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**Report on State Services
to Individuals with
Autism Spectrum
Disorders (ASD)**

**Centers for Medicare &
Medicaid Services (CMS)
ASD Services Project**

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1. Introduction and Background

Over the past 30 years, the prevalence of autism spectrum disorders (ASD) in the United States has increased sharply.¹ Today, the Centers for Disease Control and Prevention (CDC) estimates that 1 in 110 children in the US has an ASD.² While the national economic downturn persists, causing public revenues to decrease, states are challenged to meet the growing demand for publicly financed services to individuals diagnosed with ASD. To make the most effective use of limited resources, federal and state policymakers need empirical data to make informed decisions about which services and support systems are safe and cost-effective in meeting the complex needs of children, adolescents, and adults with ASD. Few initiatives have focused on providing information about the most effective services for individuals with ASD. Those that do, such as the National Standards Project (NSP), have primarily addressed the needs of individuals under age 21 years. Although these efforts provide critical information about effective services and supports for individuals with ASD, gaps exist in information about promising services for transition-age youth and adults. In particular, prior to this study, no efforts at the national level examined ASD services and supports within the context of Medicaid, which is the main public funder of such services outside the education system for affected individuals and their families.

1.1 CMS Initiatives to Align Practice with Science

CMS conducts a range of policy, program, and financing efforts to ensure the quality and effectiveness of services provided to Medicaid recipients who have ASD. In these efforts, CMS participates as a member of the Interagency Autism Coordinating Committee (IACC), established by Congress pursuant to passage of the Combating Autism Act of 2006 to advise the Secretary of Health and Human Services (HHS) and coordinate HHS's ASD initiatives. In keeping with the intent of the legislation to promote adoption of evidence-based practice and reduce barriers to screening and diagnosis, the IACC focuses particularly on advancing the science underlying identification, diagnosis, and treatment of persons with these conditions.³ Further, the IACC 2011 Strategic Plan includes the following aspirational goal: communities will access and implement necessary high-quality, evidence-based services and supports that maximize quality of life and health across the lifespan for all people with ASD.⁴ As a complement to scientific efforts, CMS is supporting Initiatives to profile promising practices in ASD services and disseminate these to stakeholder groups and the states to influence development of effective care systems.

¹ Newschaffer CJ, Falb MD, and Gurney JG. (2010). National Autism Prevalence Trends From United States Special Education Data. *Pediatrics*. 115(3): e277-e282.

² Centers for Disease Control and Prevention. *Autism Spectrum Disorders: Data and Statistics*. Available at <http://www.cdc.gov/ncbddd/autism/data.html>

³ The Combating Autism Act of 2006. Pub. Law No. 109-416 and www.iacc.hhs.gov

⁴ Interagency Autism Coordinating Committee. *2011 IACC Strategic Plan for Autism Spectrum Disorder Research*. 2011 Jan. Retrieved from the Department of Health and Human Services Interagency Autism Coordinating Committee website at <http://iacc.hhs.gov/strategic-plan/2011/index.shtml>.

Despite the growth in services to persons with ASD, including behavioral interventions, there are few randomized controlled trials providing evidence for those practices.⁵ Applied behavior analysis (ABA) is an exception, in that controlled trials have shown both the efficacy of programs based in the principles of ABA and that certain individual characteristics (age, IQ, and functional impairments) are associated with positive outcomes. Given the emergence of innovative and promising practices with early stage results, and the desire for guidance on these programs' effectiveness, metrics other than randomized controlled trials may need to be considered when evaluating interventions at a nascent stage of testing. Current efforts to support research, disseminate knowledge about evidence-based practices, and identify emerging practices that show promise are each designed to promote a better fit between the need for and use of services by persons with ASD, and to improve the quality and outcomes of services utilization, including the clinical efficacy and cost efficiency of care.

The stakes are high for both children and adults with ASD and their families, because overcoming developmental delays, avoiding or mitigating disability, and reaching one's full potential for a productive life among one's family and friends in the community is heavily dependent on the timely receipt of effective ASD services. The results of these initiatives to evaluate and promote the adoption of evidence-based and promising practices are also important to the stewards of the public trust and government resources invested in the care for beneficiaries. Given the range and depth of needs found among a diverse population of children and adults with ASD, a broad spectrum of services is required across the lifespan of the individual. CMS strives to fill critical gaps in information available to state policymakers, program practitioners, and ASD stakeholders about effective interventions and the best way to disseminate them.

Autism Spectrum Disorders Services Project

To address the gap in information on Medicaid-covered services for individuals with ASD, CMS contracted with IMPAQ International, LLC in 2008 to conduct the *Autism Spectrum Disorders (ASD) Services* project. In this multi-year project, IMPAQ and its subcontractor Abt Associates, are to complete three main tasks to obtain, synthesize, and disseminate information about available services and supports for individuals with ASD and their families:

- Comprehensive environmental scan of evidence in the research literature related to the effectiveness of services and supports for individuals with ASD,
- Assessment of the evidence-based/promising services currently being provided by nine states to individuals with ASD, and
- Design of model programs of services and supports for children, transition-age youth, and adults with ASD.

The environmental scan of the evidence base for ASD services, showed the following:

⁵ The 2010 Interagency Autism Coordinating Committee Strategic Plan for Autism Spectrum Disorder Research. Available at <http://iacc.hhs.gov/strategic-plan/2011/index.shtml>

- Of 31 interventions identified for young children, about half (48%) met the evidence-based standard, another 42% were rated as emerging evidence-based, and only 10% had no supporting evidence.
- Of 15 interventions identified for transition-age youth, only 7% met the evidence-based standard, while 73% had little or no supporting evidence.
- Of 9 interventions identified for adults, a third met the evidence-based standard, while 56% had little or no supporting evidence.⁶

Thus, the scan indicated particularly significant gaps in the evidence base for services targeted to transition-age youth and adults with ASD.

The second task – assessing the implementation of evidence-based/promising practices through the lens of state experience – is the subject of this report. The report summarizes the current state of ASD-related services in nine representative states: Arizona, California, Connecticut, Indiana, Maine, Missouri, New Mexico, Pennsylvania, and Wisconsin. It describes the types of services and supports provided under the auspices of state and local governments; the sources of funding for those programs; and the policy, staffing, and implementation issues that must be addressed to effectively serve persons with ASD.

The states were selected in consultation with CMS staff to represent a diversity of federal waivers, service coverage, funding sources and levels, and geographic areas. The IMPAQ team gathered and summarized information from interviews with an average of three contacts in each state, including representatives of state agencies, provider organizations, and advocacy groups; and from program documents and peer-reviewed and grey literature on service developments provided or recommended by the individuals who were interviewed.

The report has six sections. Section 2 describes the study methods and approach. Section 3 reviews state efforts to adopt and implement evidence-based/promising practices in ASD, including a cross-cutting analysis of progress and challenges in adoption and implementation initiatives. Section 4 presents selected state practice profiles for each state. Section 5 concludes the report by highlighting options for selecting and implementing sustainable and promising evidence-based practices targeted to different need and age groups within the ASD population. Appendix 1 contains brief state summaries of the organization, financing, and delivery of ASD services and supports in each of the nine states. Appendix 2 contains the Discussion Guide used in the discussions with state officials and representatives of provider organizations and advocacy groups.

⁶ Young J, Corea C, Kimani J, and Mandell D. (2010). Autism Spectrum Disorders (ASDs) Services Final Report on Environmental Scan. Available at <http://www.impaqint.com/files/4-content/1-6-publications/1-6-2-project-reports/finalasdreport.pdf>

2. Methods and Approach

In this section we describe the approach taken to select states for review, develop the interview discussion guide, reach out to and engage the state officials and other key organizations, and synthesize the data gathered.

2.1 State and Practice Selection Process

The states selected to participate in this exploratory project were chosen based on whether they had three or more of the following characteristics:

- Use of Medicaid waivers by the administering state agency (e.g., states with ASD-specific HCBS Medicaid waivers, as well as states with HCBS waivers that are not ASD-specific)
- Broad range of services offered to children and adults (e.g., diversity in state service models, eligibility criteria, funding streams, funding mechanisms, and funding generosity)
- Selected geographic or regional characteristics
- Of interest to CMS and other project team members because of unique conditions, innovative programs, and/or executive, judicial, or legislative developments

To develop a preliminary list of states to be included in this review the study team sought feedback and recommendations from project partners. This list was further broken into a sample of 14 states and potential alternates. These states, and the rationale for their inclusion, were discussed with the IMPAQ Project Director and CMS Project Officer. Nine were finally selected and agreed to participate.

The team interviewed contacts from each state. As part of these interviews, the contacts were asked to recommend at least one practice contact and/or program name to be featured as an example of promising practices or best services from their state. The promising practice contacts and program representatives were then either interviewed directly or asked to provide another contact. In some interviews multiple individuals participated.

2.2 Discussion Guide Development

The qualitative discussion guide developed to support the interviews was designed to gather descriptive information for a comprehensive picture of a State's best services or promising practices for individuals with ASD and associated implementation considerations. Four main areas of general interest were highlighted plus six questions of particular interest to CMS.

General Interest Areas:

- Evidence-based practices, best practices, promising practices
- Service-related topics
- Policy and fiscal issues
- Lessons learned and future directions

Questions of particular interest to CMS:

- How are states meeting the growing needs of individuals with ASD in a time of fiscal stress?
- Given that the American Recovery and Reinvestment Act (ARRA) prohibits states from changing Medicaid eligibility requirements, what strategies are states using to manage within budget constraints?
- What information can be given to states to assist them with providing the highest quality and lowest cost services to a growing population of children and adults with ASD?
- For states that have used self-directed services, is this model working?
- What are states doing to address gaps in evidence-based services targeted to transition-age youth and adults with ASD?
- What efforts are the states undertaking or supporting to conduct ASD clinical or program research?

Transition-age youth and adults were particularly highlighted in the interview discussions because of the wider evidence gaps in service effectiveness for those groups.

In judging whether to include a practice as “evidence-based” or “promising” (a somewhat less stringent criterion), we used the National Professional Development Center for Autism Spectrum Disorders (NPDCASD) definition of evidence-based practice and the CMS definition of promising practices. States were provided both definitions in preparation for the interviews, and the selected practices delineated in the rest of this report are referred to as evidence-based/promising to emphasize the either/or nature of our judgments.

The NPDCASD, a multi-university center that promotes the use of evidence-based practices for children and adolescents with ASD (described further in Section 3.4), provides the following definition of evidence-based practice:

To be considered an evidence-based practice for individuals with ASD, efficacy must be established through peer-reviewed research in scientific journals using:

- Two high quality randomized (experimental) or quasi-experimental group design studies;
- Five high quality single-subject design studies by three different investigators or research groups; or
- A combination of one high quality randomized or quasi-experimental group design study and three high quality single subject design studies conducted by at least three different investigators or research groups (across the group and single-subject design studies).⁷

⁷ The National Professional Development Center on Autism Spectrum Disorders. *What is an Evidence-Based Practice?* Available at <http://autismpdc.fpg.unc.edu/content/evidence-based-practices>

CMS provides the following definition and criteria for promising practices:

A "promising practice" must:

- Be related to the improvement of quality of care and/or life for Medicaid and/or [Children's Health Insurance Program] CHIP beneficiaries;
- Address a significant problem in health status or functioning based on trends in mortality, morbidity, quality of life, utilization, and/or costs;
- Reflect an innovative approach to meeting a common problem;
- Have been in operation for a sufficient period of time to demonstrate effectiveness (i.e., minimum 12 months);
- Have demonstrated success through tangible results (e.g., improvements in beneficiary physical or mental well-being, savings);
- Comply with federal Medicaid statute and regulations and CMS policy direction.⁸

The discussion guide appears in Appendix 2.

2.3 Summary of Study Outreach and Contact Efforts

The study team drafted an email communication for the selected states that described the project. This email was forwarded by the PO to State Medicaid Directors and other contacts on December 28, 2009. The study group then contacted the Medicaid Directors to schedule initial state interviews or identify the best individuals to interview for their state. Individuals who responded to the email or to the phone calls either (a) scheduled a telephone discussion expected to last no longer than an hour or (b) directed us to a colleague (or colleagues) identified as the most knowledgeable and/or with a designated responsibility for ASD policy and programs.

In 2010, the team interviewed 31 individuals representing 26 state departments, agencies, and organizations across the nine study states. All interviewees were senior state or program officials (directors, deputies, or assistant directors).

⁸ Centers for Medicare and Medicaid Services. *Promising Practices: Concept and Nomination Process*.

Available at

https://www.cms.gov/MedicaidCHIPQualPrac/10_PromisingPracticesConceptNominationProcess.asp

2.4 States Interviewed and Organizations Represented

Exhibit 1 indicates the nine states that were studied and the agencies and organizations that participated in interviewees for the study.

Exhibit 1: States and Organizations Interviewed for the Report on State Services for Individuals with ASD

State	Agencies and Departments Interviewed
Arizona	Arizona Health Care Cost Containment System; Department of Economic Security, Division of Developmental Disabilities; Southwest Autism Research and Resource Center
California	Department of Developmental Services; Alta California Regional Center; Therapeutic PATHWAYS/Kendall Schools
Connecticut	Department of Developmental Services; Department of Social Services; The Center for Children With Special Needs
Indiana	Division of Disability and Rehabilitative Services; Indiana First Steps Program
Maine	Department of Health and Human Services; Office of Adults with Cognitive and Physical Disabilities; Maine Developmental Disabilities Council; Autism Society of Maine
Missouri	Division of Developmental Disabilities; Department of Mental Health, Office of Autism Services; Missouri Commission on Autism; Thompson Center for Autism and Neurodevelopmental Disorders at the University of Missouri
New Mexico	Department of Health, Developmental Disabilities Supports Division; The Center for Development and Disabilities
Pennsylvania	Department of Public Welfare, Bureau of Autism; Department of Education; Keystone Human Services
Wisconsin	Department of Health and Family Services; Division of Long Term Care; Department of Public Instruction

2.5 Data Synthesis

State and program officials were generous with their time and contributions, referencing or providing a number of documents for review. Interviews were conducted by one principal accompanied by a research analyst, both of whom made written notes to document the interviews. Once the interviews were complete, the interview team consolidated and incorporated the information given by the interviewees along with the documents sent to, or accessed electronically by, the interview team. To the extent possible, information was reviewed for consistency and accuracy. The interview data and documents, along with information obtained on state agency websites and provided by consumer groups, were consolidated into brief state summary documents

(included in Appendix 1). The state summaries were sent in draft to each state's interviewees, offering the opportunity to review, comment, and/or provide additional information for incorporation into the summary. Seven states provided feedback. The cross-cutting analysis in Section 3 contains exhibits that compare state services and policies for ASD based on the interview summaries.

In addition to these discussions, the following were reviewed:

- Peer-reviewed and grey literature on service developments and program documents provided by the discussants
- Websites affiliated with the states and their contacts
- Internet searches of national organizations that provide information on autism, ASD, EBP, and other targeted information

3. State Efforts to Adopt & Implement Evidence-Based/Promising Practices in ASD

Services to children and adults with ASD are evolving as states grapple with meeting increased demand for services. Because these disorders are complex neurodevelopmental conditions, individuals are best served with a broad array of services organized for delivery across the lifespan. During the last 40 years, comprehensive community-based care systems have become the norm in serving persons with developmental disabilities and behavioral health conditions. Individuals with ASD and their families currently depend on parts of either or both of these service systems to complement education services in meeting their needs, because discrete ASD systems of care have not been firmly established. Not surprisingly, these systems have been found to provide less than optimal access for some of the most vulnerable ASD children and adults, particularly those with intensive needs.⁹ In a 2006 study, for example, states' efforts to improve access, cost, and quality of care through implementation of Medicaid managed care programs under waivers for targeted populations with developmental disabilities and psychiatric disorders were found not to increase access and service use for individuals with ASD.¹⁰ This picture is now beginning to change, as more states pass legislation establishing governmental bureaus or offices dedicated to autism, apply for Medicaid home and community-based services (HCBS) targeted to persons with autism or ASD, and move to adopt and implement on a broader scale evidence-based/promising practices targeted directly on ASD.

This section reviews the progress and challenges encountered by the nine study states involved in the adoption and implementation of evidence-based/promising practices. Our discussion is organized into four subsections:

- Policy and system administration
- Services targeted to persons with ASD--ranging from initial client screening, diagnosis, and determination of eligibility to development of a system of care
- Care system development issues--including access to services and supports, staffing and workforce, financing and sustainability, and strategies to manage growing consumer demand in the context of fiscal constraints
- Standards, quality, evaluation, and research

3.1 Policy and System Administration

The juxtaposition of the complex conditions associated with ASD across the lifespan with the siloed fragmentation of state health and human services programs sets the stage for multiple public policy

⁹ Montes G, Halterman JS, Magyar CI. Access to and satisfaction with school and community health services for US children with autism spectrum disorder. *Pediatrics*. 2009;124 (suppl 4):S407–S413

¹⁰ Ruble LA, Heflinger CA, Renfrew JW, Saunders RC. Access and service use by children with autism spectrum disorders in Medicaid managed care. *Journal of Autism and Developmental Disorders*. 2006; 35 (1): S3 – S13.

permutations and combinations. In any given jurisdiction, numerous local, state, and federal programs touch the lives of affected individuals. This fragmentation not only drives variation in policy but also flows to the organization, financing, and delivery of care.¹¹ While screening and diagnostic services may be funded by Title XIX of the Social Security Act (Act) under state Medicaid programs and delivered by pediatric or primary medical care practitioners, for example, prevention and early intervention services may be funded by Title V/Maternal and Child Health under the aegis of departments of public health. Other early treatment services may involve funds and programs from departments of mental health and/or developmental disabilities services and by departments of education implementing the Individuals with Disabilities Education Act (IDEA) mandates and child welfare agency services. As an individual with ASD ages, additional entities that plan, provide, or pay for social, medical, rehabilitative, housing and/or vocational services may play a policymaking role. Some states (e.g., California) and some federal programs (e.g., No Child Left Behind) have requirements to use evidence-based practices; however most do not.¹²

Even in states that have established dedicated entities singularly focused on autism or ASD (like Pennsylvania with a Bureau of Autism Services or Missouri with the Office of Autism Spectrum Disorders), policy is not uniform across agencies and the dedicated entity may be charged with coordinating a range of policies and programs, as is described in Pennsylvania's case below:

- In Pennsylvania, the Bureau of Autism Services works to align policy and program initiatives, promote innovation and evidence-based services, and fill gaps in care for individuals with ASD by interacting with and offering technical assistance to other State agencies with a responsibility for providing care for persons with ASD, including:
 - Pennsylvania Office of Child Development and Early Learning (OCDEL) for early intervention services to children ages 0-3
 - Office of Mental Health and Substance Abuse Services (OMHSAS) for behavioral health services to Medicaid and Medical Assistance eligible children with ASD who use, for example, behavioral health rehabilitation services
 - Pennsylvania Department of Education (DOE) for services provided through age 21
 - Office of Developmental Programs (ODP) for services under the Consolidated and Person/Family Directed Support (PFDS) Intellectual Disability waivers
 - Pennsylvania's Medicaid program, known as HealthChoices, which covers managed care plans and waiver programs that provide developmental, medical, and behavioral health services

All state interviewees, as well as those affiliated with the program providers, cited the need for a national standard and federal guidance on what constitutes evidence-based practices policy. The

¹¹ The 2011 Interagency Autism Coordinating Committee Strategic Plan for Autism Spectrum Disorder Research. Available at <http://iacc.hhs.gov/strategic-plan/2011/index.shtml>

¹² Odom SL, Boyd BA, Hall LJ, and Hume K. 2009. Evaluation of Comprehensive Treatment Models for Individuals with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders*. 40(4):425-36. Epub 2009 Jul 25.

2011 IACC Strategic Plan also notes the importance to individuals with ASD and their families of having a reference or guide to evidence-based/promising practices to support systems navigation and services selection.¹³

Threshold eligibility, fiscal, and program policies are often set by the federal government or other primary entitlement and funding sources. States, particularly in their Medicaid programs, have options to expand eligibility and modify or waive certain program and fiscal policies set by federal government agencies. However, in the absence of more formal policies or guidelines from the federal government, even the best intentioned and most collaborative state stakeholders are challenged to align and integrate policy across the different state and federal programs that individuals with ASD may qualify for and use, let alone policy to drive adoption and implementation of evidence-based/promising practices in ASD.

