters so they fully understand and can compare the benefits and out-of-pocket costs of each

Marketplace plan in their state, as well as the tax credits or subsidies for which they might be eligible in order to make coverage more affordable.

Scope of Services for Essential Health Benefits

The ACA requires all health plans sold inside the Marketplace and all new individual and small group plans sold outside of the Marketplace to offer a core package of services known as essential health benefits (EHB). EHB requirements also apply to Medicaid plans offered in states that have expanded Medicaid eligibility up to 138 percent of the FPL for newly eligible adults. Many EHB benefits are vital to children and youth with ASD/DD. EHB categories include:

- Ambulatory services
- Emergency services
- Hospitalization
- Laboratory services
- Maternity and newborn care
- Mental health and substance use disorder services, including behavioral health treatment
- Pediatric services, including oral and vision care
- Prescription drugs
- Preventive and wellness services, and chronic disease management
- Rehabilitative and habilitative services and devices.

To implement this requirement, states must select a “benchmark plan” to serve as a reference point for coverage of EHB. Benchmark plans must be selected from one of four categories:

- 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 benchmark plan establishes the state’s minimum definitions for the extent of covered services and cost-sharing limits within each EHB category. While EHB rules set a baseline, health insurance plans can vary with regards to the extent

of covered services and cost-sharing for those services. These variances can affect children and youth with ASD/DD, especially in the areas of habilitative therapies, prescription drugs and mental and behavioral health services. Most states use the largest small group market plan in their state as their benchmark plan. In cases where the state-selected benchmark plan did not include a particular EHB category, states are required to supplement the benchmark benefits and include the missing benefit category. It is important to note that all grandfathered plans are exempt from this provision, although any of them that are not self-funded are subject to existing ASD/DD-related state mandated benefit laws. Currently, 43 states mandate some level of coverage for services to individuals with ASD/DD.⁹

Historically, insurers, providers and families have commonly disagreed about whether a particular ASD/DD-related service should be covered. As a result, many states now require 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. However, in general, medical necessity includes a requirement that a service be necessary 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 is used by plans sold in the Marketplace. However, while mental and behavioral health treatment is specifically identified as an EHB, how it is defined and operationalized—and its implications for children and youth with ASD/DD—is still evolving.

Premium and Cost-Sharing Subsidies

Plans certified to be sold through the Marketplace are known as Qualified Health Plans (QHPs). All plans charge a monthly premium, which varies depending on the deductible, percentage of costs covered by the plan and other factors. The Marketplace allows consumers to compare QHPs by dividing them into four categories: platinum, gold, silver, and bronze. Bronze plans charge the

lowest premiums and platinum plans charge the highest premiums. However, when individuals and families access health care, those with bronze plans will have to pay more out-of-pocket before the plan contributes, while those with platinum plans will be required to pay less before the plan contributes. Thus, families who use many health services may find a “higher metal” plan more affordable overall. On average, platinum plans cover 90 percent of health care costs, while bronze plans cover 60 percent of health care costs. Note that each category of health plans only indicates the average amount of costs that the plan will pay.

Premium subsidies are 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 Marketplace. Families with incomes below 250 percent of the FPL will also be eligible for cost-sharing subsidies that reduce the cost of co-payments, co-insurance and deductibles on a sliding-fee scale. To be eligible for this assistance, families must purchase a silver category of coverage, meaning that the plan covers, on average, 70 percent of the costs of care and the member pays the rest.

In addition to the cost-sharing subsidies described above, the ACA places a limit on total out-of-pocket costs associated with any non-grandfathered plan. For 2016, the maximum out-of-pocket cost for an individual plan is \$6,850 and \$13,700 for a family plan.¹⁰ Premiums do not count towards the maximum out-of-pocket amount.

