



Environmental Scan:

State Strategies and Initiatives to Improve Developmental and Autism Screening and Early Identification Systems

About AMCHP

The Association of Maternal & Child Health Programs (AMCHP) is a national resource, partner and advocate for state public health leaders and others working to improve the health of women, children, youth and families, including those with special health care needs.

AMCHP supports state maternal and child health programs and provides national leadership on issues affecting women and children. AMCHP works with partners at the national, state and local levels to expand medical homes, provide and promote family-centered, community-based, coordinate care for children and youth with special health care needs and promote quality systems of care. AMCHP also provides training and leadership development opportunities to Title V MCH and CYSHCN directors and professionals.

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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 of care for children, youth and families with autism spectrum disorders and other developmental disabilities.

amchp.org/programsandtopics/CYSHCN/projects/SPHARC



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Introduction

The number of children identified with autism spectrum disorder (ASD) and other developmental disabilities (DD) has increased considerably in recent years. Current estimates from the Centers for Disease Control and Prevention (CDC) indicate that one in 68 children has an ASD.¹ Additionally, as many as one in four children between the ages of zero to five is at moderate or high risk for a developmental, behavioral or social delay.² The rising incidence of ASD/DD and heightened focus on early identification and intervention has led to an increased demand on states to develop and improve systems of care to assure that all children receive early developmental screening and those with ASD/DD receive timely identification, diagnosis and intervention services.

Signs of ASD and other developmental disabilities often present in early childhood. Screening for healthy development can help identify potential delay areas for further evaluation and diagnosis, and reduce the likelihood of developing other delays.³ Early identification allows communities to provide children with earlier treatment or interventions that are more effective in improving delays and disabilities and less costly than special education services in later childhood. Developmental screenings, which can occur in medical and early child care and education settings, are designed to be short tests that assess children's basic developmental abilities and identify possible delays.⁴ The American Academy of Pediatrics (AAP) recommends that children be screened for developmental delays or disabilities during the nine-month, 18-month, and 24- or 30-month well-child visits⁵ and specifically for ASD at 24 and 30 months.⁶ Though research suggests that children can be reliably diagnosed for autism by 24 months of age, many children do not receive a diagnosis until four years of age or later.⁷

State and national health professionals face barriers to expediting the developmental and ASD screening, evaluation, diagnosis and treatment process. The tools used to screen children can be complex, time-consuming and often costly. In addition, policymakers, researchers, medical providers and other health professionals may not be in agreement regarding the appropriate screening procedures and regulations, which sends a mixed message to state health programs. State programs, including Title V children and youth with special health care needs (CYSHCN) programs, are focusing significant efforts towards increasing the number of children who receive the recommended age-appropriate developmental screenings, improving capacity for primary care doctors and other early childhood professionals to carry out screenings, and coordinating efforts to improve services for children with ASD/DD and their families. For Title V programs, the focus is timely as there is a potential new national performance measure related to developmental screening as part of the proposed Title V Maternal and Child Health Services (MCH) Block Grant guidance.⁸

As states look to improve developmental screening and early identification, collaborations across early childhood programs, and implementation of data-driven, evidence-based strategies are critical to having functional and efficient statewide screening systems.

Purpose

This report includes initial findings from an environmental scan. The goal of the scan was to create a repository of qualitative information on state activities related to developmental screening and early identification. This data set also will offer insight into the capacity of states to provide universal screening and coordinated systems for identification, referral and services. It will provide a foundation to develop resources and tools to share best practices nationally and provide technical assistance to states to improve their capacity and systems of care. This environmental scan broadly describes the identified strategies that state Title V and early childhood programs and partners are using to improve various aspects of the developmental screening process, amidst multiple challenges. It also describes the types of information available in the qualitative data set and opportunities for further analysis.