A wide range of practices was found in the study states with regard to establishing formal policies on the adoption, implementation, and reimbursement of evidence-based/promising practices in ASD. Several states reported using the CMS definition of promising practices, while others referenced the NSP, the IACC, language in their Medicaid waivers, and/or state enabling legislation. Given the significant role that formal policy can play in setting priorities, system design, resource allocation, and public accountability, the overlapping and competing policies revealed by our case studies is bound to create barriers to full adoption and sustainable implementation of evidence-based/promising practices to meet ASD service needs. In the absence of formal federal policies, all the study states are engaged to some degree in developing or enhancing policies designed to promote and sustain use of evidence-based/promising practices. Here are examples:

- Arizona set medical necessity and evidence-based practice as the twin standards governing coverage for all services under its Medicaid waiver.
- California embedded some policies favoring use of evidence-based or “clinically determined” services in its State enabling legislation (the Lanterman Act), which now requires some modification to mitigate misuse of the latter term. California also drafted best practices in interagency collaboration, helping to integrate policies across the collaborating agencies.
- Connecticut does not have formal State policies on use of evidence-based practices, although it did embed references in its autism waiver.
- The Indiana Autism Task Force is currently developing a formal policy on best and promising practices.
- Maine’s Children’s Evidence-Based Services Committee recently published “Interventions for Autism Spectrum Disorders: State of the Evidence” to guide individuals, families, and providers in use of these practices.¹⁴

¹³ The 2010 Interagency Autism Coordinating Committee Strategic Plan for Autism Spectrum Disorder Research. Available at <http://www.iacc.hhs.gov/strategic-plan/2010/index.shtml>

¹⁴ Maine Department of Health and Human Services (DHHS) and Maine Department of Education. (2009). *Interventions for Autism Spectrum Disorders: State of the Evidence*. Available at www.maine.gov/dhhs/ocfs/cbhs/ebpac/asd-report.doc

- Missouri established a Blue Ribbon Panel on ASD, engaging a broad range of constituents and leading to enabling legislation that established the Office of ASD and framed State policy for services.
- New Mexico engaged its stakeholders in a commission appointed by the governor; families are credited with defining promising practices.

The varied status of policymaking and promulgation across the study states reveals both a slower than preferred pace of adoption and ambivalence arising from the persistent gaps in evidence-based practices in ASD. In a 2008 brief, the Institute of Medicine addressed the importance of making credible and understandable evidence available to patients, providers, and payers to support sound decision making on which services to use to obtain positive results.¹⁵ Parents and practitioners alike are looking for guidance from reliable sources, including the states, the federal government, and research institutions. Whatever their progress in developing formal evidence-based/promising practices, all the study states expressed a need for formal policy guidance from the federal government, most notably from CMS.

3.2 Services Targeted to Persons with ASD

3.2.1 Client Screening, Diagnosis, and Eligibility

Screening and Diagnostic Standards

Timely and accurate screening and diagnosis are essential for rapid assessment, eligibility determination, and the provision of early intervention services. Delays in diagnosis in turn delay treatments, some of which are optimally delivered early in the developmental period. A recent large scale study found, however, that the median age for diagnosis of ASD is 6 years and that more than one-quarter of children with ASD do not receive a diagnosis until age 8.¹⁶

A particular problem is that pediatricians and family practitioners have to screen for multiple disorders and may not know that general developmental screens do not specifically identify ASD.¹⁷ For this reason, specific guidance on ASD screening, diagnosis, and subsequent assessment is necessary to ensure that children are identified and treated for ASD as early as possible.

Although they do not use a uniform approach to ASD screening and diagnosis, all the study states have some type of standards for screening or make use of the American Academy of Pediatrics ASD

¹⁵ Institute of Medicine (2008). *Systematic review: the central link between evidence and clinical decision making*. Report Brief, January.

¹⁶ Shattuck, et al (2009). *Timing of the identification among children with autism spectrum disorder: findings from a population-based surveillance study*. Journal of the American Academy of Child and Adolescent Psychiatry, May Issue.

¹⁷ Golnik et al (2009). Medical homes for children with autism: s physician survey. *Pediatrics*. 123(3); 966-971.

screening guidelines, which notably recommend ASD screening for all 18- to 24-month-old children.¹⁸ All study states make a clear distinction among screening, diagnosis, and assessment. And all note the challenge of training pediatric and other front-line practitioners in screening for ASD and in recruiting sufficient numbers of trained developmental specialists to provide assessment and diagnostic services to determine eligibility and service needs. (Strategies to address the inadequate supply are detailed below in Subsection 3.3.2 and more detail on the shortages and related challenges is in Section 4, Subsection 4.3.)

Specific state approaches to screening, diagnosis, and assessment include the following:

- California published best practices for ASD screening, diagnosis, and assessment in 2002. The Lanterman Act of 2010 mandates the California Department of Developmental Services (DDS) to develop new standards for diagnosis and that these new standards be evaluated for effectiveness. California DDS staff collaborated with Missouri (see more below) on the development of standards.
- Connecticut includes screening and diagnosis of autism and ASD in its 2010 Guidelines for Identifying Children with Learning Disabilities related to IDEA. The guidelines suggest use of screening and assessment tools when autism is a suspected cause of learning difficulties. Guidelines for identifying children with autism and ASD were also specifically included in the State's 2005 Guidelines for Identification and Education of Children and Youth with Autism.
- Indiana concentrates more on eligibility criteria than diagnosis. The State's focus is on timely eligibility determination, with a medical diagnosis of autism welcomed. Comprehensive multidisciplinary assessments often result in a label of "developmental delay" rather than an ASD diagnosis. Either will trigger eligibility.
- Maine began universal screening for ASD in 2008. Providers in Maine use the Modified Checklist for Autism in Toddlers (M-CHAT) to screen for ASD at 18 and 24 months.
- Missouri published their own best practice guidelines for ASD screening, diagnosis, and assessment in 2010, in consultation with representatives from California. The two states' guidelines diverge, however, according to their different service and funding configurations.
- New Mexico addresses its rural and frontier status, as well as the limits in availability of trained diagnosticians, by directing diagnostic evaluation to the Center for Development and Disability at the University of New Mexico's Medical School and to New Mexico State University. The University of New Mexico has a travel clinic for children younger than 5 years so that families do not have to travel long distances for confirmation of diagnosis. Screening and diagnosis are also Medicaid reimbursable.

¹⁸American Academy of Pediatrics (AAP). *Caring for Children with Autism Spectrum Disorders: A Resource Toolkit for Clinicians*. Available at https://www.nfaap.org/netforum/eweb/dynamicpage.aspx?site=nf.aap.org&webcode=aapbks_productdetail&key=BE7A9F12-F5D9-482B-A289-D299A8B9AC64. Detail on methods and implementation is available in the peer reviewed literature. See Siegel B, Ihle E, Marco E, and Hendren RL. (2010). *Update on autism: Issues in Treatment and Comorbidity*. *Child and Adolescent Psychiatry*. 27(10). Available at <http://www.psychiatrytimes.com/child-adolescent-psych/content/article/10168/1694995>.

- Pennsylvania requires that licensed developmental specialists – pediatricians, neurologists, psychologists – perform standardized assessments to determine ASD diagnoses. Although the State reports access challenges to the required practitioners, eligibility for ASD services both in the State Medicaid’s HealthChoices program and under the private insurance mandate depends on formal diagnosis. The State also conducts functional behavioral assessments in schools, with State regulations requiring that a certified school psychologist be involved in a child’s evaluation for ASD.¹⁹
- Wisconsin’s ASD screening is covered under an insurance mandate, and Medicaid reimburses providers for screening on a fee-for-service basis.

Our comparative review of the nine states’ approaches to screening and diagnosis for ASD reveals some common ground as well as considerable variation. State and program interviewees alike, for example, were of the opinion that early screening and accurate diagnosis are critical to timely targeting of services to best mitigate the challenges associated with a diagnosis of ASD and promote the developmental gains of treatment.

Eligibility Standards

Most states use a combination of diagnosis and functional assessment and, for adult services, financial qualification to determine service eligibility. Several of the nine study states described the details of their eligibility determination standards:

- Arizona’s eligibility for services is limited to children with autistic disorder alone. Children with other diagnoses along the autism spectrum are excluded. Arizona also requires a differential diagnosis of autistic disorder for early intervention services eligibility and is in the process of spot checking the quality of the initial diagnosis and assessment and following up in cases where discrepancies are found. Arizona uses a pre-admission screening tool (PAS) to determine service eligibility. This has versions for four age groups: 0-2, 3-5, 6-11, and 12+, and is not targeted specifically at autism. It also divides children into four disability categories based on needs: moderate adaptive skills; few adaptive skills; chronic medical needs; and behavioral challenges. To be eligible for services, the child must have a diagnosis of autistic disorder (or be below age 6 and at risk for autism) and have functional impairment in the following areas: communication, self-care, economic self-sufficiency, learning, mobility, self-direction, and capacity for independent living.
- Indiana has two levels of eligibility. For the first level, the child must be identified as having a developmental delay. For the second level, the child must have a medical diagnosis of an ASD. Indiana has no income-related eligibility requirements.
- Maine requires one of seven designated clinical care specialists to complete a prior authorization for all children before they can receive services.

¹⁹ Easter Seals (2010). *2010 State Autism Profiles: Pennsylvania*. Available at http://www.easterseals.com/site/DocServer/2010_Autism_Pennsylvania.pdf?docID=140056

- Missouri’s eligibility requirement is a determination that ASD produces disability that is likely to continue indefinitely and that results in a substantial functional limitation in two or more of the following six areas of major life activities: self-care, receptive and expressive language development and use, learning, self-direction, capacity for independent living or economic self-sufficiency and mobility.
- New Mexico requires individuals to have a confirmed diagnosis of an ASD, and the family must submit evidence that supports that diagnosis. If one of the two university centers performs the screening, they confirm the diagnosis and send information on to the program. New Mexico has no financial eligibility for State funded programs. Those seeking waiver funded services must meet Medicaid financial eligibility standards. Adults with ASD need to meet the criteria for the Developmental Disabilities (DD) HCBS waiver (a diagnosis of an ASD plus three functional impairments) in order to receive services.

Other examples of requirements for adult ASD programs include:

For Connecticut’s pilot program for supported housing, the eligibility criteria include:

- Being 18 years of age or older
- Having a diagnosis of an ASD
- Having substantial functional limitations in three or more of the following areas of major life activity:
 - Self-care
 - Receptive and expressive language
 - Learning, mobility
 - Self-direction
 - Capacity for independent living
 - Economic self-sufficiency
- The State included financial independence as an additional category that could be used to enable a young adult to qualify for supported housing services.
- For Pennsylvania’s adult waiver, eligible individuals must have a diagnosis of ASD, which can include:
 - Autistic Disorder
 - Pervasive Development Disorder, not otherwise specified
 - Asperger’s Syndrome
 - Childhood Disintegrative Disorder
 - Rett Syndrome
- Individuals must also have substantial functional limitations that are likely to continue indefinitely in three or more of the following major life activities:
 - Self-care
 - Understanding and use of receptive and expressive language
 - Learning

- Mobility
- Self-direction
- capacity for independent living

In addition, these functional limitations must be evident before the person reaches age 22. Individuals must also meet the income and resource limits for the State's Medical Assistance and Payment of Long Term Care Services. The income limit is currently 300% of the Supplemental Security Income federal benefit rate.

3.2.2 System of Care

Overview of System Design and Development

States approach the construction of a system of care for ASD in different ways, driven by different mechanisms and different legislative, judicial, or executive actions. Lacking national guidelines, some states focus on filling in gaps in services historically provided to children with special needs, or adults with either behavioral health conditions or developmental disabilities. California, for example, has comprehensive developmental disabilities services in place through its mandating legislation, the Lanterman Act. Pennsylvania provides considerable services to adults through its developmental disabilities program, but historically had fewer services directed to children through its behavioral health services until the settlement of a decade-old class action lawsuit addressing the use of EPSDT to cover comprehensive benefits to meet the needs of children with ASD. In most states, Medicaid waivers have been an important avenue for putting in place coverage for more comprehensive HCBS needed to build a system of care.

As the list below illustrates, all the study states now cover a broad array of developmental and behavioral services to meet needs at different points in the lifespan. Interviewees repeatedly emphasized that despite having services listed in the array, not all were able to implement or pay for sufficient amounts of each service type to meet the needs of all eligible clients. The details of the gaps in and barriers to full coverage are discussed further in subsequent sections of this report. The following are typically covered services targeted to persons with ASD, as reported by nine states for all funding sources:

- Screening
- Diagnostic Assessment
- Functional Assessment
- Information and Referrals
- Early Intervention (Autism)
- Behavioral Support
- Applied Behavior Analysis
- In-Home Care
- Skill Training/Acquisition

- Parent Training and Education
- Respite Care
- Case Management
- Service Coordination
- Supportive Housing
- Supported Employment
- Self-Directed Services
- Other Specialized Services

Gaps in Long-Term Services and Supports

When asked to comment on future directions for building and executing a LTSS system for individuals and families with ASD, interviewees mentioned many, highlighting in the process several uniform service gaps across the study states that present significant challenges for service delivery and hinder the implementation of evidence-based/promising practices. The most common issues shared by multiple sites are discussed below (the specific state examples are chosen to be illustrative; they are not comprehensive):

- **Lack of clinical ASD expertise presents challenges in developing a knowledgeable provider network and staffing autism programs.** Several states articulated the need to improve access to skilled developmental clinicians capable of providing comprehensive assessments for individuals with ASD. Maine, for example, reported that the vast majority of statewide developmental disability programs do not possess certified ABA providers or enough qualified clinicians to address the service needs of newly-identified children with ASD and their families. Missouri and New Mexico noted challenges in obtaining providers with developmental expertise who are capable of providing necessary ASD screenings, evaluations, treatments, and interventions. In an effort to improve clinical ASD expertise, several states, including Connecticut, have established graduate programs with degree concentrations in autism and ASD service delivery.
- **Geographical location is a significant determinant of services availability.** Several states agreed that access is a key inhibitor to autism service delivery. States with significant rural regions, such as New Mexico, Maine, and Missouri, reported location and availability of services as two crucial challenges to providing ASD services and supports across the state. Individuals with ASD who live in rural areas may have particular difficulty accessing effective interventions and may have to travel long distances from their homes to receive appropriate care.
- **Shortage of specialized ASD training infrastructures among support staff presents major workforce issues.** Several states (including Arizona, Pennsylvania, California, and New Mexico) noted the need for adequate training infrastructures in order to serve persons with multifaceted service needs. When asked to touch upon lessons learned in the adoption of evidence-based/promising practices for individuals with ASD Arizona, Pennsylvania, California, and New Mexico all hope to create ASD-specific training programs in order to coach and mentor support staff and community members. Indiana’s Developmental Training Center is one of the few programs in the US that offers training and technical assistance for individuals who work specifically with persons with ASD. Pennsylvania’s ACAP program,

which utilizes a managed care delivery system, provides staff persons with targeted training in ASD, as well as ongoing ASD standardized training and materials available on DVD.

- **Lack of ASD services and supports specifically for transition-age youth and adults may put these populations at risk for “slipping through ASD care cracks” and further widens the gap between those who are receiving care for ASD versus those who are not.** While several states offer effective ASD assessments and early interventions for children and adolescents, many states lack appropriate services for transition-age youth and adults living with ASD. In New Mexico, adults living with ASD only receive Medicaid services if they meet the eligibility criteria for the State’s DD waiver. Transition-age youth and adults who are not afforded specialized ASD services and supports must rely on general developmental disability services and mental health care that may not address their autism-specific needs or provide them with the necessary level of care. Of the nine study states, only Pennsylvania has an autism waiver and a capitated autism contract that specifically address the needs of adults.
- **State plans, waivers, and other programs designed specifically for persons with ASD are necessary for life-long services and supports.** Many states identified the need for Medicaid services that provide coverage for both children and adults with ASD. Some states have HCBS waivers for persons with a diagnosis of a developmental disability and/or mental illness; as noted, however, services under these waivers are often not sufficient for persons with ASD. Interviewees reported that in order to meet the growing demand for care to children, youth, and adults with ASD, state Medicaid agencies must create autism-specific programs. Some of the study states already have autism waivers in place, and at least one reported being in the process of developing such a waiver.

In summary, the gaps in care reported by the study states are: (a) specific to particular age groups (especially transition-age youth); (b) the result of limited quantities of available services because of shortages in staffing, caps on funding, or caps on numbers of persons served; and (c) due to shortages in trained and licensed ASD specialists.

Self-Directed Services Initiatives

Throughout the past decade, various states have adopted and implemented self-directed services initiatives for people with physical and/or developmental disabilities, allowing them and their families the autonomy to manage and tailor their health services according to individual service needs. This consumer-driven, alternative approach promotes consumer empowerment, granting participants authority over available Medicaid supports and services, as well as the ability to manage their publicly funded budget.

Under self-directed models, each state determines appropriate Medicaid funding and participants are given state budget allocations that align with individual financial abilities and support needs. Self-directed care recipients work in collaboration with a consultant and financial advisor to create a service and spending plan. While each state creates its own self-directed services requirements, CMS generally requires that recipients across states be provided with the following services and supports:

- Person-centered planning process

- Development of service care plan
- Creation of individualized budget
- Quality assurance and improvement
- Continuous supply of information and staff assistance in support of self-directed services²⁰

Several interviewees reported that meaningful implementation of self-directed services for individuals with ASD presents challenges during this period of fiscal constraint, especially now that states are tightening utilization through service caps, eligibility requirements, and other coverage limitations. Officials across states did, however, stress the importance of using a self-directed services model for individuals with ASD. Four of the nine study states offer self-directed services under consumer-directed state plan options or HCBS waiver programs. Exhibit 2 shows the state agencies responsible for self-directed care implementation and associated waiver programs in these four states.

Exhibit 2: Self Directed Care Leadership for Individuals with ASD

State	Agencies and Departments Responsible for Self-Directed care	Waiver/Program
Connecticut	<ul style="list-style-type: none"> • The Department of Developmental Services, Division of Autism 	Self-directed services under Connecticut Autism Program
Missouri	<ul style="list-style-type: none"> • Missouri Division of Developmental Disabilities 	Self-directed Support Services
New Mexico	<ul style="list-style-type: none"> • New Mexico Department of Health • Aging and Long Term Care Services Department 	“Mi Via” (My Way” self-directed waiver
Wisconsin	<ul style="list-style-type: none"> • Wisconsin Department of Health Services • Aging and Disability Resource Centers • Independent Counseling Agency • Financial Services Agency 	Include Respect I Self-Direct (IRIS) waiver

- **New Mexico:** *Mi Via*, New Mexico’s self-directed waiver program, is co-administered by the Department of Health and the Aging and Long Term Care Services Department. Recipients of the *Mi Via* waiver must meet eligibility requirements for New Mexico’s four Medicaid waiver programs: Medically Fragile, DD, Disabled and Elderly, and AIDS programs. Individuals who have brain injury and are eligible for New Mexico’s HCBS are also able to receive services under *Mi Via*. Once enrolled, the State provides recipients with a budget and an individual consultant to help participants choose customized supports that tailor individual service needs. In addition to a *Mi Via* consult, self-directed care (SDC) recipients work with a *Mi Via* Financial Management Agent who is responsible for service payment and helps the recipient complete necessary paperwork.²¹

²⁰ Centers for Medicare & Medicaid Services. *Self Directed Services Community Services and Long Term Supports*. Available at http://www.cms.gov/CommunityServices/60_SelfDirectedServices.asp.

²¹ Mi Via: New Mexico's Self-Directed Waiver Program. *Frequently Asked Questions*. Available at <http://www.mivianm.org/faq.htm>

- **Wisconsin:** Wisconsin’s Include, Respect, I Self-Direct (IRIS) HCBS waiver, administered by the Wisconsin Department of Health Services (DHS), provides long term services and supports to individuals with physical and developmental disabilities. IRIS is organized through multiple administrative and contract agencies, including regional Aging and Disability Resource Centers (ADRC), the Independent Counseling Agency (ICA), and the Financial Services Agency (FSA). ADRC and the ICA offer enrollment and benefit counseling for IRIS recipients and their families, while FSA is responsible for all spending under the IRIS waiver.²² As noted in the Wisconsin state summary (see Appendix 1), DHS uses a strength-based, “circle of support model” for all IRIS participants, allowing recipients control over their own cost savings for self-directed services and the ability to reinvest their savings into additional Medicaid services. Wisconsin is currently in the process of renewing the IRIS waiver to include a more thoroughly defined IRIS consultant role, so that recipients can receive proper SDC support and training.