SYSTEMS IMPROVEMENTS

Medicaid Health Homes¹¹

Section 2703, an optional provision of the ACA, allows states to create “health homes,” which provide integrated primary care, mental, behavioral and substance use disorder services for individuals with certain chronic conditions who are enrolled in Medicaid. Medicaid Health Homes have the potential for ensuring that Medicaid-enrolled CYSHCN with certain chronic conditions receive care coordination services, connections to

community and social support services and other benefits not generally part of the Medicaid benefit. States must submit a Medicaid State Plan Amendment (SPA) to CMS in order to implement Section 2703 of the ACA. The SPA does not need to be statewide; states may choose to serve certain geographic regions and/or implement the SPA over time in different parts of the state. Individuals eligible for health home services must be eligible for and enrolled in Medicaid. In addition, they must experience at least one of the following: two or more chronic conditions; one chronic condition and the risk of developing another; or at least one serious and persistent mental health condition. In order to include CYSHCN in their health home program, some states have included chronic conditions such as congenital and circulatory anomalies, genetic disorders, autism spectrum disorders and other developmental disabilities. Because serious and persistent mental health conditions are generally adult diagnoses, some states have redefined them as serious emotional disorders in order to include children and youth.

Services under the Health Home provision as defined by CMS include 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 receive 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's regular matching rate. Several states have Health Home SPAs that include children with chronic conditions, as well as adult enrollees.

Implications for State Title V MCH and CYSHCN Programs

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 intensive, interventions in improving health outcomes for children with ASD/DD creates 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 that address the six Maternal and Child Health Bureau (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.

Title V leaders have many roles to play in the successful implementation of the ACA. 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 and implementing opportunities 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 EHB requirement. Moreover, the full impact of the ACA on reducing underinsurance and improving systems of care for children and youth with ASD/DD.

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 ACA provisions and the opportunities and limitations presented by them. 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. The leadership from state Title V MCH and CYSHCN programs must ensure that the needs of children and youth with ASD/DD are recognized and considered.

Resources

- **Association of Maternal & Child Health Programs:** [State Public Health Autism Resource Center](#)
- **Catalyst Center:** [The ACA and Children and Youth with Special Health Care Needs](#)

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AMCHP Contact Information

This fact sheet is part of a series of AMCHP tools, documents and resources on implementation of the Affordable Care Act and its impact on maternal and child health populations. For more information, please visit the [National Center for Health Reform Implementation](#). All AMCHP staff can be reached via phone at (202) 775-0436.

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 hyperactivity 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 headache; 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 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.

⁵ Parish, S., Rose, R., Grinstein-Weiss, M., Richman, E. & Andrews, M. (2008), Material hardship in U.S. families raising children with disabilities, *Exceptional Children*, 75(1), 71-92.

⁶ Kaiser Family Foundation. *Status of State Action on the Medicaid Expansion Decision*. Retrieved online 11/9/15 at: <http://kff.org/health-reform/state-indicator/state-activity-around-expanding-medicaid-under-the-affordable-care-act/>

⁷ Georgetown Center for Children and Families. *About CHIP*. Retrieved online 11/9/15 at: <http://ccf.georgetown.edu/chip/about-chip/>

⁸ Kaiser Family Foundation. *Medicaid and CHIP Income Eligibility Limits for Children as a Percent of the Federal Poverty Level*. Retrieved online 11/9/15 at: <http://kff.org/health-reform/state-indicator/medicaid-and-chip-income-eligibility-limits-for-children-as-a-percent-of-the-federal-poverty-level/>

⁹ Autism Speaks. *State Initiatives*. Retrieved online 11/9/15 at: <https://www.autismspeaks.org/state-initiatives>

¹⁰ HHS/CCIIO. *Final HHS Notice of Benefit and Payment Parameters for 2016*. Retrieved online 11/9/15 at: <https://www.cms.gov/CCIIO/Resources/Fact-Sheets-and-FAQs/Downloads/2016-PN-Fact-Sheet-final.pdf>

¹¹ The Catalyst Center, *Section 2703, The Medicaid Health Home Provision of the Affordable Care Act: An Overview*. Retrieved online 11/9/15 at: <http://www.hdwg.org/catalyst/publications/factsheet-2703>

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, D.C., 2011.