METHODOLOGY

AMCHP compiled a total of 185 source documents⁹ in an effort to capture the wide range of developmental screening activities occurring within all U.S. states and territories. These source documents include HRSA State Autism Planning and Implementation Grant Narratives and Reports,¹⁰ CDC *Learn the Signs. Act Early*. State Systems Grant applications and reports,¹¹ Act Early Summit Plans and recommendations, State Blueprints and Plans, State Taskforce Reports, State Guidelines, State Autism Resource Documents, case studies and other related reports on state activity from national and partner organizations. These source documents do not represent an exhaustive list of every state activity related to developmental and ASD screening.

Additionally, AMCHP conducted a scan of the Title V Information System (TVIS)¹² and data submitted by 59 U.S. states and jurisdictions from the annual Title V MCH Services Block Grant applications and reports. AMCHP identified state priority needs and state performance measures related to developmental screening and early identification. AMCHP also conducted a keyword search within TVIS of the state narratives to capture any additional text referencing activities on developmental screenings. Text used for the keyword search included “development screen,” “developmental monitoring,” “developmental screening,” “autism state plan,” and “autism plan.”

AMCHP used ATLAS.ti software¹³ to conduct a qualitative analysis of all the identified source documents and identify themes across state activities. All text was double coded with a state code and content code to indicate the state or territory where the text originated and reference the content of the text. Content codes can be grouped into general categories that include screening tools, guidelines and recommendations, training methods and audiences, screening processes, screening coordination efforts, family involvement, health equity, data collection, quality improvement, funding, sustainability, and challenges.

Findings

The search of the TVIS online database revealed a total of 19 states with a priority need specific to developmental screening/early identification, and a total of 21 state performance measures related to developmental screening/early identification in 20 states. The environmental scan of the TVIS reports and all source documents revealed a wide range of involvement of state programs in developmental and autism screening activities. Broadly, the information collected included:

- Challenges and barriers to comprehensive, effective developmental screening systems
- Strategies and activities states are implementing to increase screenings and improve systems for screening and early identification
- How states are coordinating systems of screening and care
- How states are tracking, measuring, collecting and using data
- Efforts to address health equity
- Efforts to involve and engage families
- State guidelines and recommendations (including evidence-based practices and/or screening tools)
- Strategies for funding and sustainability of developmental screening efforts

What is Developmental Screening?

Developmental screening is an important part of promoting healthy child development and ensures that children at risk for, or those who have a developmental delay, are identified as soon as possible and receive needed care and services.



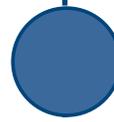
Developmental Monitoring

Recognizing developmental milestones in order to know what to expect, how to promote positive development, and when there are potential concerns about development.



Developmental Screening

A short test – administered with a standardized tool – to assess if a child is learning basic skills, and to identify if a child is at risk for a developmental delay.



Evaluation

A thorough review of a child’s behavior and development to identify developmental delays or disorders that are affecting a child.



Diagnosis

When a developmental pediatrician, child neurologist, child psychiatrist, or child psychologist uses the results of the comprehensive evaluation to determine if a child has an ASD or developmental disorder.

Linkage to appropriate, coordinated care and services for the child and family

The Autism CARES Act

One crucial support to state Title V and the larger public health community's ability to address ASD/DD-related issues was the enactment of the Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act, formerly the Combating Autism Act. Funding through the Autism CARES act includes support for:

- the Centers for Disease Control and Prevention (CDC) for surveillance and public awareness efforts,
- the Health Resources and Services Administration (HRSA) for autism education, early detection and intervention, and
- the National Institutes of Health (NIH) for research grants and the Interagency Autism Coordinating Committee

The HRSA implementation of this law addresses some of the most urgent issues affecting people with ASD/DD and their families. Among the goals of the HRSA effort are to enable all infants, children and adolescents who have, or are at risk for developing, ASD/DD to reach their full potential by:

- Developing a system of services that includes screening children early for possible ASD/DD

- Conducting early, interdisciplinary evaluations to confirm or rule out ASD/DD
- Providing evidence-based, early interventions when a diagnosis is confirmed

As part of this implementation, the Association of Maternal & Child Health Programs received a cooperative agreement to implement the State Public Health Coordinating Center. This center, better known as the State Public Health Autism Resource Center (SPHARC), is a comprehensive resource center intended to provide ongoing technical assistance for states as they build and sustain a system of care for children and youth with ASD/DD. In addition to this funding, state or nonprofit agencies in 30 states, including 12 Title V programs, have received State Planning and Implementation Grants for Improving Services for Children and Youth with Autism Spectrum Disorder and Other Developmental Disabilities to improve access to health care and related services for children and youth with ASD/DD. Grantee activities have focused on implementing existing state plans to improve services for these young people.