Exhibit 3: Wisconsin IRIS Success Story

Andy works; he volunteers, and now, in his last year of high school, has decided that he does not want to be at a vocational workshop after graduation. Andy is pursuing vermiculture - a worm farm business - for which he has already lined up customers. He also is considering a shredding business, which could complement the vermiculture. By combining several different but related job ideas, Andy, his family, and the local Department of Vocational Rehabilitation office are developing viable ways for Andy to generate an income. The IRIS program has been extremely helpful to Andy and his family. With the IRIS program, they have organized a very tightly knit group of friends and providers who know how to best support Andy in exactly the ways he needs help. It is this self-directed focus of IRIS that is so appealing and helpful to Andy and his family, and they all look forward to helping Andy get the life that he wants.

- **Missouri:** The Missouri Division of Developmental Disabilities helps individuals with disabilities and their families gain greater independence through SDC support services,²³ with enrollment organized by regional offices throughout the state. As outlined in the Missouri state summary (see Appendix 1), individuals using Missouri’s self-directed services have control over hiring and firing employees as needed, training employees to deliver services at their direction, creating an optimal work schedule, and determining employees’ earnings within State guidelines.²⁴ Service coordinators are available to work with

²² The Arc Wisconsin Disability Association. IRIS Waiver, Self Directed Services and Self Determination Resources and Information. Available at [http://www.arc-wisconsin.org/arcwisconsin/iris waiver and sds/default.asp](http://www.arc-wisconsin.org/arcwisconsin/iris%20waiver%20and%20sds/default.asp).

²³ MoDMH Self-Directed Services, Funded by Missouri Division of Developmental Disabilities. Available at <https://modmhselfdirected.com/>

²⁴ MoDMH Self-Directed Services. *Employer Manual*. ASIWorks, Inc., *Fiscal Management Services for Missouri DD Self-Directed Supports*. Available at <https://modmhselfdirected.com/pdf/administrative/EmployerManual.pdf>

individuals to create a budget, but the individual is responsible for management of services within the budget. The Division contracts with ASIWorks, Inc. as the fiscal management service for administrative functions such as payroll, taxes, and Workers Compensation insurance.

3.3 Care System Development Issues

3.3.1 Access to care

Several conditions impact access to care, even for eligible individuals, including geographic and cultural issues, problems in services capacity, and differential gaps in care across the lifespan.

Geographic Distance

Access to care is a crucial step toward receipt of evidence-based/promising services. Individuals and families living in rural areas in all the study states have many more obstacles to care than those living in cities. Geographic distance is particularly problematic for access to scarce screening and diagnostic services, as well as specialty services.

Screening and Diagnosis

States such as Arizona, which are primarily rural, have creatively addressed access to screening through mobile assessment clinics. Other study states with difficult-to-access rural areas, such as Maine, are harder pressed to provide remote access to screening and diagnostic services. The northern counties in Maine, for example, are six or more hours drive from the nearest population centers where families might obtain diagnostic services. Telemedicine for diagnosis and assessment is being considered in a number of the study states.

Access to Services

In rural areas such as Dunklin County Missouri, Washington County Maine, the Central Valley of California, and Apache County Arizona, among others, services are not easily accessible. For these families, timely and accurate diagnosis is only the first hurdle to service access. Although many services are home based, services such as vocational training and social skills training are not. Missouri has treatment centers located in the corners and center of the state. Maine, like most states, has service providers concentrated in population centers. School based services are, of course, local but school based consultants may not be as present in rural as in urban schools.

Culturally and Linguistically Sensitive Services

Significant disparities persist in access to health care for children and families from cultural and linguistic minorities--a condition that is manifested in late diagnosis of ASD for children and adults from these minorities, delaying critical treatment and intervention that could mitigate

developmental lags.²⁵ Arizona, for example, noted the need for cultural tailoring of ASD services for Hispanic and Native American populations, including bi-lingual bi-cultural providers trained in providing ASD assessment and services. All the study states identified a need for services for culturally and linguistically competent services.

Service Availability for Children, Transition-Age Youth, and Adult Populations

Because services targeted to young children have the strongest evidence base, young children have the greatest opportunity to access evidence-based/promising services. ABA is the most commonly available service, and many early intervention programs combine inclusive classroom or clinic based services, designed on replicable evidence-based models (including, for example, LEAP, Walden, Denver, and DIR/Floortime), with in-home parent training using ABA methods. Other services are available once a child reaches preschool age under the IDEA, which mandates services designed to provide children who have ASD with a free and appropriate public education.

Transition-Age Youth. Youth with autism and their families face substantial challenges at the point of transition from federally mandated public education services to state-specific adult services that may include post-secondary education, vocational training, and supported employment. IDEA mandates transition planning as a part of the youth's Individual Education Plan (IEP) at age 16, in preparation for typical graduation at age 18. IDEA guidance suggests that transition planning include the student, parents, and members of the IEP team, collaborating to determine a future plan that meets individual needs and preferences. Although IDEA provides for education based transition planning, case study interviewees reported a number of obstacles to formulating a feasible plan, including the lack of evidence-based/promising practice capacity targeted to this age group.

Most interviewees stated concerns about a projected influx of transition-age youth in the next decade, because of improved autism surveillance, without the service system capacity or evidence-based supports to address the need. One identified the emerging problem as a "great wave".²⁶ States that provide for life skills training and independent living planning early on in the child's life may be the best equipped to meet the rising tide of transition-age youth. Many youths, however, will still require intensive and expensive services for community living. States such as Wisconsin have used funds not spent on Intermediate Care Facilities for the Mentally Retarded (ICFs/MR) to finance community services, but even they will feel the pressure for increased numbers of services. Maine was awarded an autism implementation grant, which is being used in part to develop transitional youth services. Overall, there is a need across all the study states to develop and enhance transition-age services for vocational and educational support, independent living, social skills, and sexuality.

²⁵ Mandell DS, Wiggins LD, Arnstein Carpenter L, Daniels J, DiGuseppi C, Durkin MS, Giarelli E, Morrier MJ, Nicholas JS, Pinto-Martin JA, Shattuck PT, Thomas KC, Yeargin-Allsopp M, and Kirby RS. (2009). Racial/Ethnic Disparities in the Identification of Children With Autism Spectrum Disorders. *American Journal of Public Health*, 99(3): 493-498.

²⁶ That a substantial number of children will soon be reaching transition age has been noted by Lawer, L. and Mandell, D. 2009. 2005 Pennsylvania Autism Census Project: Final Report. October 2009. Pennsylvania Department of Public Welfare, Bureau of Autism Services. Available at http://www.dpw.state.pa.us/ucmprd/groups/public/documents/report/s_000920.pdf

Adults. Adults with ASD were eligible for waiver-based services in study states with some exceptions. Arizona, for example, provides HCBS to individuals with autism but not other ASD. Connecticut does not offer HCBS waiver based services for adults with ASD unless they have a co-occurring diagnosis of intellectual disability or a mental illness.

The few individuals with ASD who were not diagnosed until adulthood have been mostly left without services altogether. These tend to be older individuals who may have been left with the family farm or homestead and thus do not qualify for Medicaid and do not have the capacity to ask for evaluation or assistance, thus falling through cracks in the service system. An informant in Maine noted a woman who had inherited her family's house but was too impaired to work or to work through the system to determine eligibility. Most states now make concerted efforts to identify individuals with ASD at an early age, which should lessen the problem of ASD diagnoses only in adulthood.

3.3.2 Staffing and Workforce

Problems in the supply of trained and licensed ASD specialists, as noted, pose barriers to care access for individuals with ASD and their families. Every interviewee in the study cited shortages in personnel (a) trained in ASD screening, diagnosis, and management and (b) credentialed in key disciplines to treat individuals with ASD. While training is a challenge throughout the health and human services field, several considerations are unique to the ASD workforce, including:

- Rapidly growing demand for services concomitant with the explosion in diagnosis of ASD
- Complexity of needs associated with ASD, demanding multiple interventions and practitioners
- Fragmentation in bureaucratic responsibility for ASD services that involve numerous providers across multiple home, health care, developmental, and educational settings
- Significant and unique role that consistency plays in the effectiveness of interventions for persons with ASD
- Levels of precision required in methods of delivery in evidence-based/promising ASD services²⁷

States require that licensed, credentialed and/or certified specialists deliver assessment, diagnostic, treatment, and education services to individuals with ASD. For example, in most states determination of eligibility for services is predicated on diagnosis by an appropriately credentialed physician or psychologist. Medicaid and private insurance alike will not reimburse treatment and supportive services unless rendered by the appropriately licensed personnel. Early intervention and education programs have similar requirements for licensed special educators and certified behavioral specialists to deliver structured interventions in classrooms and home based programs.

²⁷ LeBlanc, L. A., Gravina, N., & Carr, J. (2009). Training issues unique to autism spectrum disorders. In J. Matson (Ed.), *Practitioner's guide to applied behavior analysis for children with autism spectrum disorders*. New York: Springer. Available at <http://behavioralspeech.com/memberpubs/Tx%20issues%20ASD.pdf>

Physicians reported in 2009 to the American Academy of Pediatrics that they were significantly less competent to provide primary care to children with autism than they were to meet those needs in children with other complex medical conditions.²⁸ Primary care physicians also report significant problems nationally in accessing specialists such as child and adolescent psychiatrists for consultation and assistance.²⁹

An adequate supply of credentialed diagnosticians is essential to timely determination of an ASD diagnosis, which is a threshold requirement for ASD services eligibility, and for the better developmental and functional outcomes associated with early intervention. All states accept physician diagnosis of ASD. Some also accept reviews by licensed child psychologists. Illustrative study state approaches include the following:

- California has produced training protocols for university courses through the work of its Blue Ribbon Commission's Education and Professional Development Task Force.
- Maine is in the process of developing guidelines for those who should do ASD screening, specifying that these individuals should:
 - Be developmental pediatricians, child neurologists, or child psychologists or psychiatrists, and
 - Demonstrate a series of 9-10 competencies (not yet finalized).
- New Mexico elected to concentrate the few credentialed developmental specialists at the University of New Mexico's Medical School Center for Development and Disability and provides transportation to families from rural areas to its campus at Albuquerque for screening, assessment, and diagnosis.
- Pennsylvania permits credentialed developmental and clinical psychologists, as well as physicians, to perform ASD assessments.

Problems in the supply of credentialed diagnosticians are an indicator of a larger problem in the sufficiency of trained clinicians to staff all elements of an ASD care system. The study states are mounting several different strategies to increase the numbers of trained and credentialed ASD program staff, including the following illustrative examples:

- California's aforementioned Blue Ribbon Commission has devised training protocols and university courses, as published by the State's Education and Professional Development Task Force.
- Connecticut is training persons with ASD alongside their caregivers, to build common ground and common knowledge on ASD and the interventions that are most effective.
- Maine is developing a curriculum for a Masters in ASD to be awarded at one of its State colleges.

²⁸ Golnik et al (2009). Medical homes for children with autism: s physician survey. *Pediatrics*. 123(3); 966-971.

²⁹ Cunningham (2009). Beyond parity: primary care physicians' perspectives on access to mental health care. *Health Affairs*; 28(3): 90-501.

- Missouri has developed a number of training programs targeted to individuals, families, and program staff that are accessible on line.
- New Mexico's Center for Development and Disability, situated at the University of New Mexico Medical School, provides 40 hours of autism-specific course work, reinforced by mentoring and coaching.
- Pennsylvania has developed regional training collaboratives composed of provider and academic partnerships.

In summary, across the study states a range of strategies to improve the capacity and capability of the ASD workforce is under way, including curriculum development, in-person and on-line professional development and coaching, expert consultation models, and degree granting programs. Strategies that supplement individual state efforts are also needed to make training in ASD and effective services interventions available on a nationwide basis. Technology-mediated distance education is a promising strategy being developed to solve problems in training of staff to serve in rural areas, and holds promise for increasing the numbers of individuals participating in post-baccalaureate certification and Masters programs with a concentration in ASD.³⁰

3.3.3 Financing Care through the Medicaid Program

States are facing rapidly increasing demand for ASD services at a time of declining state revenues. In a March 2010 report, the U.S. Government Accountability Office (GAO) projects a continuing decline in state revenues through the year 2060, absent some policy changes.³¹ A critical link exists between financing and access to services that pervades health care. Rarely is this link as important as with children who have complex and chronic health conditions. For children with ASD, in particular, timely access to diagnosis and treatment can be life altering, as the evidence points strongly to the significance of developmental gains made after intensive interventions applied at a young age.

Funding for services provided to children and adults with ASD in the study states derives from multiple sources. Funds from Title V (maternal and child health, children with special health care needs, and early intervention), the state Medicaid program (medical, therapeutic, and rehabilitative services), and state (special education) and local education funding are the common denominators of ASD services financial support. However, several states often must rely on state appropriations and foundation and federal grants to support innovation and establish new practices. Once new practices are implemented and tested, subsequent funding may be provided under a Medicaid mandated, optional, or waiver program.

³⁰ Ludlow, B. L., Galyon Keramidas, C., & Landers, E. J. (2007). Project STARS: Using desktop conferencing to prepare Autism specialists at a distance. *Rural Special Education Quarterly*, 26(4), 33-45.

³¹ US Government Accountability Office (US GAO). (2010) *State and Local Governments: Fiscal Pressures Could Have Implications for Future Delivery of Intergovernmental Programs*. Available at <http://www.gao.gov/products/GAO-10-899>

Our focus here is on illustrating the range of funding sources with particular focus on the use of Medicaid funds to support HCBS to children, adolescents, and adults with ASD and their families. States interviewed stressed that individuals with ASD who met the relevant eligibility and qualifying criteria could be covered by more than one Medicaid program or waiver. For example, the state of Missouri has both a 1915(c) autism waiver and several 1915(c) developmental disabilities waivers, for which individuals with ASD may qualify. Medicaid program funding sources are illustrated for each of the nine states studied in Exhibit 4. It is important to note that this information is based on discussions with state respondents and a review of external sources on states' Medicaid plans.

Exhibit 4: Medicaid Financing of Services to Persons with ASD

	AZ	CA	CT	IN	ME	MO	NM	PA	WI
Mandatory	✓	✓	✓	✓	✓	✓	✓	✓	✓
Optional			✓	✓	✓	✓	✓	✓	✓ State plan HCBS
DD 1915 (c) Waiver		✓		✓		✓	✓	✓	✓
Autism 1915 (c) Waiver			✓	✓		✓		✓	✓
Other Waiver	✓ All Medicaid Services fall under the 1115 Waiver		✓ Aged and Disabled	✓ Support Services	✓ Aged and Disabled		✓ Medically Fragile, Self- Directed Waiver	✓ 1115 Rehabilitation Waiver	✓ IRIS Waiver, ICF-MR Expanded, Children's Mental Health
TEFRA			✓		✓			✓	✓

Although Medicaid is a significant payer for ASD services in the states, other sources of funding represent a considerable proportion of the funds covering ASD services, including state appropriations for public education and state appropriations for social, medical, and disability services as managed by several different state health and human services agencies. These latter sources are listed, by source, below:

- State Medicaid Agencies or Medicaid Managed Care Organizations
- State Autism Bureaus or Offices
- State Health and Human Service Agencies
- State Developmental Disabilities and/or Mental Retardation Agencies
- State Mental Health or Behavioral Health Authorities
- State Rehabilitation or Vocational Rehabilitation Services Agencies

- State Social Services, Child Welfare, or Child, Youth, and Family Agencies
- State Public Health Agencies
- State Department of Education
- State Offices of Child Development or Early Learning

Medicaid Mandated, Optional, and Waiver Services

Medicaid benefits are typically provided to persons who meet established income and categorical criteria. States determine the design of Medicaid eligibility and benefits within broad federal guidelines, setting the terms or reimbursement, program administration, and operating procedures. Children with ASD may qualify for Medicaid because their families have limited income, they are Social Security Income (SSI) recipients and medically needy, or meet optional targeted coverage directed at low income children and families under the Children's Health Insurance Program (CHIP). States also have options to cover children with disabilities whose families would not otherwise qualify for Medicaid. States use the Katie Beckett Waiver, known as the Deeming Waiver or the 2176 Model Waiver, for example to cover children with disabilities in home and community-based settings, with eligibility based on the individual child's income and assets rather than the income of the legally liable relatives. Connecticut is an example of a state using this option, setting the eligibility threshold at or below 300% of the SSI federal benefit rate and an asset limit of \$1000. Similarly, TEFRA 134(a), a provision of the Tax Equity and Fiscal Responsibility Act of 1982, is used by other states to qualify certain children with disabilities for Medicaid benefits.

Once qualified, children with ASD may rely on a range of mandated and optional benefits that vary from state to state. For children with ASD, Early and Periodic Screening, Diagnostic and Treatment (EPSDT) is one of the most important of the mandated benefits. Under the EPSDT provision, a child's pediatrician may screen and diagnose, then prescribe a range of medically necessary treatments pursuant to diagnosis. EPSDT has been an important source of coverage for Medicaid-eligible children once a diagnosis of ASD is established, although it is statutorily limited to a certain set of benefits that does not include HCBS.

Some states use EPSDT to cover child rehabilitative service or targeted case management for individuals with ASD. Medicaid waivers, particularly Section 1115 and Section 1915 HCBS waivers are often used by states to target services to individuals with ASD. This has usually been done as part of larger targeted groups of persons with intellectual disabilities, developmental disabilities or mental illnesses. However, the number of autism-specific waivers is increasing. As Exhibit 4 above illustrates, more than half of the study states have autism-specific waivers, and others are planning to apply for them. Under the terms of a waiver, states can target specific services (thus waiving comparability) to defined client groups, while limiting services to certain geographic areas of the state (thus waiving state-wideness) and establishing wait lists, rather than providing services to all Medicaid eligible persons.

Here are the waivers in place or planned in the study states:

- All of Arizona’s Medicaid programs and services, including those for persons with ASD, are provided under its umbrella Section 1115 demonstration project. This includes EPSDT. All service delivery is contracted out to health plans. Self-directed services are provided under the waiver, mainly for adults. The waiver is administered by Arizona Health Care Cost Containment System (AHCCCS), which has a strong working relationship with the Arizona Division of Developmental Disabilities (DDD). These agencies work together to meet regulatory requirements and members’ needs. The waiver requires the State Medicaid Agency to meet Medicaid budget-neutrality requirements. The State is in the process of renewing the waiver.
- California’s HCBS-Developmentally Disabled (DD) waiver is one of the largest HCBS waivers in the country. In order to receive services and supports under this waiver, individuals with ASD must:
 - Meet the Lanterman Act definition of “developmentally disabled”;
 - Meet eligibility requirements for Medi-Cal;
 - Receive services through one of the State’s 21 regional centers;
 - Meet the level of need necessary for an ICF-MR.³²

The State’s HCBS-DD waiver covers a diverse range of ASD services, including transportation services, habilitation, respite care, home health aide services, family training, adult residential care, crisis and behavior intervention services, and nutritional consultations. In addition to the HCBS-DD waiver, the State’s Department of Developmental Services has been working to implement self-directed services for persons with developmental disabilities.³³

- Indiana’s HCBS autism waiver serves Medicaid-eligible individuals of all ages who are diagnosed with autism. As with the other HCBS waivers offered by Indiana Medicaid, individuals are eligible for the waiver if the recipient would require institutionalization in the absence of the waiver and/or other home based services. Within its approved capacity, the autism waiver covers a broad range of services, including evidence-based behavioral support services.
- Maine has two waiver programs that serve individuals 18 years and older who have a diagnosis of intellectual disability/autism and meet the eligibility requirements for an ICF-MR level of care. The Maine Office of Adults with Cognitive and Physical Disability Services determines eligibility. The community supports waiver (Section 29) provides services primarily to people living with their families. Services under this waiver include: community supports, respite care, employment specialists services, supported employment, home accessibility adaptations, communication aids, speech therapy, physical therapy, transportation, and specialized medical equipment. The HCBS waiver program (Section 21) is the primary program for supporting people outside their family home. This is a comprehensive waiver providing a wide range of residential options as well as additional supports, including: independent living supports, shared living, traditional group home

³² Department of Health Care Services. *Home and Community-Based Services for the Developmentally Disabled*. 2007. Available at <http://www.dhcs.ca.gov/services/ltc/pages/dd.aspx>

³³ California Department of Developmental Services. *Self-Directed Services Program*. June 2010. Available at <http://www.dds.ca.gov/SDS/index.cfm>

settings of up to four people, community supports, employment, transportation, crisis intervention, therapies, and home adaptations. The Children's Behavioral Health System (CBHS) provides a full continuum of services for children and youth with cognitive disabilities and ASD, including respite services, therapeutic recreation funds, case management services, medication management, family education and support services, crisis services (crisis phone supports, mobile outreach assessments and crisis stabilization residential units), outpatient treatment services, early intervention services, home and community-based treatment, individual planning funds ("Flex Funds"), and information & referral services.