Congress reauthorized the Autism CARES Act for five years in August 2014. For more information about Autism CARES and HRSA's autism initiatives, visit <http://mchb.hrsa.gov/programs/autism/index.html>.





This information is catalogued in a qualitative database, which, as noted above, will provide the foundation for further analysis and development of resources to assist states in building and improving developmental screening and early identification systems. A high-level summary of the findings is outlined below, with a focus on the strategies being used to improve developmental screening, as well as state data collection and measurement efforts:

Strategies to Increase Developmental Screenings and Improve Systems:

The majority of state program activities to increase developmental screenings focus on improving the capacity for pediatricians, primary care providers, health care professionals and other early childhood professionals to conduct screenings and make appropriate referrals to resources and follow up.

- **Trainings to Improve Screening Rates and Capacity:** State programs develop modules and conduct trainings for physicians and health care providers on a variety of topics to increase developmental screenings. Popular topics include:
 - Early signs of ASD/DD and the importance of developmental screening
 - Processes for screening, referral and evaluation, including state and community specific resources
 - How to use and implement validated screening tools

- Screening within the medical home
- Working with families
- How to implement screening in a practice, including recommended guidelines and periodicity, available screening tools, billing codes and data collection

Such trainings take place during provider Grand Rounds, via webinars, in-person meetings and other avenues. Some states are partnering with universities to incorporate developmental and autism screening as part of the medical school curriculum. Other trainings are conducted for early childhood professionals, such as child care providers, early childhood educators, WIC staff and home visitors. These can range from trainings on early warning signs and screening tools to how to communicate with families and the referral process. Many states are also training parents to be advocates and educators on the importance of screening and early identification, as well as care coordination and ease of use of services.

- **Efforts to Increase Awareness and Education:** State programs work to provide education and awareness around developmental screening to providers, early childhood professionals and families. Activities under this strategy often included public service announcements, webinars, dissemination of materials through websites, community events and health fairs, and workshops. Many states have used national resources in awareness

efforts, such as CDC *Learn the Signs. Act Early.* campaign materials. To specifically reach providers, many states collaborate with their state AAP chapter to disseminate information and education opportunities through newsletters, Web portals, mailings and conferences. Many states are also using parent partners to educate providers.

- **Intensive Technical Assistance/Quality Improvement and Learning Collaboratives:** Implementing quality improvement projects and/or learning collaboratives are popular strategies states employ to help healthcare provider practices improve their screening rates and processes. Intensive technical assistance that is provided includes helping these practices establish a screening process, a data entry process, and a referral process for secondary screening and full diagnostic evaluations, and to improve ability to address family needs.
- **Developmental Screening Resources:** Many states have developed and/or adapted resources for healthcare providers and early childhood professionals to improve screening rates and coordination of referrals and linkage to services. Examples of these resources include:
 - Screening guidelines and best practices documents, such as a “pocket guide”
 - Screening and referral algorithms or roadmaps
 - Toolkits for physicians and early childhood providers
 - Guidance regarding care coordination needs and how to make referrals

- Letter or brochure templates providers can give to parents
- Cultural competency vignettes

- **Other strategies to increase screenings by providers** included identifying physician champions to promote screening and serve on advisory councils, providing incentives to screen such as continuing medical education credits to attend trainings or quality improvement collaborative and incentives to screen (such as reimbursement), and policies to increase proper screening (e.g. an Early Periodic Screening, Diagnosis, and Treatment (EPSDT) requirement to use validated screening tools).

Data Collection, Measurement and Infrastructure:

Incomplete data on the numbers, functional level and location of children and youth with autism and other developmental disabilities is a barrier for states in developing a comprehensive assessment of this population and assessing the quality and availability of services for these children and families. The collection, management and dissemination of data are critical to developing an effective and accountable system. States are building data infrastructure to assure needs and gaps are identified, programs are designed to meet the needs of the population, and efforts are measured to ensure they are having the desired impact and result in improved screening and health



outcomes. The scan identified information related to data in the following primary areas:

- **The Range of Data Sources States Use to Assess Rates of Screening, Early Identification and Children and Families affected by ASD/DD:** This includes national and state level sources of data that states use to assess developmental screening and rates of identification in their state. National data sources include the National Survey of Children’s Health, the Behavioral Risk Factor Surveillance System, Census data, and data from the CDC Autism and Developmental Disabilities Monitoring network (for participating states). Examples of data sources collected by states include Medicaid and insurance claims, Title V CYSHCN program data, state needs assessments, early intervention services data (Part B/C), vital records, newborn screening and hearing systems, focus groups and family surveys, provider surveys and home visiting data.
- **Strategies to Improve and Streamline Systems for Data Collection and Tracking:** Strategies in this area included developing and implementing an autism registry,

implementing a universal developmental screening system or adding a screening module to an existing child health data system, implementing data-sharing structures and agreements across local and state agencies regarding data on screening and follow up, and creating an inventory of existing data systems and elements to assist in data integration.

- **Measurement and Evaluation Approaches to Determine Progress and Outcomes:** The environmental scan documented the types of measures and evaluation methods that states are using to assess developmental screening and the outcomes of efforts in the state. This included examples of performance goals or targets, measures to indicate outcomes of better screening or better screening systems and process measures to assess progress towards goals of better screening and early identification systems. Figure 1 highlights examples of the types of measures states are using. This is not an exhaustive list of measures that were collected as part of the scan. Additionally, it does not represent recommended goals and measures that one state would implement;

Figure 1: Examples of State Goals/Performance Targets, Process Measures and Measures of Improved Developmental Screening Systems

Goals/Performance Targets

- Ensure that children are screened, evaluated, diagnosed, and subsequently referred for treatment in a timely manner
- Increase the number of Medicaid and CHIP enrollees under the age of one year who receive at least one screening
- Decrease the average time between screening and diagnosis
- Use standardized assessment tools for screening and diagnosis
- Increase the number of qualified providers who can administer developmental screenings
- Increase knowledge and skills of developmental screenings for non-medical professionals (e.g. early childhood educators and childcare personnel) and for parents

Process Measures

- The percent of pediatric primary care providers using validated screening instruments (e.g. ASQ, M-CHAT)
- The percent of primary care providers that conduct routine age-specific developmental screenings in their practice
- The number of referrals by providers or child care professionals
- The number of trainings provided on developmental screening tools and methods and number of providers /professionals reached
- Pre- and post-test changes in knowledge and skills related to screening, identification and management of ASD
- The average wait time between screening and diagnosis

Improved Systems Measures

- Improved systems of care for children with ASD/DD and their families through expedited the screening, evaluation, diagnosis and referral processes
- Increased percent of families of children with ASD/DD who have culturally competent, family-centered medical homes; increased percent of families that partner in decision-making at all levels and are satisfied with quickness of screening and coordination of services
- Increased percent of children with ASD/DD who are enrolled in services by 48 months

NOTE: This figure provides examples of ways state programs may currently measure success of efforts and assess system improvements. It is not intended as guidance or recommendations for the measures and goals that any one state should use.

rather it is a collection of examples from different states to highlight how they may measure success of efforts and ensure activities are resulting in improved screening and systems, and ultimately better services and health for children and families.