- As of July 2009, Missouri has had an autism waiver in place to provide services for individuals with autism ages 3-18 who live with their family in the community. Eligibility for autism waiver services requires that a qualified professional make one of the following diagnoses:
 - Autistic disorder
 - Asperger's syndrome
 - Pervasive developmental disorder--not otherwise specified
 - Childhood disintegrative disorder
 - Rett syndrome³⁴

Additional criteria for eligibility include requirements that the child experiences behavioral and/or social or communication deficits that meet developmental disability requirements and that these deficits interfere with the child's participation in community activities. The child must also meet ICF-MR level of care as determined by a Regional Office. Finally, the Regional Office must determine that the individual's needs for services can be met within the annual limit of \$22,000.

- The State's autism waiver includes coverage of the following services for persons ages 3-18:
 - In-home respite
 - Personal assistant
 - Behavior analysis
 - Environmental accessibility adaptations
 - Out-of-home respite
 - Specialized medical equipment (adaptive equipment) and other supplies
 - Support broker
 - Transportation

There are annual limits on services supported by the autism waiver. Up to \$22,000 per child per year is allowed and there can be no more than 150 persons receiving services under the waiver at any time.³⁵

³⁴ Missouri Families for Effective Autism Treatment (MOFEAT). *Autism Waiver Implementation*. September 4, 2009 (Revised). Available at http://www.mo-feat.org/files/DMH_Autism_Waiver%20FAQ.pdf

Health Care Reform Opportunities

The Affordable Care Act of 2010 (ACA) contains several provisions that hold promise for better meeting the needs of Medicaid eligible persons with ASD:

- The ACA significantly expands Medicaid eligibility, beginning in 2014, for people with incomes below 133% of the federal poverty level (FPL). This will include coverage for some parents of children with ASD who have been qualified under CHIP, Katie Beckett, or TEFRA and other adults. The Act permits states to elect to “phase in” coverage for the newly eligible group of people at any time after April 2010. States that adopt this new coverage option will receive federal matching payments at their regular federal medical assistance percentage until January 2014, when a higher federal matching rate will be provided (initially 100%).³⁵
- Patient-centered medical homes or health homes have been recognized as a model for effectively delivering care for persons with complex conditions. The ACA contains provisions (Section 2703) that authorize a state option for Medicaid beneficiaries with chronic conditions to select a health home, building on the experience of Medicaid’s current Medical Home demonstration programs. During the first eight quarters of operation, the federal government will provide a 90% match rate to states that implement health homes. Federal guidelines have just been released for this pilot, and the National Committee for Quality Assurance has developed standards for medical homes that include the use of patient self-management support, care management, evidence-based guidelines for chronic conditions, and performance management and improvement. Core attributes of patient-centered medical homes include comprehensive whole-person care, improved and timelier access to care, and coordination across all elements of the complex health care system and the patient’s community. Children and adults with ASD and special health care needs may benefit from this model.
- The ACA contains a number of provisions designed to increase community-based long term care options and provide alternatives to institutional or ICF care, psychiatric hospitals, nursing homes, or other restrictive settings. These provisions will benefit states working to develop unified strategies for creating and financing comprehensive HCBS systems for persons who have ASD and significant functional impairments. This may provide opportunities for states to develop a more consistent strategy for financing a continuum of ASD services, as well as a more coordinated and consistent policy framework regarding supportive services for people with disabilities and high levels of vulnerability who need long term services and supports. Section 2402(b) changes the rules for 1915(i) State plan HCBS, permitting states to cover it more widely under a Medicaid state plan option. The HCBS option offers states a clearer path to covering statewide a comprehensive array of services and supports for persons with ASD, not only avoiding the burden of applying for a waiver but also eliminating the longstanding requirement to prove “cost neutrality” in HCBS, where the cost of community services is measured against the cost of institutional services.

³⁵ Missouri Department of Mental Health. *Autism Waiver*. Available at <http://dmh.mo.gov/dd/progs/waiver/autism.htm>

³⁶ Mann C. CMS State Medicaid Director Letter #10-005 Re: New Option for Coverage of Individuals under Medicaid. April 9, 2010. Available at <https://www.cms.gov/smdl/downloads/SMD10005.pdf>

While services could be targeted to specific need groups, waiving comparability, states will not be permitted to limit the number of eligible individuals in the target group, establish wait lists, or restrict availability to limited parts of the state.

Private Insurance Mandates

As of 2010, twenty-three states have passed legislation mandating coverage for the diagnosis and treatment of ASD. Private insurance coverage is an important component of care financing in ASD, relieving a portion of the burden that would otherwise fall to local, state, and federal governments. Here are highlights of several of the study states' private insurance mandates:

- In March of 2008, Arizona passed Steven's Law, which requires group health insurance coverage for the diagnosis and treatment of ASD. This law prohibits health service or medical service corporations from excluding or denying coverage for ASD diagnosis, assessment, treatment, and services.³⁷ The law also explicitly prohibits the exclusion or denial of coverage for medically necessary behavioral therapy, including ABA, provided by or under the supervision of a licensed or certified provider. Eligible individuals are covered for behavioral therapy for a maximum of \$50,000 per year up to age 9 and at a maximum of \$25,000 per year for ages 9-16.³⁷
- The Connecticut Autism Insurance Reform Act was effective as of January 1, 2010.³⁸ The Act requires private insurers to cover the cost of diagnostic assessments for ASD and services to individuals with ASD who are under age 15. Benefits can be capped at \$50,000 per year for children under age 9, at \$35,000 per year for ages 9-12, and at \$25,000 per year for ages 13-14. Insurers may not place higher copayments, deductibles, or other out-of-pocket expenses on care related to ASD than for any other medical, surgical, or physical health conditions. The Act requires coverage of the following kinds of services: behavioral therapy (including ABA), pharmacy care, direct psychiatric or consultative services, direct psychological or consultative services, physical therapy, and occupational therapy. These services must be medically necessary, prescribed by a licensed clinician or clinical social worker, and based on a treatment plan.
- In the 2010 legislation session, Missouri became the 21st state to approve autism insurance legislation. The law (HB 1311) requires private insurance companies operating in the State to provide coverage under group health insurance policies for the following types of care:³⁹
 - Psychiatric care
 - Psychological care
 - Habilitative or rehabilitative care (including ABA therapy)
 - Therapeutic and pharmacy care for children diagnosed with ASD

³⁷ Easter Seals, 2010. 2010 State Autism Profiles: Arizona. Available at

http://www.easterseals.com/site/DocServer/2010_Autism_Arizona.pdf?docID=139866

³⁸ Autism Votes. *Frequently Asked Questions About the Connecticut Autism Insurance Reform Act*. Available at

http://www.autismvotes.org/atf/cf/%7B2A179B73-96E2-44C3-8816-1B1C0BE5334B%7D/Connecticut_FAQs.pdf

³⁹ Department of Insurance, Financial Institutions & Professional Registration (DIFP). *Autism FAQ*. Available at <http://insurance.mo.gov/consumer/autismFAQ/>

Individuals with an individual health benefit plan may add this coverage; however there may be additional costs. This law also establishes licensure requirements for therapists who provide ABA therapy for children with ASD.

- In July 2008, Pennsylvania passed a law (Act 62) that addresses insurance coverage, requirements, and treatment for children and youth below age 21 who have a diagnosis of an ASD. The Autism Insurance Act (Act) mandates benefits to children or young adults below age 21 who are covered by specific types of employer group health insurance policies, Medical Assistance, CHIP, or AdultBasic. Overseen by the State's Department of Insurance, the Act requires many private health insurance companies to cover the costs of diagnostic assessment and treatment of ASD for the insured population up to a total of \$36,000 per year. In addition, the State's DPW must cover the cost of services for persons enrolled in the Medical Assistance program who do not have private insurance coverage, or for individuals whose costs surpass \$36,000 per year. The Act also requires the State to license professional behavior specialists who provide services to children,⁴⁰ and allows for coverage of diagnostic assessment services and treatment of ASD (including prescription drugs, blood level tests, and services provided by a psychiatrist and/or psychologist; ABA; and other rehabilitative care and therapies). Treatment provided under the Act must meet certain requirements, including that services are:
 - For an autism spectrum disorder
 - Medically necessary
 - Identified in a treatment plan
 - Prescribed, ordered, or provided by a licensed physician, licensed physician assistant, licensed psychologist, licensed clinical social worker or certified registered nurse practitioner
 - Provided by an autism service provider or a person, entity, or group that works under the direction of an autism service provider

3.3.4 Strategies to Manage Growing Consumer Demand in the Context of Growing Fiscal Constraints

As economic constraints become ever more prevalent while the number of individuals and families eligible for Medicaid and state-funded services increases, states have had to develop strategies to manage the growing service demand. The study states described four such strategies:

- **Evidence-Based/Promising Practice Requirements.** Many states have opted to limit service coverage to interventions with an evidence base or those determined to be promising practices. As of the date of this report's publication, the only established evidence-based practice available is ABA. Most states report a dearth of qualified ABA providers, which further limits the scope of services covered. In addition, states are working to educate

⁴⁰ Pennsylvania Department of Public Welfare. *Autism Insurance Fact Sheet*. Available at <http://www.dpw.state.pa.us/foradults/autismservices/paautisminsuranceact62/autisminsuranceactfactsheet/index.htm>

families about which services are effective, an effort that should lead to fewer requests to cover expensive, unsubstantiated services. States are also increasing family education in evidence-based/promising practices, so that families can both fully understand the services they are receiving as well as supporting the intervention in the home. This may also reduce demand more costly and time-consuming services.

- **Rate Reduction.** Some states have chosen to reduce the rates paid to providers in an effort to increase the potential number of individuals and families served, or decrease expenses.
- **Increased Care Management.** Some states, such as Wisconsin, have opted to introduce more involved care management strategies for their waiver populations. The savings resulting from these efforts have been reinvested in service provision and covering the growing population.
- **Caps on the Number of Individuals Served.** States with Medicaid waivers targeted to specific populations sometimes limit the number of individuals who may be served on the waiver at any given time. Missouri's autism waiver, for example, covers no more than 150 children at any given time. In addition, services are limited to \$22,000 per year per child.

3.4 Standards, Quality, Evaluation, and Research

Standards-based care is a central issue for states, according to those interviewed for this report, informing practice adoption, implementation, and reimbursement, as well as forming a basis for quality improvement, program evaluation, and research. Standards ideally align with the evidence of what treatment and supportive services are most effective in meeting the needs of persons who have ASD. Gaps in the evidence base for ASD services create significant challenges in setting standards and determining quality in state programs, while also underlining the urgency of developing a more robust program evaluation and research effort across the country.

Local and National Standards Development and Adoption

The National Standards Project (NSP) was established by the National Autism Center to gather, analyze, and submit to expert review comprehensive information about the evidence base for interventions for individuals under age 22 who have ASD.⁴¹ Although the nine study states all referenced the national standards, they all developed or used their own standards or selection criteria for services implemented and/or reimbursed to meet the needs of persons with ASD. States described efforts to align with the work of the NSP; California, for example, collaborated with the NSP directly. However, most of the states had completed or were undertaking local standards setting initiatives in response to legislative mandates or executive directives, as well as to a policy of incorporating ASD stakeholders into the process. Family advocates have been involved in the formal state standards setting processes, and state officials report striving for a balance between family preferences and available evidence. The majority of the study states identified gaps in the evidence available to inform their local standards development initiatives and called for more research on

⁴¹ The National Autism Center. (2009). *National Standards Report*. Available at <http://www.nationalautismcenter.org/pdf/NAC%20Standards%20Report.pdf>

evidence-based interventions--especially for the growing group of transition-age youth with ASD. Here are illustrative issues and findings from study states:

- California ranked treatment categories by the strength of their evidence and came up with more specific distinctions between interventions than the NSP's merged categories. One issue California has faced is that much of the research on which standards are based is now outdated and funds for new research and evaluation are restricted. This poses challenges for the State in complying with the Lanterman Act of 2010, which mandates the State's Department of Developmental Services to develop standards for diagnosis and evaluation, including implementation of an evaluation of the effectiveness of the standards once they are developed.
- Maine produced their own 2009 report on the state of the evidence regarding interventions for individuals with ASD and their families. The report concludes that services should be based on the available evidence regarding effectiveness and that resources should be used wisely.
- Missouri was one of the first states to address the need for standards. Predating the NSP effort, the State convened a panel in 2003 to examine the State's ASD research and professional development agenda. The effort, entitled the Missouri Autism Research and Response Agenda (MARRA), led to a pilot community initiative. Its goal is to link with universities across the State to ultimately conduct longitudinal studies of the effectiveness of interventions for children with ASD.
- New Mexico has defined its own approach to promising practices based on family member input. Its definition is a practice that provides family support, is generalizable across settings, is evidence-based and fiscally responsible, and targets specific family needs.
- Pennsylvania reported that ABA was deemed necessary for children with complex behaviors, with other interventions to be based on a functional behavioral assessment.

Data Management and Outcomes Evaluation

States universally recognize the importance of program evaluation and research to improve the quality of current programs and establish the evidence base of proliferating practices in ASD. But they are more often involved in data collection and reporting activities associated with Medicaid reimbursed and contracted services than directly in research and evaluation. Most study states have established linkages with state universities that conduct program evaluation and research activities on ASD programs. They report a diverse range of data gathering, claims analysis, program monitoring, and evaluation activities. Some of these are pursuant to state mandates for ASD services or tie to Medicaid waiver reporting requirements, but others are long standing activities states have used to assure accountability in the purchase of services for vulnerable populations. Here are study state illustrations:

- Arizona's Health Care Access and Cost Containment System, the State Medicaid program, operates a claims based information system that tracks both (a) prevalence of persons with ASD using care, services utilization rates, types and amount of services provided, and (b) costs of treatment and supportive services for eligible children and adults with ASD.
- California maintains a large database on persons served with developmental disabilities including ASD. Penetration, utilization, and cost rates are analyzed and reported on a

monthly basis. The State DDS collaborates with the M.I.N.D. (Medical Investigation of Neurodevelopmental Disorders) Institute at the University of California at Davis in studying every baby born in California. This study includes biomarker collection. The State is interested in improving/clarifying the diagnostic integrity of autism as a disorder and noted specifically the need for more epidemiological studies.

- Wisconsin counties conduct annual services audits to assure quality of care, adherence to care plans, and satisfaction with care. The audit protocol includes record reviews and family surveys. For intensive waiver funded services, child progress is reviewed quarterly or semi-annually, depending on the measure and the need.
- Pennsylvania conducts a needs assessment to prepare for the large number of youth who will be transitioning to adult services by 2015. Their data tracking systems include age at first diagnosis, number of hospitalizations, access to diagnosticians, and service data.
- Indiana subcontracts for external review of the quality and outcomes of their waiver program.

The Role of Universities

All the study states have some type of formal or informal tie to universities for the conduct of evaluations and for research on intervention effectiveness. Several have also participated in a research and training consortium, the National Professional Development Center on Autism Spectrum Disorders (NPDCASD), whose definition of evidence-based practice was adopted for this study (see page 6 above). This is an avenue through which states can move forward on ASD research. Universities participating in the NPDCASD include the University of North Carolina Chapel Hill Frank Porter Graham Center, the University of Wisconsin Waisman Center, and the University of California at Davis M.I.N.D. Institute. These university centers work with different states for two-year blocks to assist them to disseminate best practices, to promote the use of evidence-based practice for ASD, and to access technical assistance for program evaluation. To date, nine states have worked with the NPDCASD, including Wisconsin, and three more states have been chosen to start in 2011.

Among the study states, the following research initiatives were highlighted:

- Connecticut collaborated with the University of Connecticut in developing a level of need tool for their new autism waivers. The State also conducted the evaluation of its adult autism pilot project.
- Indiana works closely with Indiana University to implement research-based treatment.
- Missouri, as part of the Missouri Autism Research and Response Agenda (MARRA), is working to coordinate research and professional development as well as services. The six largest research universities in the State have been convening to develop a unified research agenda in order to capture the collaborative funding necessary to implement longitudinal studies of child outcomes on ASD interventions. The State noted numerous privacy issues with the implementation of longitudinal collaborative research with children, including compliance with Health Insurance Portability and Accountability Act of 1996 (HIPAA) and the Family Educational Rights and Privacy Act (FERPA).

- New Mexico is collaborating with the University of New Mexico on several evaluations. One, whose results are still pending, looks at services for transition-age youth. Another found that parent home training for families with children ages 0-5 was more effective than other forms of family services. The State would like to examine the use of emergency physical restraints for children because it found no available research to assist providers. It is also working with the University Centers for Excellence in Developmental Disabilities Education, Research, and Service to mentor and coach providers in practice change.
- Pennsylvania has established a regional consortium of hospitals, colleges, and universities around evidence-based practices. It has funded several studies to date and collaborates with the research community on implementing research and developing a pipeline of research to practice in order to address gaps in the knowledge base.

Gaps in Standards

As stated earlier, practice often outpaces research, and much of the research upon which national and state standards are based has become outdated. When evidence about service effectiveness is lacking or out of date, gaps in standards are likely to occur. Families may ask for treatments that have only anecdotal evidence of effectiveness. And some states attempt to offer families the treatments they request regardless of evidence.

Related challenges noted by interviewees include:

- New Mexico noted the problem of evaluating socialization interventions because socialization is such a complex process.
- Connecticut recommended assessing the effectiveness of current clinical and support practices to build effectiveness data to translate these to best practices. Also suggested was research into the specific needs of the wide variety of subgroups diagnosed along the autism spectrum: autism, PDD, Asperger's, etc.

Evidence gaps were identified across the board for transition-age youth services, services for individuals with medical and behavioral comorbidities, and basic epidemiologic research.

Finally, there is an acute gap in evidence about approaches to addressing the independent living and community support needs of the wave of children diagnosed with ASD who will be transitioning to adult services in the next 5-10 years.

Provider and Program Licensing Issues

Medicaid has long required specifications for the use of licensed and credentialed personnel in its programs. State insurance mandates are also increasing pressure for the use of licensed or certified practitioners:

- In Wisconsin, the insurance mandate increased pressure to produce more licensed behavioral analysts. The Wisconsin Department of Regulation and Licensing, which had had some concerns in the past about qualifications, reviewed the national process for ABA board certification and determined it had sufficient documentation for State-level licensing. The State is working more generally to ensure that provider qualifications are outlined very specifically, tying provider qualifications to provider titles, so that qualifications are clear to

families. For example, the State will clarify the qualifications providers hold in order to be called a “therapist”. Wisconsin also noted the importance of using qualified providers to deliver evidence-based practices, to ensure fidelity to practice standards.

- Maine legislation 1198 requires private insurers to cover evidence-based services for children under age 6. This legislation, which took effect January 1, 2011, does not cover self-insured plans. Services must be deemed medically necessary and must be provided or ordered by a licensed physician or psychologist. It covers ABA if provided by a board certified behavioral analyst. The University of Southern Maine has a degree program in ABA.
- California received a grant in 1992 from local health plans for home based services. As a result of this grant they were able to train Masters and PhD level behavior specialists, as well as attract staff to the field. California identified nine academic programs from which they could recruit students, who got credit for working in the program. The State qualifies providers and agencies as “vendors” for Medicaid services through the regional center system.
- Indiana providers enrolled with Medicaid submit their qualifications and must meet continuing education requirements with yearly documentation. The State has no requirements for provider supervision but is in the process of developing a formal supervision/quality mentoring process. ABA providers can be licensed or unlicensed. Unlicensed providers must submit their qualifications to the state. There is a dearth of qualified ABA providers in the state, which will pay for an associate level person to provide ABA under the supervision of an ABA provider.

Several study states identified the need to incentivize states to create and support training and licensing infrastructure for professionals working with children and adults with ASD. As in other human service and behavioral health fields, there is no clear educational pipeline for individuals to follow toward careers in the ASD field. New training and mentoring opportunities are needed, as is social marketing about the need for qualified professionals in the ASD field.

- Arizona emphasized cultural and linguistic competence for families that are bi-lingual or mono-lingual Spanish speakers and Native American children and families. The State also brought up the issue of the evolution of ABA and what training and qualifications in ABA are sufficient for cultural/ethnic minorities.⁴²

Finally, there is proposed legislation regarding board certification for behavior analysts.

⁴² Association of Professional Behavior Analysts. (2009). *Behavior Analyst Certification Board, Inc. Introduction to the BACB Model Act for Licensing Behavior Analysts*. Available at <http://www.apbahome.net/model-licensing-act.pdf>

4. Selected State Practice Profiles: Innovation and Feasibility

All nine study states have implemented evidence-based practices, particularly those based on ABA principles. Development of promising practices, which may in the future evolve into evidence-based practices, is proceeding, but in a highly individualistic manner--with innovations ranging from training protocols to services interventions designed for different age and need groups.

Each of the nine states was asked to identify a promising practice or practices that, from their perspective, approximated some if not all of the characteristics embodied in the CMS definition and criteria for promising practices (see page 6 above). This section focuses on a particular practice profile for each study state (Missouri features two profiles). These 10 practices (see Exhibit 5) were built to incorporate evidence-based/promising practice elements and findings from clinical and services research. Included are practices used in states to train clinical professionals, as well as to screen, diagnose, and care for young children, transition-age youth, and adults with ASD. Exhibit 5 lists the selected promising practice for each of the nine states studied.

Exhibit 5. Selected State Practice Profiles

States	Promising Practices
Arizona	SARRC Community School
California	California: Therapeutic PATHWAYS' The Kendall School
Connecticut	Connecticut Pilot Program for Young Adults with Autism Spectrum Disorders
Indiana	First Steps Early Intervention Program
Maine	Primary Care Clinician Training
Missouri	Best Practices for Screening Diagnosis and Assessment
New Mexico	The Center for Development and Disability
Pennsylvania	Adult Community Autism Program (ACAP)
Wisconsin	Transition Action Guide for Post-School Planning; a Model of Interagency Collaboration

The practice profiles presented below, which are organized alphabetically by state name, provide a program overview and a series of implementation considerations. Depending on differences in practice types across states, the overviews include some or all of the following subtopics:

- Program Eligibility
- Services Description
- Staffing
- Funding

4.1 Arizona SARRC Community School

Program Overview

The Southwest Autism Research & Resource Center (SARRC) was established in 1997. Its mission is to advance research and provide a lifetime of support for individuals with autism and their families.⁴³ SARRC's Community School is a preschool located in downtown Phoenix that operates full inclusion classrooms for children ages 18 months to 5 years. The purpose of the school is to provide a normative preschool experience to both children who are developing typically and children who are experiencing developmental delays and have been diagnosed with ASD.

The SARRC inclusive preschool sets a minimum 1 to 1 ratio of typically developing children to children with ASD and actually enrolls more children who are developing typically than children with developmental delays and ASD. The SARRC Community School has 3 classrooms:

- Toddler: Ages 18 months to 3 years (this classroom has the highest number of typically developing children)
- Preschool: 3-4 year olds
- Pre-K: 4-5 year olds

The overall ratio across all classrooms is presently at about 2 typical children to 1 child with ASD, with the school serving 19 children, of whom 13 are developing typically and 6 are diagnosed with ASD. The average number of students in school on any given day is 16, and the school schedule has the flexibility necessary to meet individual child and family needs.

Program Eligibility

The SARRC Community School is open to any typically developing child in the defined age range who lives in the local community. Developmentally delayed children are eligible if they have an established diagnosis of autism or ASD. Functional impairment is not a factor in establishing eligibility. These eligibility requirements were established at program inception since the initiative was funded by a special appropriation from the Arizona State Legislature targeting services to children with ASD.

SARRC confirms the ASD diagnosis at point of entry into the school, and also evaluates the typically developing children to confirm their developmental status. The SARRC assessment process sometimes discovers that a child admitted in one or the other category has been incorrectly evaluated. If the admissions assessment reveals that a child has a previously unidentified developmental delay that is not ASD, that child is unable to participate in the program. A child previously identified with ASD that is found to have been incorrectly diagnosed is similarly ineligible for the program.

⁴³ Southwest Autism Research & Resource Center. *About SARRC*. Available at http://www.autismcenter.org/about_sarrc.aspx

Services Description

The SARRC Community School is an inclusive preschool program designed to provide 20 hours per week of early intensive behavioral intervention to children with autism. The school uses Pivotal Response Treatment (PRT) to provide both natural and motivating learning opportunities for toddlers, preschoolers, and pre-kindergarten-age children. PRT is based on ABA methods and supports an innovative, naturalistic, and play-based program. The goal of PRT is to improve language and social communication. For children who are not responsive to PRT, considered a “verbal” approach, the program uses other interventions, for example the Picture Exchange Communication System (PECS), a “visual” approach, or other augmentative communications systems. The school is modeled after the Walden Early Childhood Programs of Emory University.⁴⁴

The school operates daily from 8 AM to 5 PM. Children with ASD attend from 8 AM to noon, while typically developing children may remain on site until 5 PM. Afternoon programming is provided to children with ASD by SARRC teachers going into the home to provide parent training and align interventions at home with those applied at school. Children with ASD are provided 20 hours per week of school-based services and 8 hours per month of in home care and parent training, for an overall average of 22 hours per week of intensive intervention. More hours are provided in individual cases as needed.

Results of the initial baseline assessment are used to establish and Individual Services Plan (ISP), to set goals, and to engage parents in their child’s educational services and developmental objectives. School staff members assess and monitor progress daily, weekly, and monthly, with periodic assessments measured against the comprehensive baseline assessment conducted at admission. Data on language and socialization performance and progress are collected daily. Staff members measure language development weekly and reassess child’s language development. Assessment of Educational Preschool Skills (AEPS) is administered on a quarterly basis. The Preschool Language Scale (PLS) is administered twice yearly. The program also uses Adaptive Physical Education (APE) measures on a semiannual basis. All data collection and evaluation activities are conducted pursuant to defined protocols. Data are collected on each child, typically developing and with ASD, and shared with his/her parents. All interventions are linked to developmental goals established for the individual child. The range and intensity of interventions are modified in direct response to the evaluated needs of the children.

The SARRC Community School is responsive to the cultural needs of the surrounding community and the children and families served. The students hail from diverse cultures, including Latino, Asian, African-American, and Caucasian communities. A small number of the children with ASD come from families where English is the second language. Hispanic outreach is a significant element of recruitment efforts for typically developing children, reflecting the composition of the surrounding community. While most of the classroom interventions are delivered in English, other languages are spoken in delivering home based and parent training services. The program uses bicultural/bilingual

⁴⁴ SARRC. *Autism Clinical Services*. Available at http://www.autismcenter.org/clinical_services.aspx#3

therapists to accommodate needs and to mitigate the language delays that children from dual language families may experience regardless of developmental status.

Staffing

Each classroom is staffed by 2 lead teachers. Toddler and preschool classrooms also have 2 level-one teachers; the Pre-K classroom has 1 level-one teacher. Lead teachers are required to have more than 1 year of experience with the community school model and a Bachelor's degree. They are essentially behavioral therapists in the classroom and provide the in-home services. Of the 11 teachers in the school, 10 have Bachelors' degrees and 6 of those are pursuing Masters' degrees. The teachers are drawn from diverse educational backgrounds (e.g., sociology, special education, psychology), and not required to be credentialed as teachers.

The Community School Director is a certified behavioral analyst, serves as the school's Clinical Director, and provides supervision in the classroom and in weekly one-on-one supervision sessions with each staff person. Group supervision is provided weekly for 2.5 hours, during which videotaped classroom sessions are reviewed. In addition, the SARRC Clinical Director provides a full day each week of clinical supervision to all staff in both school and home settings. Supervisors are provided an additional 2 hours of group supervision each week.

Implementation Considerations

SARRC leaders identified several implementation challenges centering on staffing and program funding:

- *Recruitment of Clinically Capable and Culturally Competent Staff.* Finding staff with experience in the inclusive community school model that are trained to deliver structured behavioral interventions is a challenge for SARRC. Competing for bilingual teachers at the preschool level is another challenge, and there are even fewer bilingual candidates for senior clinical positions.
- *Financial Support for the Program.* The Arizona legislature funded the first 3 years of program operation at \$500K per year, covering children with ASD. The school raised funds and charged tuition to cover typically developing children. Since the legislative funding ended, SARRC has been challenged to develop funding to cover services to children with ASD, as well as low income children who are developing typically. Arizona Medicaid does not reimburse the program and it is not a covered early intervention service. SARRC has now developed several new sources of income for the program, including:
 - 10 scholarships available from a State tobacco tax fund for qualifying families with incomes at or below 200% FPL. Both typically developing children and those with ASD use the scholarships.
 - Education tax credits available to all children
 - Private pay
 - At the rate of \$2,150 per month for children with ASD, supplemented by \$400 per month from school fundraising efforts, for a total monthly cost of \$2,550

- At the rate of \$700 per month for the full day program and \$350 per month for the half day program for typically developing children (cost pegged to community median for preschool)
- Private insurance coverage, reimbursed at a rate higher than the private pay rate, under the terms of Steven’s Law, Arizona’s autism insurance mandate for children with ASD

SARRC leadership noted several lessons learned that will be addressed in the year ahead and may inform replication efforts:

- *Measuring Gains.* For children with ASD, the largest gains are made in development of language, social, and broader communications skills. With those gains, there are also reductions in problem behaviors, improvement in play skills, and achievement of a range of developmental milestones, including toilet training. The linkage between classroom-based interventions and skills acquisition and home based and parent training is not only reinforcing, but also boosts results for children and their ability to participate in family life and family routines. Documentation of these gains is critical to informing program improvement and sustaining program investment. SARRC is planning to invest in researching the long term outcomes of the program for the benefit of both children with ASD and those who are developing typically.
- *Classroom Organization.* Community School classroom teachers operate “on a line,” rotating through 4 different activity “zones.” Line or zone teachers work in the zone – and children enter the zone not because they are scheduled to do so but because they are drawn or motivated to work with a toy or zone. Lead teachers manage the ratio of students (typical and ASD) in any given zone. Lead teachers also facilitate interactions and handle the problem behaviors so that zone teachers can focus on instruction.
- *Building Future Staff Capacity.* SARRC has a partnership with Arizona State University, employing 4 early childhood education students per semester on a part-time basis in the classroom. This practice increases adult contact available to the children, while imparting innovative educational methods to the students and developing better teachers with an interest in and commitment to working with children with ASD.

4.2 California: Therapeutic PATHWAYS’ The Kendall School

Program Overview

Therapeutic PATHWAYS’ The Kendall School is certified as both a nonpublic agency and a school by the California Department of Education (DOE) and is also licensed as a vendor by California’s Department of Developmental Services (DDS). It provides intensive behavior analytic early intervention to children ages 12 months to 8 years. DOE and DDS co-fund the school.

Children attending the Kendall School receive intensive one-on-one behavior analytic intervention, either at one of the Kendall School centers or as a home-based intervention. Kendall School students gain experience interacting with typical peers through The Kids Helping Kids Program, through which the school trains typically developing children as peer helpers to provide the special assistance needed to teach children with PDD to play and make friends, and to learn the things that come more naturally for most children. Peer helpers teach them how to take turns, play games, share toys, and

converse. When it is appropriate for the individual child, Kendall School students also participate in an off-site preschool along with typically developing children, as part of their intensive intervention program.

Many children attending The Kendall School receive some portion of their intervention hours at home each month. Parents are encouraged to work closely with school staff to reinforce the generalization of skills learned at the school for use in the home. Each child's parents attend the bi-monthly staff meetings focused on their child, as well as meeting individually with school staff to select and develop the functional and adaptive skills that are most meaningful for the family. These programs are then delivered by the trained parents in home and community settings, with consultation and support from school staff.

Program Eligibility

The Kendall School serves children ages 12 months-8 years who:

- Have been diagnosed as having ASD disorder by a clinician.
- Are without significant medical complications or severe intellectual disability.
- Have completed a comprehensive pretreatment test battery including measure of cognitive, language, and adaptive skills.
- Live within a geographic area that permits recruitment of qualified instructional assistants and adequate supervision by the Directors, the Clinical Supervisor/Consultant, and Clinical Assistant.
- Have a home situation and parents who appear capable of providing the necessary program support.
- Are provided with sufficient funding (i.e., from the DOE or DDS Regional Center).

Services Description

Therapeutic PATHWAYS and The Kendall School place special emphasis on:

- Errorless learning procedures to promote rapid acquisition and retention of skills
- Functional language taught early
- Individualized curriculum and treatment plans that are developmentally appropriate; reflect each child's strengths as well as needs; incorporate the body of current empirically validated intervention and teaching practices; and fully integrate ABA with techniques from speech and language therapy.
- Establishing interactions with people as reinforcing
- Programs selected and developed in which the child must interact to receive more "reinforcers"
- Peer interactions introduced early during treatment
- Generalization of skills programmed for, and measured concurrently with, learning in structured teaching situations

- Self-management procedures, including the use of photographic activity schedules and self-reinforcement systems to create independence and promote generalization
- Effective use of "downtime" to create incidental language opportunities and expand play and social skills
- Data-based decision making
- Strong presence of the clinical team led by board certified behavior analysts with specialized training and experience in child development, autism, developmental disabilities, and educational strategies designed to accelerate learning
- Training of parents and other family members to promote generalization of the child's behavioral changes, use of language, and newly acquired adaptive skills. When parents and other family members act in concert this contributes not only to the child's rate of progress but to the well being of the whole family.
- Program directors that include a speech and language pathologist and a licensed psychologist with expertise in ABA (board certified)

Staffing

Therapeutic PATHWAYS' ABA-based intensive treatment and educational programs are designed and monitored by the clinical team and delivered primarily by instructional assistants. Each child is assessed and directly observed in a variety of situations. Goals and objectives are written for each functional or skill domain, individualized for each child, and updated quarterly. Parents play critical roles in furthering the effects of treatment. They do this, in part, by implementing components of treatment outside therapy hours. As described above, in order to effectively extend treatment, parents are expected to participate in the staff meetings for their child as well as any scheduled agency-wide workshops and trainings. Services are provided in naturalistic settings, with peers and siblings when and where possible. Children are taught self-management procedures to help promote behavior generalization and maintenance.

Progress in meeting goals and objectives at the level of the individual child is reported to parents and funding agencies quarterly. These reviews are based on data largely collected through direct observation collection methods (event recording, time sampling, etc.). Mastery of the 10-16 targeted domains is characterized by the percentage of goals and objectives met within each domain. In addition, normative data describing the age at which children typically demonstrate these skills allows members of the team to evaluate each child's response to the intervention.

In addition, Therapeutic PATHWAYS uses scores from annual testing by independent evaluators using standardized measures of cognitive functioning, language development, and adaptive skills to evaluate their progress. In some areas, independent evaluators are under contract to the regional center to provide this testing as part of placement in an intervention program. In other areas, school personnel conduct the testing. In some cases, families need to access these services through private practitioners or centers such as the University of California at Davis M.I.N.D. Institute.

Outcomes of the intervention for 29 children who received treatment at Kendall School/Therapeutic PATHWAYS are described in a study published by Howard, Sparkman, Cohen, Green, and

Stanislaus.⁴⁵ At baseline, average cognitive standard score equaled 59. Developmental equivalents for both receptive and expressive scores averaged 15 months. At the end of 14 months of treatment, average cognitive standard scores increased by 31 points and developmental equivalents for receptive and expressive language by 16 months. Children in two comparison groups showed significantly less progress on standardized measures of cognitive, language, and adaptive skills.

Implementation Considerations

The program leadership cited several implementation considerations, including:

- It is important not to underestimate how large a proportion of agency resources must be devoted to staff training and management.
- Retention can be a challenge, due to the preparedness of the staff hired to implement the interventions. The Kendall School hires college students and trains them to provide the school's behavioral interventions; given their student status, these staff members typically have a high rate of turnover and fairly brief tenures.
- The use of staff who have not yet achieved a Bachelors degree can also cause concerns, as it is not generally part of the treatment model.
 - However, this kind of staffing is essential to the success of the intervention as it is labor intensive and the cost of licensed personnel would be prohibitive. Careful supervision, extensive training, and tying staff advancement to success leads to measurable results.
- Staffing, in general, is an important key to the success of the intervention. It is necessary to have a wide range of staff, in skills, backgrounds, and personalities. It is also important to hire staff who will accept and support to the Kendall School's specific intervention paradigm.

4.3 Connecticut Pilot Program for Young Adults with Autism Spectrum Disorders

Program Overview

In 2006, Connecticut established the Pilot Program for Young Adults with Autism Spectrum Disorders to address the needs of young adults with ASD who did not have a co-occurring condition of intellectual disability, or require an ICF-MR level of care, as was required under the State's Medicaid waiver for people with developmental disabilities. The experience of the two-year pilot, funded by State appropriations, was used as part of the basis for development of Medicaid HCBS waivers targeted to persons with ASD. The pilot focused on improving the skills of adults with ASD in the areas of employment, social relationships, and independent living, including financial management. The program served 25 adults with ASD in New Haven, Connecticut.

⁴⁵ Howard JS, Sparkman CR, Cohen HG, Green G, and Stanislaw H. (2005). A comparison of intensive behavior analytic and eclectic treatments for young children with autism. *Research in Developmental Disabilities*. 26: 359-383. Available at <http://www.ctfeat.org/articles/ABAvEclectic.pdf>

Program Eligibility

Eligibility criteria for the pilot program included:

- Traditional ICF-MR criteria of impairment in three of six functional areas:
 - Self-care
 - Understanding and use of language
 - Learning
 - Mobility
 - Self-direction
 - Capacity for independent living
- A seventh criterion was later added:
 - Economic self-sufficiency

The last criterion was to allow individuals with higher IQs to be included, as these individuals were still in need of community supports to transition to successful community living and education or employment.

Services Description

The primary goal of the skill building focus of the pilot was to help individuals become part of the workforce, and ultimately, to work toward financial independence. Services were designed to support consumers to develop the functional skills required to secure jobs and perform as successful participants in the workforce. Other services provided as part of the pilot included independent living skills, social skills, educational and job coaching, as well as money management and safety in the community. Group and individual interactions were used to help individuals acquire social skills and understand their supervisor's expectations on the job.

A key factor in the success of the pilot program was monthly clinical reviews. These reviews include key staff, a representative from the state, private provider agencies, support programs, a representative from vocational rehabilitation, a parent advocate, a psychologist, and autism support program representation. The individual attends their case review and brings their family and their provider staff to the review. The team reviews goals and progress toward desired outcomes. The review group provides feedback and practical suggestions to the individual, their family, and their provider staff. State agency participation in the meetings helps connect administrative staff to what is happening with the program on the ground. Providers receive useful information through the reviews and families receive information from professionals about the services needed for their family member. Finally, the meetings hold providers to a level of accountability.

Implementation Considerations

Program enrollment was slower than desired. Steps were taken to recruit participants through multiple sources including family advocacy groups, State health and disability agencies, and provider organizations. Because of lags in enrollment, program participation was not at capacity for the first

year. Meeting enrollment requirements to support the pilot program's evaluation necessitated recruitment outside the original geographic area.

Another significant challenge to implementation was building a network of knowledgeable and experienced providers capable of delivering services to persons with ASD. In particular, pilot implementers found that some of the younger support providers in the program did not have the skills or insight required to work effectively in meeting the needs of this unique group of individuals with ASD.