- **Additional Data Elements that Provide Insight into State Screening and Early Identification Systems:**

Other data elements that were identified through the scan include examples of elements that states were able to track, such as a child level identifier, the types of screening tools used, where screenings took place, results of screenings, wait times for referrals and evaluations, and communication of results to providers, among other elements. These elements were not necessarily tracked in one system but provide an opportunity for linkages of data and improved ability for quality assurance that screenings result in timely referral, evaluation and services.

Coordinating Systems and Services:

Family-centered, community-based coordinated care for CYSHCN, including ASD/DD, is a key responsibility of state Title V programs and key focus for state ASD/DD grantees. Families and children affected by ASD/DD are part of a larger framework of ongoing services and programs. These often include education, medical services, physical and behavioral health care systems, social services, child care, and other early childhood programs. Many states are building/pursuing/strengthening partnerships across systems that maximize resources, reduce duplicative efforts and coordinate services to decrease the burden on families and more effectively promote the healthy development and well-being of children. Examples of state strategies identified in the scan included establishing communication mechanisms and portals to receive information on screening and early intervention services, interagency committees for developmental and autism screening, establishing a statewide system for referrals and timely evaluation, and establishing cross-agency policies and procedures to coordinate resources. State autism grantees and Title V programs reported a focus on developing partnerships with health care providers, child care providers, schools and educators, Medicaid/EPSDT, Part C and large insurance providers, WIC and state home visiting programs, among others. Collaborations and efforts were also aligned with other programmatic investments in early childhood, such as Part C, Early Head Start/Head Start, Early Childhood Comprehensive Systems (ECCS), Help Me Grow funded programs, Project LAUNCH and Race to the Top grants.

Challenges/Barriers:

The most common challenges cited by states were related to provider barriers to screening, access and coordination among service and data systems. For providers, the lack of time during visits and the costs (or lack of adequate reimbursement) associated with screening, not knowing where to refer a child for further evaluation, as well as a lack of trained health care professionals in evaluation and diagnosis, were commonly reported challenges.

Additionally, many providers were not using validated screening tools, which could be associated with lack of awareness of other tools, and higher costs or time needed to use standardized tools. Common challenges also included access to screening and referral services, especially in rural locations, and the lack of coordination or communication among the various service programs and agencies involved in screening, evaluating and providing needed health care services. Obstacles in data collection, such as not being able to link data systems, can result in the inability to properly assess for gaps in systems and services or to develop programs and policies that best meet the needs of children and families in the state. Other challenges states reported included the need to increase general public and family awareness and to develop accurate, culturally relevant resources.



Other Findings on State Activities:

While not detailed in this document, the environmental scan captured a number of other themes related to state developmental screening activities. These activities include specific guidelines or recommendations by state task forces or commissions, as well as policy strategies and levers to increase screenings. Information was collected on which standardized screening tools were most commonly used in or recommended by state programs; the most cited of which were the Ages and Stages Questionnaire and the Modified Checklist for Autism in Toddlers (M-CHAT). The scan also captured strategies and initiatives to address health equity and reduce disparities in access to screening and early intervention services. This included efforts to increase cultural competence and outreach to underserved populations. Specific efforts around family involvement also were commonly reported. As noted above, parents as educators and trainers are effective strategies to increase knowledge and awareness among providers, health care professionals and other families. Finally, the environmental scan data set contains information on sustainability strategies to ensure developmental screening efforts are continued and supported statewide. Further analysis in these areas will provide valuable information to national, state and community partners on how developmental screening is being addressed in states, and provide potential recommendations for improving systems and ensure quality of care.



State Highlights: Developmental Screening and Beyond

In August 2014, the AMCHP SPHARC and Maryland HRSA State Autism Implementation Grantee team hosted a Peer-to-Peer Exchange event on “Screening and Beyond: Improving Systems for Developmental Screening and Early Identification” where eight HRSA state autism grantees met to share resources, program strategies, challenges and successes. As part of the meeting, each grantee provided a one-page profile of developmental screening activities in their state. Highlights of activities from the profiles are outlined below. These highlights are part of the broader activities captured in the source documents for this environmental scan, specifically the HRSA grantee narratives and reports. They illustrate the types of activities that were collected as part of the scan and will be the basis for case studies or similar resources.