In response to the identified gaps in experienced staff, the State contracted in 2009 with the ASD Resource Center to produce two training DVDs that address skills for and approaches to working with individuals who have autism. The State now requires staff to pass competencies based on the DVDs before they can work. Individuals who have ASD watch these DVDs with their support staff. This dual training for staff and individuals with ASD is an effective way to teach support staff and enables individuals with ASD to find affirmation and gain knowledge through participation in the training. The trainings, which have reportedly spurred social relationships between peers with ASD, have received very positive feedback. Here are important particulars:

- Planning for change with all stakeholders at the table facilitates implementation; a steering committee was used to define the vision, eligibility criteria, service package, and provider training components of the pilot program.
- Innovation can be implemented on a small scale with lessons learned applied to planning more comprehensive initiatives.
- Monthly clinical reviews are important for coordination and to address client needs.
- There is a need to train a largely uninformed workforce to support adults with ASD.
- Training for clients, with support staff in attendance, is an effective way (a) to train the staff without staff feeling belittled and (b) to create a positive activity for clients where they help teach the staff and have the opportunity to build their own social skills and networks.

As a result of the pilot experience, Connecticut's new ASD waivers will cover a new service--using a live-in companion for individuals who need minimal support for independent living. The idea is for the individual in need of support to rent a two-bedroom rather than a one-bedroom apartment. The State would pay the difference in rent for the extra bedroom, thus providing the live-in support person rent-free housing in return for providing assistance as needed.

The new three-tiered waiver system was developed with input from researchers, agency staff, and provider organizations. Access to the new three-tiered HCBS waivers will be determined using a level of need tool. The State has just published a level of care tool to determine what level of services by helping case managers identify needs and targeted outcomes. Individuals who need small amounts of assistance to remain independent will receive \$35,000 of services, in the middle range of need \$80,000, and in cases of high need over \$80,000. To qualify for one of the new waivers, individuals must show evidence of an ASD diagnosis with no intellectual disability.

4.4 Indiana: First Steps Early Intervention Program

Program Overview

The Indiana First Steps program is run by the Indiana Family & Social Services Administration (FSSA) under the aegis of the Bureau of Child Development Services (BCDS).

Started in 1995, the program's mission is:

*To assure that all Indiana families with infants and toddlers experiencing developmental delays or disabilities have access to early intervention services close to home when they need them. This is accomplished through the implementation of a comprehensive, coordinated statewide system of local interagency councils called first steps.*⁴⁶

Program Eligibility

First Steps serves children ages 0-3 years who have either a diagnosed developmental delay or a medical diagnosis with a high probability of leading to a developmental delay. First Steps is not designed to serve at-risk children without a diagnosis. Children with ASD are often enrolled in services with a diagnosed developmental delay that is later determined to be the result of ASD. First Steps is designed to intervene quickly, eliminate or reduce any developmental delays or disabilities, prevent costly service needs later in life, involve the family, and support the child within the community. There are no income-related eligibility requirements.

Services Description

The core components of the First Steps program include:

- Early identification of children with developmental delays or disabilities
- Delivery of timely services
- Promotion of public awareness and education of the public with regard to developmental delays
- Identification of qualified providers

The assessment of developmental delay relies on a comprehensive multidisciplinary assessment which does not necessarily produce an ASD diagnosis, but rather a measure of the degree of developmental delay. The program does not pursue a differential diagnosis of ASD unless the family requests support and further evaluation.

The 16 services available through First Steps include:

⁴⁶ Indiana DRS. *Current DRS Policies: First Steps (Early Intervention)*. Available at <http://www.in.gov/fssa/drs/2633.htm>

- Assistive technology (AT)
- Audiological services, including signed and cued language services
- Developmental therapy (DT)
- Family education, training, counseling
- Health services
- Medical services
- Nursing services
- Nutrition services
- Occupational therapy (OT)
- Physical therapy (PT)
- Psychological services
- Service coordination (SC)
- Social work services
- Special instruction [developmental therapy (DT)/early childhood education]
- Speech-language pathology (SLP)/speech therapy
- Transportation
- Vision services
- Other services

The category of “Other services” can be used to support children and families whose needs do not fit well into the named categories of service. For example, “Other services” can be used to provide training in ABA methods. First Steps provides services in the child’s natural environment with the support of parents and/or caregivers. If necessary, the program can send children to therapy or off-site treatment programs (for example, for horseback riding therapy or to a specialized clinic).

First Steps services are delivered in accordance with an Individualized Family Service Plan (IFSP) which specifies long and short term goals, strategies to utilize family resources, developmental priorities, and assessments of developmental status. IFSPs are flexible and designed to be respectful of and responsive to family culture, language, interactions, and traditions. In general, the IFSP determines the intensity and duration of services under the guidance of the treatment team.

First Steps is in the process of transitioning to more research-based treatment, although at this time they do not endorse one treatment modality over another. They cover “floor time” and “play project” services, which have a solid base of evidence for the developmentally delayed population. While First Steps has explored introducing ABA as a provided service, they have found that locating qualified ABA providers is very difficult. First Steps is now monitoring these providers and taking action with individuals and providers who claim to be providing ABA services but are without licensure or certification. First Steps does provide some ABA services, mostly via the services of developmental therapists and speech therapists. If the family requests ABA services specifically, the State must approve the rate paid on a case-by-case basis. If a provider is enrolled with the State as another kind of therapist, they may be reimbursed for ABA services at the rate paid for that other service. Non-licensed providers who are certified in ABA must report their desired rate to the state, which then negotiates reimbursement based on those qualifications.

Staffing

First Steps is responsible for identifying qualified ASD providers. Provider qualifications include participating in a training process that First Steps has implemented, as well as completion of prequalification and credentialing processes. In addition, First Steps providers must pass an assessment by First Steps staff, and are responsible for participating in ongoing education and credentialing processes. First Steps does not set specific staffing requirements for provider programs. Providers must meet State qualification and credentialing standards during the open enrollment process to become First Steps providers. The State requires that districts ensure there are adequate numbers of providers to meet their local needs. As of 2011, the State will require most therapists qualified to treat persons with ASD to be associated with an agency (rather than be a solo practitioner) that is a qualified provider for the state. While the State will still contract and reimburse on a fee-for-service (FFS) basis, teaming expectations will be built into all new contracts. In addition, new contracts will include a supervision or quality assurance requirement. Currently, providers are reimbursed for team meetings and collaborative efforts. The new system will reinforce and strengthen this collaborative approach.

Typical reimbursement rates in Indiana include:

Provider Type	Rate
Psychologist	In office: \$100/hour In home: \$120/hour
Speech Therapist	\$80/hour Service only provided in home
Physical Therapist	\$65/hour
ABA Certified, no Masters degree	\$65/hour
Paraprofessionals	\$25/hour at last rate negotiation

Funding

A combination of State and federal funds supports the First Steps program, representing about 15% of the First Steps budget. State funds are awarded via the legislative process; federal funds come as a result of the State's Part C grant from the Department of Education (DoE). The rest of the program cost is carried in part by private insurance and in part by Medicaid. Medicaid is the biggest payer for the First Steps program: \$7 million (over 10% of the State's Medicaid budget) goes to pay for direct services. In addition, First Steps receives \$4 million in Medicaid administrative funds. Finally, families pay on a sliding fee basis for the cost of program participation. Families at 250% of the Federal Poverty Level (FPL) pay about \$3 per service; as incomes increase, so do the out-of-pocket fees paid by the family. As with any other service, children who live at some distance from metropolitan areas have a more difficult time finding qualified providers who accept the current rate. First Steps has had to be flexible when determining how to provide services to children in more rural settings. Some providers are paid to visit distant families; some families choose to travel to one of Indiana's six Resource Centers, which can provide higher quality services than those in rural communities.

First Steps records federal outcomes data for all children enrolled in program services. These outcomes data, in addition to IDEA measures, are not broken out by specific diagnosis, reporting information only on children with developmental delays versus children with disabilities.

Implementation Considerations

The State offers the following considerations for future implementation:

- Best practices are turning out to be services that Indiana already provides:
 - Relationship-based services
 - Caregiver/parent involvement
- Developing a partnership with the parents, the community, and the primary care physician is the key to success.
- Misinformation about what works in treating children diagnosed with ASD is widespread, and families are desperate to find a treatment that works. This poses a challenge when trying to provide research-based treatment.
 - Building a good relationship with the family helps to fight misinformation and steer them to experts in ASD.
- Significant costs are associated with services to children with ASD. Indiana has attempted to reduce these costs by working with families and training them to be consistent in the application of practices/services, which appears to have reduced costs over time. This reduction may also reflect the decrease in demand for ABA services, which have a high number of billable hours associated with them.
 - Indiana has emphasized with parents and providers that no single service is going to provide everything their children need. In addition, they have educated child care providers so they can provide effective support on an everyday basis in child care settings.

In an ongoing effort to reduce costs, the State is also working with insurance companies to cover ASD services and reimburse eligible providers.

4.5 Maine Primary Care Clinician Training

Program Overview

Maine is a predominantly rural state with a limited number of developmental behavioral pediatricians. During a state-developed quality improvement process called LEAN, the Maine Department of Health and Human Services (DHHS) became aware that many physicians were not comfortable treating children with ASD, even for simple problems such as sore throats. This discomfort led to an overwhelming number of referrals to developmental pediatricians for conditions that could be satisfactorily addressed in primary care. In these instances, families found they had to travel several hours to reach treatment, regardless of the severity of the child's physical health condition.

DHHS obtained funding from Maine’s Center for Disease Control and Prevention (CDC) to facilitate training families, pediatricians, and family practitioners in ways to provide physical health care to children with ASD. DHHS chose two groups of physical health practitioners whose patients lived outside a reasonable travel radius from Maine Medical Center to receive the initial training. Developmental behavioral pediatricians provided the training at each practice site. The first pilot training workshops were held in 2009. Each consisted of two one-hour training sessions. Medical assistants and front office staff attended the training at one of the sites. The topics covered in the workshops included:

- Autism screening,
- Psychotropic medication management,
- Community and family supports,
- Methods pediatricians could use to address co-morbid medical conditions, and
- Conducting physical examinations in a way that is sensitive to the children’s hypersensitivity to pain and external stimuli

The ultimate goal of the workshops was to address parent-physician communication and other obstacles that can lead to miscommunication and unnecessary referrals, with the goal of promoting family-centered care. At the training, physicians were given toolkits which included peer reviewed literature on ASD, screening tools, and handouts for families. The training has helped avert inappropriate referrals to developmental behavioral pediatricians. Physicians who attended the trainings reported increased self-rated knowledge about ASD.⁴⁷

As a result of the positive feedback received from the first two training workshops, trainings were provided for several other primary care practice groups. DHHS presented results from the evaluation in May 2010 at the annual meeting of the Maine Chapter of the American Academy of Family Physicians, which also served as an opportunity to recruit other practice groups to receive training.

The State is now in the process of developing technical assistance to support physicians in their work with children with ASD, which will be modeled after the “train the trainer” model used by consultants. The two developmental pediatricians who led the Maine effort will train other developmental pediatricians so they can provide technical assistance and support when needed. Maine DHHS is also in the process of developing online training for physician office staff that will address how to respond to the needs of children with ASD in the waiting room.

Ultimately, the State hopes (a) to reduce the current burden on developmental behavioral pediatricians so they can concentrate their specialty, and (b) to allow children with ASD to be treated for routine conditions by their primary care physicians.

⁴⁷ Hubbard, C., Dalzell, V., Schwalberg, R. (2010). *Autism Education Workshops for Primary Care Pediatricians in Maine*. Evaluation. Altarum Institute.

Implementation Considerations

- Training in ASD was welcomed by physicians.
- Training for primary care physicians alone is insufficient. They also need ongoing support and consultation in order to address the health needs of children with ASD.

4.6 Missouri Best Practices for Screening, Diagnosis, and Assessment

Two initiatives to improve screening, diagnosis, and assessment are featured as promising practices from Missouri. The first describes the development and dissemination of guidelines. The second describes the formation of state-level centers of excellence to reduce delays in diagnosis for children with autism.

Autism Spectrum Disorders: Missouri Best Practice Guidelines for Screening, Diagnosis, and Assessment

In order to fulfill the recommendation of the State’s 2007 Blue Ribbon Panel on Autism, a steering committee of four professionals was appointed to lead the Missouri Autism Guidelines Initiative (MAGI). The steering committee gathered input from 42 stakeholders, including parents, physicians, and other professionals, to provide input into guidelines for ASD screening, diagnosis, and assessment. This group met regularly through teleconferences, with consultation from individuals who had been involved with the California initiative to develop similar guidelines.⁴⁸

The MAGI group published consensus guidelines on screening diagnosis and assessment in 2010.⁴⁹ The Missouri Foundation for Health provided a grant for the development of an ASD guidelines website and printing of 10,000 screening, diagnosis, and assessment guideline books entitled, *Autism Spectrum Disorders: Missouri Best Practice Guidelines for Screening, Diagnosis, and Assessment*. These books are available at no cost to the public upon request. Within the first five months after publication, 6000 copies had been distributed. In addition to the lengthy guidelines, additional documents are provided for professionals. Shorter summaries of the guidelines are available that target the following groups:

- Families
- Clinicians
- Educational professionals
- Service providers

⁴⁸ Missouri Department of Mental Health Division of Development Disabilities. *Autism Spectrum Disorders: Missouri Best Practice Guidelines for Screening, Diagnosis and Assessment*. Available at <http://www.autismguidelines.dmh.mo.gov/pdf/Guidelines.pdf>

⁴⁹ Missouri Department of Mental Health Division of Developmental Disabilities. *Missouri Autism Guidelines Initiative*. Available at <http://www.autismguidelines.dmh.mo.gov/>

Other than distributing the guidelines and family education through the organization Autism Speaks, there is no formal plan for implementation of the screening guidelines.

Before dissemination of *Autism Spectrum Disorders: Missouri Best Practice Guidelines for Screening, Diagnosis, and Assessment*, the average age of ASD diagnosis was 5-8 years. The goal now is to screen children early and move rapidly from screening to referral for assessment and diagnosis.

The Missouri guidelines also emphasize a family-centered approach to autism screening, diagnosis and assessment, along with guidance for family-friendly ways of communicating with and engaging families. Options for screening, diagnostic, and assessment tools are presented by age group, along with information about costs for the tools and administration time.

The guidelines further lay out a tiered approach to providing an ASD diagnosis. The tiers make distinctions between the complexity of a child's clinical presentation and the professionals who should be involved in assessing the child. The tiered approach represents a compromise between those who felt a multi-disciplinary approach to diagnosis was best and those who felt that a single diagnostician could make an accurate diagnosis in most cases. The tiered approach makes efficient use of a limited number of diagnosticians who specialize in ASD. This multi-disciplinary approach to diagnosis is reserved for those children with the most complex symptom presentations (see diagram below).⁵⁰ The guidelines also outline the steps for referral for further evaluation, comprehensive diagnosis and, if needed, intervention and a comprehensive service plan. The standardized tools recommended for use include:

- Modified checklist for autism in toddlers (M-CHAT) screener
- Childhood autism rating scale (CARS)
- Autism diagnostic observation schedule (ADOS)
- Autism diagnostic interview revised (ADI-R)

As an example of how the guidelines have been used, 55 physicians in St. Louis County have received consultation from one of the Missouri Autism Guidelines Initiative (MAGI) steering committee members to increase their screening of children for ASD. Before consultation and training began, 30% of those physicians were conducting general developmental screening and only 10% were specifically screening for ASD. After training and consultation this increased to 90% and 80%, respectively. The St. Louis County group established a process that enables diagnosis to be confirmed and the assessment process begun within three weeks of referral.

⁵⁰ In column three, "Consultation with other Professionals", consultation with multiple professionals refers to use of a multidisciplinary approach to diagnosis.

OVERVIEW OF DIAGNOSTIC EVALUATION TIERS			TABLE 1.1
	INDIVIDUAL PRESENTATION	USE OF STANDARDIZED INSTRUMENTS	CONSULTATION WITH OTHER PROFESSIONALS
TIER 1	Presentation of symptoms that unambiguously indicate an ASD	May be used; not required	None
TIER 2	Milder or more complex symptoms, difficult differential diagnosis, question about cognitive level	Yes	Possibly; consult with at least one other professional, as indicated
TIER 3	Very subtle or complex symptoms, some ASD symptoms with multiple co-existing concerns, complex medical or psychosocial history	Yes	Yes; consult with multiple other professionals

Missouri Autism Centers of Excellence

In 2008, funds were appropriated to establish Autism Centers of Excellence in Missouri. At that time, three regional Autism Centers of Excellence were funded:

- The Thompson Center for Autism and Neurodevelopmental Disorders at the University of Missouri, Columbia
- The Knights of Columbus Developmental Center at Cardinal Glennon Medical Center, St. Louis
- Developmental and Behavioral Sciences Section, Children’s Mercy Hospitals and Clinics, Kansas City

In 2010, a fourth was added at the Autism Center for Diagnosis and Treatment at Southeast Missouri State University.

The goals of these centers are to:

- Reduce wait times from first expression of symptoms or caregiver concern to receipt of an appropriate ASD diagnosis.
- Provide critical and timely diagnostic information to families and make appropriate referrals for services.
- Strengthen training efforts on the recognition of ASD within the clinics and their complementary community-based service providers and family caregivers.

These centers report data directly to the Missouri Division of Developmental Disabilities Office of Autism Services, so that wait times and age of first diagnosis can be tracked and gaps addressed. The centers also report performance data on educational presentations and outreach on autism awareness.

4.7 New Mexico: The Center for Development and Disability

Program Overview

New Mexico is a frontier state with a diverse population dispersed across large rural, desert, and mountain areas. These characteristics, combined with high levels of poverty and low numbers of licensed health care professionals, make the delivery of effective care to persons with complex conditions, including ASD, a huge challenge. The Center for Development and Disability (CDD) is organized to solve several core elements of the challenge confronting New Mexico as it strives to meet growing demands for effective care from persons with ASD and their families.

Established in 1990, CDD is located at the University of New Mexico, School of Medicine. CDD is a University Center for Excellence in Developmental Disabilities, Education, Research and Service (UCEDD). It is also part of the national network of National Professional Development Centers. CDD's mission is to achieve "full inclusion of people with disabilities and their families in their community."⁵¹ CDD works in a manner that respects and addresses the cultural and linguistic diversity of the population of New Mexico, promoting inclusion and accessibility, supporting individuals in making life choices, building capacity and resources through community partnerships, innovating and improving care systems, and implementing interdisciplinary, science driven practice. CDD provides a range of services designed to achieve its mission, including:

- Disseminating information about ASD to families, providers, practitioners, schools, and other interested parties
- Providing education and training to all disciplines involved in serving children and adults with ASD
- Providing technical assistance to practitioners and caregivers
- Filling services gaps
- Conducting applied research

Seventeen years ago, CDD founded a clinic that was open two afternoons per week to perform diagnostic assessment for children and adults with autism and ASD. The clinic was rapidly overwhelmed with demand, creating a three-to-four year waiting list. That demand for care inspired the effort to acquire more resources and develop a core ASD program.

Program Eligibility

CDD is concerned with all children and adults with ASD in New Mexico. CDD performs screening and assessment to establish a diagnosis, using multiple methods and defined criteria to determine eligibility for ASD services. When children who do not meet ASD criteria appear for services but have related developmental disabilities, CDD makes every effort to assist the child and family.

⁵¹ UNM Center for Development and Disability. *Welcome to the UNM Center for Development and Disability*. Available at <http://cdd.unm.edu/>

Services Description

New Mexico is a frontier state, with limited budget resources to grow a long term services and supports (LTSS) system, few trained providers, and limited reimbursement for ASD services. In light of these conditions, CDD works to maximize the impact of its professional staff resources to support system development, strengthen clinical competence of programs, and fill critical service gaps service. CDD serves as a single portal for access to (a) LTSS and (b) seasoned professionals who do everything from diagnosing and determining eligibility to training system professionals and spawning development of new programs.

Core autism services are provided in English and Spanish and include:

- Clinical and Family Support Services:
 - Neurodevelopmental Clinic that performs diagnostic evaluation, staffed by a developmental pediatrician, neuropsychologist, clinical psychologist, speech-language pathologist, clinical social worker and family specialist, plus a broad range of trainees from multiple disciplines
 - Project SET for early identification and intervention, building competence in evaluation and program planning in early intervention and preschool programs
 - Parent Home Training, which (a) provides individually tailored and evidence-based practices taught to parents to promote their child's optimal development of communications and social skills, using positive behavioral supports; and (b) engages community teams to carry on the work with and support of families
 - Intensive Case Management Services, focused on children in Adaptive Skills Building services, monthly consultation, and resource assistance to families
 - Adaptive Skill Building provided in multiple communities throughout the state
 - Camp Rising Sun, a one-week residential camp for children ages 8-13 with a threefold purpose: respite for families, socialization for children, training for students
- Information and Referral Services:
 - CDD Information Network, includes a library staffed by information specialists who link and refer clients and families to services and information resources, Disability Resource Directory, links to online tutorials and training, publications
 - Parent Network, using trained family members for consultation, support, referral and resource linkage
- Professional Development and Coaching/Family and Community Training Services:
 - ASD professional development, which trains and mentors 12-15 teams per year with a focus on evidence-based methods
 - Family and Community Education in ASD (FACE), offering training and technical assistance statewide to families, providers, and practitioners
 - ASD school based services, including (a) consultation to school districts and training of teachers, and (b) establishing model classrooms as training and dissemination

sites, as part of its National Professional Development Center role to promote adoption of evidence-based practices, as funded by the DoE

- Mentoring and coaching educators and service providers to improve practice and expand effective services
- Mentoring and coaching State developmental disability team with UCEDD staff
- Contractual services, providing consultation, training, and technical support to individual school districts
- LEND Program (Leadership Education in Neurodevelopmental Disability), funded by the Combat Autism Act through the Health Resources and Services Administration (HRSA), which provides 300 hours for trainees drawn from interdisciplinary graduate programs in OT/PT/Education, during a two-day course and one week at Camp Rising Sun, mixing didactic and practical training

Staffing

The team structure at CDD is a strong factor in recruitment of staff members who are competent and knowledgeable in ASD and have experience with psychosocial interventions. Development of a clinically sophisticated team allows CDD to conduct comprehensive evaluations, formulate robust initial care plans, and provide appropriate, on-going case consultations to inform future care plans. The CDD team's advanced capabilities are also the foundation of effective professional development, caregiver training, and staff coaching services.

Funding

Federal Administration on Developmental Disabilities (ADD) funding supports the UCEDD functions. The New Mexico Special Education Office of the Public Education Department funds the teacher training and support work. The New Mexico legislature funds training through the Department of Health. The State's Human Services Department and Medicaid provide reimbursement for the services of the diagnostic team. The CDD also bills private insurers for diagnostic services. The National Professional Development Center is funded by the DoE.

Implementation Considerations

- As noted above, New Mexico is a rural, frontier state with significant geographical challenges in staffing and siting services, particularly low-demand services. Health care and disability professionals in New Mexico are clustered in Albuquerque and Santa Fe. CDD is located at the Medical School in Albuquerque and the program works to provide access to low-demand services such as evaluation and consultation at the cluster sites. This practice protects limited professional staff time and associated costs that would be incurred in traveling to rural areas.
- New Mexico faces recruitment challenges in attracting capable and culturally competent licensed professionals to serve persons with ASD.
- CDD has worked to develop culturally competent caregiver training, designed to effectively transmit technical knowledge and care giving skills to family caregivers, enabling them to

meet the needs of their children with ASD for continuous and consistent behavioral and adaptive skill building services.

- New Mexico is now implementing an Intensive Services pilot, for up to 12 hours per week

4.8 Pennsylvania: Adult Community Autism Program (ACAP)

Program Overview

Pennsylvania is one of the few states in the country to address services needs for the increasing number of adults living with autism spectrum disorders (ASD). Keystone Human Services (KHS) is one of the State's primary developmental disability organizations and is responsible for serving individuals with intellectual disabilities, including autism and mental health conditions. Since its founding in 1972, KHS has provided a range of services to its target clients across their lifespan. KHS began with evaluation and early intervention services for children and their families. Over the last few years, KHS has created a subsidiary division, Keystone Autism Services (KAS), to meet the service needs of children and adults with ASD as well as their families.

In 2009, Pennsylvania's Bureau of Autism entered into a contract with KAS to implement a program that offers adults with ASD and their families a range of comprehensive services and supports through a managed care delivery system. KAS launched the Adult Community Autism Program (ACAP) in four Pennsylvania counties. As a provider organization, ACAP is committed to developing and facilitating a system of care in the State for adults with ASD. It is the first program in the country specifically designed to tackle meeting the comprehensive service needs of adults living with ASD through an integrated and managed specialty care program. ACAP currently serves 45 State residents, is continuously growing, and has the ability to serve up to 200 clients.

ACAP functions as a managed care organization, and is responsible for clinical and administrative oversight of all services provided pursuant to an individual care plan. ACAP manages all health services for its clients, including hospital, diagnostic, laboratory, and pharmacy services. In addition to its medical assistance services, ACAP contracts with a small provider network of physicians, as well as psychologists and nutritionists, and an administrative third party organization (TPO) that is responsible for processing billing and claims.

Pennsylvania's Department of Public Welfare is the primary funding agency for ACAP services. KHS is paid on a capitated basis; however, ACAP does not pay out of the capitation rate for patient hospital stays, diagnostic care, laboratory services, or in-patient care. These costs are paid under clients' benefits pursuant to enrollment in HealthChoices, another Pennsylvania Medicaid managed care program.

Program Eligibility

The ACAP program is available to individuals who meet the following eligibility criteria:

- Age 21 years or older

- Eligibility for Medical Assistance
- Diagnosis of an ASD (IQ score is not considered)
- Certification as meeting Medical Assistance program clinical eligibility for ICF services in the state
- Not enrolled in a Medical Assistance HCBS waiver program at the time of enrollment
- Able, upon enrollment, to live in the community without 16 or more awake paid and unpaid staff and supervision hours per day
- Not exhibiting behaviors that would present a danger to self or others or threat to property
- Residence in the service area (Chester, Cumberland, Lancaster, or Dauphin counties) at time of enrollment
- Not enrolled in a Medical Assistance managed care organization at time of enrollment⁵²

After an individual applies to ACAP, he/she must meet “functional eligibility” requirements set by the Pennsylvania Bureau of Autism Services. The Bureau conducts an in-person evaluation and uses the “Adult Community Autism Eligibility Worksheet” to determine whether the individual has significant impairment and daily limitations (such as communication, mobility, or ability to live independently).⁵³ To qualify for ACAP services, adults must show significant impairment in at least three areas. Once the individual is declared eligible, ACAP providers create an ISP with the client and family based on the Bureau’s comprehensive assessment.

Services Description

KAS operates ACAP under a Medicaid section 1915(a) contract with Pennsylvania. ACAP supports the delivery of a broad range of services, with options for tailoring services to individual, cultural, and linguistic needs. Selected services, such as pharmacy, are provided through HealthChoices. ACAP providers are required as a condition of participation to receive training specific to supporting adults with an ASD.⁵⁴

The following is a summary of the covered HCBS offered by ACAP:

⁵² Keystone Human Services. *Keystone Autism Services - Adult Community Autism Program ACAP*. Available at <http://www.keystonehumanservices.org/keystoneAutism/adultCommunityAutismProgram/acapEligibility.php>

⁵³ Autism Society of America. *Pittsburgh Pennsylvania Chapter, PA Bureau of Autism Services Adult Waiver*. 10 Mar. 2009. Available at http://www.autism.society.org/site/Clubs?club_id=1190&sid=7070&pg=news

⁵⁴ Pennsylvania Department of Public Welfare. *Comparison of Medicaid Programs that Serve Adults with Autism Spectrum Disorders (ASD)*. Available at http://www.dpw.state.pa.us/ucmprd/groups/webcontent/documents/communication/s_000918.pdf

ACAP Community-Based Services

- All physician services
- Certified Registered Nurse Services
- ICF services
- Nursing facility services
- Nonemergency medical transportation to services covered under the Medical Assistance Program
- Optometrists' services
- Chiropractors' services
- Audiologist services
- Dentist services
- Health promotion and disease prevention services
- Medical supplies and durable medical equipment
- Prosthetic eyes and other eye appliances
- Hospice services
- Mental health crisis intervention services
- Outpatient psychiatric clinic
- Assistive technology
- Behavior support services
- Education support services
- Home accessibility adaptations
- Vehicle accessibility adaptations
- Unlicensed home and community habilitation
- Home finding
- Homemaker/Chore
- Licensed day habilitation
- Licensed residential habilitation (consolidated only)
- Unlicensed residential habilitation
- Nursing services
- Prevocational services
- Respite
- Companion
- Specialized supplies
- Supported employment
- Support of broker services
- Support of coordination services
- Respiratory services
- Targeted case management
- Assistive technology
- Behavioral support (similar to Behavioral specialist services in waiver)
- Community transition services
- Crisis intervention services
- Adult day habilitation
- Environmental modifications
- Family counseling
- Habilitation
- Homemaker/chore services
- Non-medical transportation
- Personal assistance services
- Pre-vocational services
- Residential support (similar to residential habilitation)
- Respite
- Supported employment
- Visiting nurse
- Physical, occupational, vision and mobility, and speech therapies (group and individual)
- Certified nurse practitioner
- Podiatrist
- Additional services determined necessary

The ACAP program operates much like a special needs plan (SNP), in which KAS serves as the plan administrator: facilitating member enrollment, assessing their needs and preparing care plans, organizing and qualifying the provider network, paying claims, and reporting on results. The Bureau of Autism plays a significant role in determining eligibility, enrollment, and assessment. While KAS received a global capitated payment for ACAP services, there is no cost limit or cap imposed on care to individuals served in the program. All services provided under ACAP must be considered medically necessary and listed as part of the participant's ISP. One of the important differences between ACAP services and a typical SNP is that care plans are developed pursuant to comprehensive diagnostic and functional assessment of need.

Staffing

ACAP providers are mobile and offer services in the family home, school, or occupational setting. Providers operate services 16 hours per day, with 24-hour on-call back-up support. ACAP's comprehensive provider network allows the program to conduct thoughtful evaluations and provide appropriate and individually based ASD services to its clients. The ACAP team structure is made up of clinically sophisticated staff members. The support service coordination role is performed by a Master's level senior clinician who then supervises a staff of four additional clinicians, each carrying a caseload of 10-12 clients. Additionally, each team works with a behavioral specialist who supervises community support activities for clients. Before employment, ACAP offers a two-week orientation with structured classroom activities as well as community-oriented trainings. Trainings are conducted every three months throughout the first year of employment, with ongoing support and mentoring by senior staff members.

The ACAP program has already documented positive outcomes in reduced levels of behavioral challenges, increased moves to independent living, and higher levels of competitive employment.

Implementation Considerations

There has been increasing support for and interest in ACAP throughout the state of Pennsylvania. One of the most distinguishing characteristics of the client population compared to those enrolled in other programs, as noted, is that this program targets the adult ASD population and uses a capitated rate payment methodology. Since its creation, ACAP team members have observed several individual outcomes, including increases in independence, self-determination, management of psychological and medical needs, and percentage of adults in the workforce. Furthermore, ACAP providers have witnessed changes in caregiver quality of life, including decreases in caregiver stress and increases in consumer and family satisfaction.

As the ACAP clientele continues to grow, the program is actively working to improve ASD service delivery. ACAP providers note several challenges to the implementation of an adult-specific ASD program, including:

- Enrollment of ACAP consumers/members is slower than anticipated. This may in part be due to cumbersome eligibility processes at the State level, and hesitancy of consumers and families to switch service providers from the FFS model.
- Recruitment of sufficient numbers of staff with knowledge about and skills in serving persons with ASD is slower than hoped, which in turn has led to difficulty building a provider network. ACAP team members have reached out to local colleges and are currently offering internships for interested students. However, ACAP executives note that the adult ASD workforce needs to be further developed and should begin to focus more on consumer skill development rather than associated behavior challenges.
- Recruitment of physicians who are geographically accessible to ACAP consumers, willing to work with persons with ASD and available to participate in required training, has also lagged. Establishing mechanisms to pay physicians to participate in ASD training is an additional challenge.

- Recruitment of program staff in more rural parts of the four Pennsylvania counties served by ACAP has posed difficulty, in particular hiring the right blend of staff members that live close to ACAP clients.
- Providing services for consumers ages 18-21 is a particular challenge. Historically, service development and program resources have been limited for this age group, as Medicaid reimbursement under the adult autism waiver is limited to services to persons over age 21.
- ACAP providers have faced challenges with the 16-hour limit on services provided per client per week. This cap on service hours makes it impossible to serve individuals with ASD who have intensive service needs.

The following lessons learned and actions taken were also noted:

- To address a gap in services for persons ages 18-21, ACAP has proposed to the State that the program begin at age 18.
- ACAP is currently working with the State to lift the 16-hour cap on ASD services.
- ACAP is actively recruiting and is searching for staff in various geographical locations to serve clients in the four Pennsylvania counties.
- Physician education is important and clinical expertise is imperative for effective ASD service delivery.

Keystone Human Services makes information about the Adult Community Autism Program available on their website. <http://www.keystonehumanservices.org/>

4.9 Wisconsin Transition Action Guide for Post-School Planning: A Model of Interagency Collaboration

Program Overview

Wisconsin is a county-driven state with adult services coordinated by county-based Aging and Disability Resource Centers (ADRCs). In 2007, the State implemented an interagency agreement to address transitional services for children with disabilities, including children with ASD. State agencies involved in the interagency agreement include the Department of Public Instruction, the Department of Workforce Development, and the Department of Health Services.

In 2010, these three agencies published the Transition Action Guide For Post-School Planning (TAG). The goal of the TAG is to improve communication between staff and increase shared knowledge of each child's needs and strengths. The TAG also aims to enhance coordination of services and support the smooth transition of children with disabilities from school to further education, work, and independent living.

The model for post-school transition includes six domains:

- Identification of measurable employment goals

- Sharing knowledge of applicable Department of Workforce Development's Division of Vocational Rehabilitation (DVR) services and Department of Health Services (DHS) resources at least two years prior to graduation
- Early referrals for DVR and DHS when needed (two years before graduation)
- Joint transition planning through the IEP process
- Cross-departmental service plan coordination
- Yearly review of IEP and service plans, with plans shared between agencies with parent/guardian consent.

Wisconsin's TAG outlines the expectations of each member of the transition team including children, parents, teachers, rehabilitation counselors, and case managers. Furthermore, the guide outlines a number of successful practices for transition planning. These include techniques to involve students and families in their care, strategies that guide students and families to prepare for IEP and ISP meetings, and ways the ADRCs can engage schools in transition planning.

The interagency agreement for transition services reinforces coordination of services for children with ASD as they grow toward adulthood. For children identified with ASD, the DHS case manager coordinates with schools early in the child's development, emphasizing daily living skills and community engagement with an eye toward independence. A family and child service support coordinator attends IEP planning and transitional planning activities, which can help shape the transitional process from the start of services. DHS is working hard to improve expectations around employment and to shape positive, enhanced vocational opportunities. When youth reach the age 17 years 6 months, they can be referred to their ADRC to determine eligibility for adult waiver services. They also receive counseling for long term support waiver planning at age 18.

The Wisconsin Department of Public Instruction also sponsors the Wisconsin State Transition Institute, which holds a yearly conference and provides transitions resources for professionals, parents, and youths. Among these resources is an ASD guide targeted at Wisconsin Technical College staff, to assist them in addressing the needs of students with ASD. The guide includes a section on planning for the transition between high school and technical college, and one on the transition from college to employment.

Implementation Considerations

Other states or programs contemplating implementation may consider the following:

- Formal agreements support interagency collaboration.
- Transition planning should be addressed early on, not just when the child is "aging out."
- Interagency participation in the IEP process provides an opportunity to help support the child and family to identify and address realistic vocational goals.

The Wisconsin Transition Action Guide is available on the State's website:

http://dwd.wisconsin.gov/dvr/pdf_files/tag.pdf. More information about the Wisconsin Transition Initiative can be found at <http://www.wsti.org/>.

5. Conclusions

In this section we draw conclusions from the main information sources for this report and cite illustrative examples from the case study interviews.

Federal and state agencies have a shared interest in adopting and expanding the availability of evidence-based practices in screening, diagnosis, and treatment of ASD. CMS policies and the IACC Strategic Plan both seek to promote the adoption of evidence-based practices and to reduce barriers to the screening, diagnosis, and treatment of ASD. Similarly, the study states (Arizona, California, Connecticut, Indiana, Maine, Missouri, New Mexico, Pennsylvania, and Wisconsin) share a common commitment to adopting and implementing evidence-based/promising practices in serving children and adults with ASD. In these nine states, significant gains have been made in reducing barriers to screening and diagnosis, including widespread use of standards-based assessment. Still, each state noted continuing shortages and uneven geographic distribution of credentialed practitioners skilled in the diagnosis of ASD. They have found that goals to provide effective ASD treatment to all age groups and to develop comprehensive ASD care systems are still elusive due to gaps in the evidence, limited provider capacity, and funding constraints.

Challenging economic conditions in the study states, combined with the growing demand for ASD LTSS, create a potentially favorable context for the integration of standards and evidence-based practices. This is because, in the face of economic challenges, public officials wish to direct limited resources to the most effective services. States report two serious impediments, however: gaps in evidence-based practices that make it difficult for states to provide a complete services continuum; and lack of investment in standardization and evaluation of promising or emerging practices that could produce the outcome data required to establish new evidence-based practices. Gaps in resources are also impacting efforts to implement the existing evidence-based practices on a broad scale and with fidelity to staffing and protocol standards.

There is a high degree of concurrence among states regarding the need to build effective systems of support for individuals with ASD across the lifespan. All informants agree that closing the gaps demands a broader and more intensive range of services designed for discrete age groups.

- *Children:* Universal screening and early diagnosis of ASD is the pathway to timely care connections that advance development. Missouri's Best Practices for Screening, Diagnosis and Assessment and the work under way at New Mexico's Center for Development and Disability offer examples of effective state initiatives. Maine's Primary Care Clinician Training aims to expand the universe of knowledgeable physicians to aid in universal screening and early diagnosis, and also builds competence and capacity among primary care practitioners who can provide informed, lifelong medical homes to individuals with ASD. Although more evidence exists for child services, particularly those modeled on or incorporating ABA than for other approaches, these programs are not available in sufficient supply to meet the need in states and communities. Intensive programs provided in integrated community, school, and home settings are effective in helping children with ASD to acquire critical social, communication, and learning skills. Arizona's SARRC Community School, California's Therapeutic Pathways/Kendall School, and Indiana's First Steps Early Intervention Program are three successful models for these services, with manualized

staffing, training and practice protocols, as well as a track record of positive outcomes for children served and their families.

- *Transition-age youth:* States identify the largest gaps in care for this group. Only one state interviewed, Connecticut, identified a service targeted to this age group as a promising practice; a second state, Wisconsin, identified a model administrative protocol aimed at this group. Connecticut's Pilot Program for Young Adults with Autism Spectrum Disorders represents a sound test of a comprehensive care model designed to address significant unmet needs as youth transition from school to work or vocational rehabilitation, and from family homes toward more independent living. As an individual's eligibility status shifts from former government entitlements to that of adult services, more resources are required to plan and coordinate benefits and preserve needed supports across the boundaries of numerous state and local agencies that administer benefits and programs. Wisconsin's promising practice, the Transition Action Guide for Post-School Planning: A Model of Interagency Collaboration, is designed to support vulnerable youth through eligibility and life transitions.
- *Adults:* Adults with ASD often depend on developmental disability and/or behavioral health services systems that are not designed explicitly to meet their unique needs. Adults with ASD who have significant intellectual disabilities may qualify to be served under states' Medicaid HCBS waivers. For adults with ASD who do not qualify for developmental disabilities services, participation in Medicaid waivers targeted to persons with behavioral health conditions may be a path to more comprehensive HCBS care. However, all states interviewed indicated that, although adults with ASD need a range of rehabilitative, employment, housing, supportive and therapeutic services that are similar to those delivered in developmental disabilities and behavioral health systems, the optimal approach to serve them should be tailored to their specific needs. Moreover, although those other care systems use many evidence-based services, such as supportive housing and supported employment, the evidence for those interventions does not include evaluations of programs serving exclusively individuals with ASD. Some states have addressed ASD services for adults through autism waivers. Autism waivers in Connecticut, Indiana, Pennsylvania and Wisconsin, for example, target services to adults with ASD. Connecticut, Missouri, New Mexico, and Wisconsin also promote self-directed services, which allow programs to customize responses to meeting the special needs of adults with ASD. Pennsylvania's selected promising practice is a specialty managed care network, the Adult Community Autism Program (ACAP), designed to integrate, coordinate, and manage care across all Medicaid reimbursed services (medical, disability, and behavioral services customized for persons with ASD). Services are authorized and delivered according to a plan of care developed pursuant to a comprehensive assessment of the unique needs of each participant.