Training Providers and Early Childhood Professionals

- Using the Collective Impact framework, Virginia provides training on developmental screening tools for early intervention providers and childcare professionals twice per year at three sites within the state. To increase diagnostic capacity, Virginia is developing interdisciplinary community based diagnostic teams.
- North Dakota has provided trainings to daycare providers, as well as the medical community, on how to utilize screening tools, specifically the MCHAT. Through the grant, the state has trained 375 medical professionals in 43 of the 53 counties, as well as 480 childcare and preschool professionals at 29 facilities across the state.

Quality Improvement & Learning Collaboratives

- The Maryland Screening and Beyond Quality Improvement Learning Collaborative employs trained Parent Partners as equal members of the quality improvement (QI) team. The Parent Partners work directly with participating providers, give valuable input, provide resources to families, and collect and report data.
- Ohio provided autism education and training to nearly 900 of the state licensed general pediatricians through the Concerned about Development Learning Collaborative.

Increasing Awareness, Education and Outreach

- Mississippi held a statewide developmental screening day during Autism Awareness Month to promote resources and provide an opportunity for concerned parents and pediatricians to have young children screened for ASD.

Coordinating Systems and Services

- The Colorado Collaborative for Autism and Neurodevelopmental Disabilities Options (CANDO) is an all volunteer committee to help evaluate and support the state 10-year strategic plan effort individuals for ASD/DD. It has wide representation from many community and ASD sectors.

Data Collection and Infrastructure

- Connecticut integrated a developmental screening data collection tool into the Connecticut Medical Home Initiative database in order to track whether a child has received a developmental screening, screening results, confirmation of screening results and referrals made.

Policies to Increase Screening

- In Arkansas, there is legislation in place that requires pediatricians who provide Medicaid services to conduct screenings with the ASQ at nine months, 12 months, and 18 months.

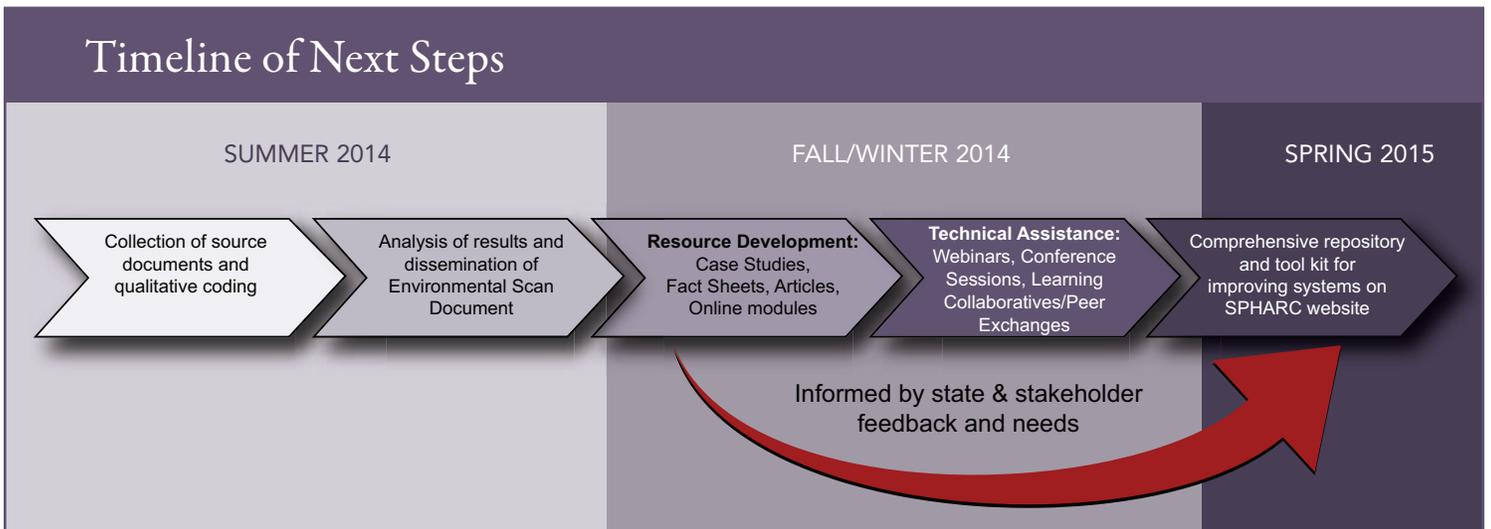
To learn more about the developmental screening profile and resources of each state, visit the “Peer-to-Peer Exchange” section of the SPHARC website:
www.amchp.org/programsandtopics/CYSHCN/projects/spharc/Pages/default.aspx.



CONCLUSION AND NEXT STEPS

The environmental scan revealed a wealth of information on state activity related to developmental screening and early identification. The data available provides insight into common strategies and identified needs to improve state systems of care and collect and use data to drive efforts and measure impact, as well as the resources, training modules and tools that have been developed and used to date. The scan provides a broad picture of current state activities; however, it does not describe developmental screening trends over time, or provide recommendations on best practices and how states should implement initiatives moving forward. Over the coming year, this data will be further analyzed to develop resources to assist states in building and improving developmental screening and early identification systems. These tools and resources will be housed on the AMCHP SPHARC website and disseminated broadly. This data also will be used to inform technical assistance opportunities, such as webinars, conference sessions and in-person meetings. The goal will be to have an easy to access repository of information that states can access to compare and improve systems of care in their state, and for state and national partners to identify promising trends, practices and opportunities to have wide and sustained impact that improves the health and access to care for all children and families.

Timeline of Next Steps



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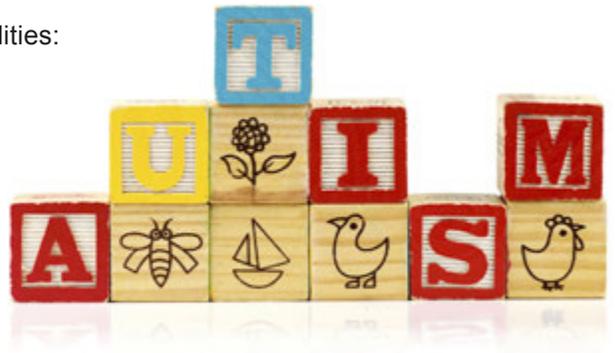
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¹⁴ The Ages and Stages Questionnaire (ASQ) 3rd edition is a developmental screening system made up of 21 age-specific questionnaires completed by parents or primary caregivers of young children. Each questionnaire can be completed in 10-15 minutes. The ASQ also has a complementary social and emotional screener (ASQ:SE). More information is available from: <http://agesandstages.com/>. The MCHAT is a 2-stage parent-report screening tool to assess risk for Autism Spectrum Disorder (ASD). The autism screening tool is designed to identify children 16-30 months of age who should receive a more thorough assessment for possible ASD/DD. More information is available from: <https://www.m-chat.org/>. For the purposes of this report, the citations coded under “ASQ” and “M-CHAT” included all versions reported for each tool, e.g. ASQ, ASQ-3, ASQ-SE, M-CHAT, M-CHAT-R/F, etc.



ADDITIONAL RESOURCES:

- Association of University Centers on Disabilities: Interdisciplinary Technical Assistance Center on Autism and Developmental Disabilities:
www.aucd.org/itac/template/index.cfm
- Birth to Five: Watch Me Thrive!
www.acf.hhs.gov/programs/ecd/watch-me-thrive
- CDC: *Learn the Signs. Act Early.*
www.cdc.gov/ncbddd/actearly/index.html
- HRSA: Autism CARES – Resources on Autism and Other Developmental Disabilities:
<http://mchb.hrsa.gov/programs/autism/>
- State Public Health Autism Resource Center (SPHARC):
www.amchp.org/programsandtopics/CYSHCN/projects/spharc/Pages/default.aspx



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