State key informants and program providers cited a range of cross-cutting issues that they consider instrumental to the implementation of evidence-based systems of care designed to meet the needs of individuals with ASD.

These include:

- Active stakeholder and advocacy engagement will assure inclusion of multiple points of view and a range of diverse input – factors that are essential to creating robust ASD LTSS development plans and to building broad support for implementation.
- Alignment, if not integration, of policy and financing goals and incentives across the organizational boundaries of government agencies will promote accountability to mandates to serve individuals with ASD and their families.
- Training clinicians, educators, and program staff about ASD standards, evidence, and methods is fundamental to provider readiness and the capacity of systems to deliver sound and effective services. In most states, university partnerships are instrumental in meeting training and technical assistance objectives.
- Manualized standards and training programs are needed to promote quality and assure consistency in the application of evidence-based/promising practice methods. Careful data collection and analysis is essential to care planning, quality improvement, program evaluation, and research directed at producing the next generation of evidence-based practices.

The study states report that Medicaid is the most significant source of support for building systems of LTSS that can produce accountable results for individuals with ASD and their families, with recognition of the role that IDEA plays in funding public education for children with ASD. States cited Medicaid waivers as offering the best option to target and demonstrate not only science-based ASD services but also emerging and promising practices that have the potential to become the evidence-based practices of the future. Autism-specific HCBS waivers are, as noted above, in use in five of the nine states studied and in each case cover a flexible and broad range of services designed to meet the diverse needs of eligible Medicaid recipients. Private insurance mandates, passed in about 20 states, are providing another important source of funds to cover treatment services for children with ASD, and typically specify reimbursement for evidence-based practices.

The prominent role that federal policy and financing plays in the development and reimbursement of ASD services at the state level is reflected in the universal call from the nine states interviewed for:

- Building a national ASD knowledge network or learning community to advance the capacity of state systems
- Creating a national resource center to serve as a state information exchange
- Issuing federal guidance on adoption and reimbursement of evidence-based/promising practices for ASD

Appendix 1: Brief State Summaries

These summaries of the nine states interviewed contain more detailed information about state services as related to autism spectrum disorders (ASD) and their efforts to use evidence-based/promising practices. They are presented in alphabetical order by state name.

Arizona

System Overview

Arizona provides a range of services to children and adults with autism ASD and their families. State-sponsored services fall under the purview of the State Medicaid program, the Arizona Health Care Cost Containment System (AHCCCS), and the Arizona Department of Economic Security (DES), Division of Developmental Disabilities (DDD).

Coverage Summary

Medicaid

The implementation of the state of Arizona's Medicaid program is unique because AHCCCS is a Medicaid waiver granted under the section 1115 demonstration project authority of the Act. The project covers both Medicaid and CHIP. Over time, Arizona has amended or renewed the demonstration several times. It presently includes the following:

- Exemptions from certain provisions in the SSA and corresponding regulations
- Expenditure authority for certain items under section 1903 of the Act
- Terms and conditions that AHCCCS must fulfill, which includes documents and reports that must be submitted periodically
- Approved federal budget amounts
- Attachments that outline financial, legislative, and budget neutrality requirements

All of Arizona's Medicaid programs and services are provided under the 1115 waiver. This includes Early and Periodic Screening, Diagnostic, and Treatment (EPSDT), which is Medicaid's comprehensive preventive child health program for children under age 21. All service delivery is contracted out to health plans. There are no Medicaid services provided as part of a separate benefit structure. Self-directed services are provided under the waiver, mainly for adults.

The waiver is administered by Arizona AHCCCS, which has a strong working relationship with the State's Division of Developmental Disabilities (DDD). The agencies work together to try to meet regulation requirements and members' needs. The waiver requires the costs of the program to be budget neutral. The State is in the process of preparing to continue the current waiver and is researching ways to provide medically necessary services in a time of significant economic challenges.

The AHCCCS Program includes the Arizona Acute Care Program (AAP) and the Arizona Long Term Care System (ALTCS). Both of these programs contract with managed care organizations to deliver services to Medicaid beneficiaries in a managed care environment.

Department of Economic Security, Division of Developmental Disabilities

DES/DDD offers programs and services to eligible persons with developmental disabilities with the goal of helping them to achieve self-sufficiency and independence,⁵⁵ supporting people who meet the following eligibility requirements:⁵⁶

- Residence in the state of Arizona
- Voluntary application
- For children up to age 6, be at risk of having a developmental disability
- For persons over six age 6, with a diagnosis of
 - Epilepsy
 - Cerebral palsy
 - Cognitive disability
 - Autism (for eligibility purposes, autism is a condition characterized by severe disorders in communication and behavior resulting in limited ability to communicate, understand, learn, and participate in social relationships.)
- Disability occurred prior to age 18
- Substantial functional limitations in three of seven major life areas
 - Self-care (eating, hygiene, bathing)
 - Receptive and expressive language (communicating with others)
 - Learning (acquiring and processing new information)
 - Mobility (moving from place to place)
 - Self-direction (managing personal finances, protecting one's self-interest, or making independent decisions that may affect well-being)
 - Capacity for independent living (need for daily supervision or assistance)
 - Economic self-sufficiency (ability to financially support oneself)

The ALTCS Eligibility Administration (AEA) within the AHCCCS Division of Member Services determines financial and medical eligibility for ALTCS. Medical eligibility is determined by the Pre-

⁵⁵ Arizona Department of Economic Security, Division of Developmental Disabilities. *Developmental Disabilities Home*. Available at https://www.azdes.gov/developmental_disabilities/

⁵⁶ Arizona Department of Economic Security, Division of Developmental Disabilities. *Eligibility Requirements*. Available at https://ddd.azdes.gov/ddd/EligibilityReferral/frm_EligibilityRequirements.aspx

Admission Screening (PAS) process.⁵⁷ Clients who are developmentally disabled (DD) over age 6 and who reside in nursing facilities are also assessed using the EPD PAS tool. PAS is used to assess persons of all ages with DD and children with physical disabilities under age 6 (who are not clients of DES/DDD) who apply or are currently clients of ALTCS. The goal of the PAS tool is to ensure the appropriate eligibility determination of ALTCS clients. Individuals who are determined to be at risk of institutionalization and require care at the same level that is provided in a Nursing Facility (NF), or Intermediate Care Facility for the Mentally Retarded (ICF-MR), are considered to be medically eligible for ALTCS services.

Private Insurance Mandates

In March of 2008, Arizona passed Steven's Law, which requires group health insurance coverage for the diagnosis and treatment of ASD. This law prohibits health service or medical service corporations from excluding or denying coverage for the diagnosis, assessment, treatment, and services, for ASD.⁵⁸ The law also explicitly prohibits the exclusion or denial of coverage for medically necessary behavioral therapy, including applied behavior analysis (ABA), provided by or under the supervision of a licensed or certified provider. Eligible individuals are covered for behavioral therapy for a maximum of \$50,000 per year up to age 9 and for a maximum of \$25,000 per year for persons ages of 9-16.

Adoption and Promotion of Evidence-Based/Promising Practices in ASD

Innovation

Arizona officials are aware of the definition of promising practices provided by CMS. The AHCCCS uses the State-defined criteria for medical necessity as its standard. According to the officials interviewed, AHCCCS does not cover any service that is not evidence-based.

Arizona established a "Sustainability and Innovation" work group, chartered by the director of DES. The work group included: family members, providers, self advocacy representatives, and other stakeholders in the DD community. The work group assessed consumer needs and desires, the current fiscal situation, spending patterns, how Arizona ranks nationally in terms of community services, and other data-driven discussions. The report is finalized and includes proposed recommendations for innovation and efficiency. While the work group was not specifically centered on autism services, parents of family members with autism were represented on the work group, providing input and insight into the system change recommendations.

DDD has identified their interest in obtaining guidance from CMS on evidence-based, promising, and innovative practices. National guidance would support local policymaking and research initiatives.

Lessons Learned

⁵⁷ Arizona Health Care Cost Containment System. *Eligibility Manual*. Available at http://www.azahcccs.gov/shared/Downloads/EligibilityManual/EPM_AllChapters_Internet.pdf

⁵⁸ Easter Seals, 2010. 2010 State Autism Profiles: Arizona. Available at http://www.easterseals.com/site/DocServer/2010_Autism_Arizona.pdf?docID=139866

Arizona State officials raised the following considerations that states should take into account when planning and implementing services for persons with ASD:

- States should strive to be proactive and “get ahead” of making system changes to support individuals with autism and their families.
- Federal guidance for states on evidence-based/promising practices and payment streams is needed.
- Interagency work and collaboration with families and self advocates is critical to better aligning services.
- Implementation issues were raised from the standpoint of state agencies. There are challenges and will be until autism is more clearly defined on what is covered, to what degree, and for whom. There is a need for stronger evidence-based services. It can be difficult for agencies dependent on Medicaid funds because there are growing family requests for increased services and they must balance factors such as individual need, covered services, and costs. States want to support children, families, and adults with autism, work closely with providers and manage within a well defined policy framework.

California

System Overview

The Department of Developmental Services (DDS) is California’s lead agency for administering and funding services and supports to individuals and families with autism spectrum disorders (ASD) who meet specified eligibility criteria. DDS directs statewide policy and leadership initiatives to ensure that persons with developmental disabilities are afforded equal opportunities for diagnosis, treatment, and intervention services.

While DDS is the lead agency for administering services to persons with developmental disabilities, several California agencies are responsible for the delivery of services and supports to individuals and families with ASD. The Department of Education collaborated with DDS to provide early intervention services for children ages 0-3 with developmental disabilities; the two departments also produced a report entitled *Best Practices for Designing and Delivering Effective Programs for Individuals with Autism Spectrum Disorders*.

DDS works with the Department of Rehabilitation to fund vocational rehab for the beginning stages of supportive employment/work activity for adults with ASD. While the Department of Mental Health does not directly serve individuals with a sole diagnosis of ASD, the agency does offer support to persons with a dual diagnosis of a mental illness and an autistic disorder; however, the mental illness must be recognized as the primary condition. Other State appropriations directed to ASD services flow from the Department of Managed Health Care, the Department of Social Services, and the Department of Public Health.

California employs a stakeholder process when planning the development of ASD services. DDS operates the Home and Community Based Services for the Developmentally Disabled (HCBS-DD)

Waiver under the Department of Health Care Services' (DHCS) administration, and supervises the implementation of waivers in state-funded, non-profit regional centers.⁵⁹ DHCS is the State Medicaid agency in California and is responsible for oversight of the HCBS-DD waiver. According to DDS, as of November 27, 2010, there were 86,005 regional center consumers being served under the HCBS-DD Waiver.

The Lanterman Developmental Disabilities Services Act (Lanterman Act), implemented in 1972, established an entitlement to services and supports for persons with developmental disabilities, those at risk for developmental disabilities, and their families. California is the only state in the country with comprehensive entitlement legislation for these individuals. In conjunction with the Lanterman Act's objective to develop a network of service agencies, DDS created a system of 21 non-profit regional centers covering all 58 counties in California. Regional centers provide diagnostic assessment, determine program eligibility, and provide support, care coordination, and referrals to community providers (vendors) for eligible children and their families. DDS also operates 4 State developmental centers, and one community facility, to provide habilitation and treatment services for individuals with developmental disabilities.

The number of consumers with developmental disabilities in the community served by regional centers is expected to grow in fiscal year 2011 to 243,704. The number of consumers living in state-operated residential facilities will decrease by the end of fiscal year 2011 to 1,870. As of February 1, 2009, there were 44,559 consumers diagnosed with ASD.

Regional centers contract with and refer to vendors that deliver day-to-day services to individuals with ASD. For example, the University of California-Davis's Neurodevelopmental Disorders Clinic contracted with regional centers to conduct diagnostic assessments for ASD, and offers recommendations for intervention to individuals and families.

In response to the rising number of individuals living with ASD in the state, California's DDS launched the Autism Spectrum Disorders Initiative in 1997. This initiative is part of a larger effort to identify promising ASD practices as well as publicize the need for better detection, diagnosis, treatment, and prevention of ASD.

The California Legislative Blue Ribbon Commission on Autism, established by the State Senate in 2006, has been influential in reducing gaps in the diagnosis and treatment of individuals with autism. As a first step towards addressing policy, programmatic, and financial gaps within the ASD system, the Blue Ribbon Commission created three task forces, each including a variety of parent and professional stakeholders with experience and expertise in ASD. Each task force concentrated on one of three areas in autism services: early identification and intervention, education and professional development, and transitional services and supports.⁶⁰ In 2006, DDS also collaborated

⁵⁹ California Department of Developmental Services. *The HCBS Waiver Primer and Policy Manual...* Apr. 2008. Available at <http://www.dds.ca.gov/waiver/>

⁶⁰ California Legislative Blue Ribbon Commission on Autism. *Task Force Process and Implementation.* Available at <http://senweb03.senate.ca.gov/autism/index.html>

with the Mental Health Task Force to establish the Mental Health/Developmental Disability Collaborative in an attempt to advance services for individuals living with a dual diagnosis of a mental illness and a developmental disability. The collaborative comprises family advocates, representatives from the California Departments of Mental Health and Developmental Services, and private mental health service providers.

Coverage Summary

Medi-Cal, California's State Medicaid program pays for medically necessary treatment services, medicines, and medical supplies and equipment needed by people with disabilities who satisfy income and resource guidelines. Medically necessary services include rehabilitation and other services needed to attain or retain the capability for typical activity, independence, or self-determination.

The HCBS-DD waiver is one of the largest HCBS waivers in the country. In order to receive services and supports under the waiver, individuals with ASD must:

- Meet the Lanterman Act definition of "developmentally disabled";
- Meet eligibility requirements for Medi-Cal;
- Receive services at one of the 21 regional centers;
- Meet the level of need necessary for an ICF/MR, which in California is known as an intermediate care facility for the developmentally disabled (ICF-DD).⁶¹

The HCBS-DD waiver covers a diverse range of ASD services, including transportation services, habilitation, respite care, home health aide services, family training, adult residential care, crisis and behavior intervention services, and nutritional consultations. In addition to the HCBS-DD Waiver, the Department of Developmental Services has been working to implement self-directed services (SDS) for persons with developmental disabilities.⁶² See Exhibit 2 for an outline of the range of services available in California.

Adoption and Promotion of Evidence-Based Practices and Promising Practices in ASD

California does not utilize CMS's formal definition of "promising practice"; however, the State does employ the term "evidence-based" in reference to behavioral approaches to serving persons with ASD. ABX4 9 (Statutes of 2009) Section 95021 (d) 3 specifies that "evidence-based practice" means a decision making process which integrates the best available scientifically rigorous research, clinical expertise, and individual's characteristics. Evidence-based practice is an approach to treatment rather than a specific treatment. Evidence-based practice promotes the collection, interpretation, integration, and continuous evaluation of valid, important, and applicable individual- or family-

⁶¹ Department of Health Care Services. *Home and Community-Based Services for the Developmentally Disabled*. 2007. Available at <http://www.dhcs.ca.gov/services/ltc/pages/dd.aspx>

⁶² California Department of Developmental Services. Self-Directed Services Program. June 2010. Available at <http://www.dds.ca.gov/SDS/Index.cfm>

reported, clinically observed, and research-supported evidence. The best available evidence, matched to infant or toddler circumstances and preferences, is applied to ensure the quality of clinical judgments and facilitates the most cost-effective care.

To date, DDS has published 2 documents that outline best practices: *Autistic Spectrum Disorders (ASD): Best Practice Guidelines for Screening, Diagnosis, and Assessment* and *Autistic Spectrum Disorders (ASD): Best Practice Guidelines for Inter-organizational Collaborations*. DDS will soon release *Autism Spectrum Disorders (ASD): Best Practice Guidelines for Effective Interventions*. The upcoming document contains evidence-based practice recommendations drawn from systematic reviews of scientific research on the effectiveness of specific interventions. DDS, in partnership with the National Standards Project (NSP), utilizes research findings from the NSP on behavioral/education interventions.

The research findings (from all of the reviews) are categorized by the levels of scientific evidence available for each intervention. This system of categorization was developed by the NSP and adopted for the upcoming DDS document.

The Lanterman Act, the original enabling and entitlement legislation, was amended in 2009. The 2009 Trailer Bill Language (TBL) requires California regional centers to purchase only evidence-based services, and prohibits them from purchasing experimental treatments that have not been clinically determined or scientifically proven⁶³ to be effective or safe, or for which risks and complications are unknown. The intent of the amended legislation is to (a) promote evidence-based practices and (b) ensure the cost-effectiveness of services.

Lessons Learned

When asked to comment on future directions for adoption and execution of evidence-based and best practices for ASD services, California State officials detailed numerous lessons learned in the effort to encourage and maintain evidence-based services for persons with developmental disabilities. These include:

- Ensuring that “clinically determined” services are also evidenced based
- Promoting the importance of educating and training families on effective intervention techniques
- Promoting the importance of measuring ASD intervention outcomes
- Identifying and filling service gaps for transition-age youth
- Improving quality of care by investing in training infrastructures where interested undergraduate and graduate students can participate, and be motivated to work in the field of ASD

⁶³ Department of Developmental Services. State of California—Health and Human Services Agency. *TRAILER BILL LANGUAGE AFFECTING REGIONAL CENTERS*. , 29 July 2009. Available at http://www.dds.ca.gov/Director/docs/LtrRC_StatutoryChanges_2009.pdf

Connecticut

System Overview

Connecticut provides a range of services to children and adults with autism spectrum disorders (ASD) and their families. Services are provided by several State agencies carrying out historical mandates in developmental, mental health, and educational services. These agencies include:

- The Birth to Three program
- The Department of Developmental Services, Division of Family and Community Services (DDS)
- The Department of Children and Families (DCF)
- The Department of Education (DOE) and Vocational Rehabilitation (VR)
- The Department of Mental Health and Addiction Services (DMHAS)

In recognition of the growing population of persons with ASD, Connecticut established the Division of Autism Services within DDS in 2006. The division quickly developed a pilot program to provide model services to adults with ASD.⁶⁴ The pilot ended in June 2009, but the funding for the services continues, incorporated into the mainstream of a growing LTSS system.

The Division of Autism has also been instrumental in the development of new Medicaid services intended to bring assistance to children and adults with ASD and no co-occurring diagnosis of mental retardation. Provider agencies will need to pre-qualify to be able to provide services under the proposed Medicaid waivers as they are now required under the Autism Adult Program.

A large advisory council offers advice to DDS regarding the work of the program and the development of future services. The council includes representation from families, advocates, providers, agencies, and researchers. Services under the Autism Program include:

- Self-directed services
- Employment supports
- Social skills training
- Daily living skills
- Financial management skills
- Educational supports

Coverage Summary

In Connecticut, all Medicaid-covered services, including rehabilitative services, are available to individuals with ASD so long as they meet regular eligibility requirements, including medical

⁶⁴ O'Meara, PH. *Re: Report on the results of the Pilot Autism Spectrum Disorders Program, pursuant to Section 37 of Public Act 06-188*. January 12, 2009. Available at http://www.ct.gov/dds/lib/dds/autism/final_autism_report.pdf

necessity. Medicaid-eligible individuals with ASD and a diagnosis of intellectual disability are generally enrolled in Medicaid through a managed care delivery system. One exception is the Birth to Three program, which is a carve out of Medicaid managed care. Birth to Three provides in-home services and supports for children under age 3, including those with ASD. All referred children 16 months and older are screened for an ASD. Birth to Three provides intensive in-home supports individually tailored to the child and family. It has established 9 autism-specific early intervention programs across the state, and families have the choice of enrolling with those programs or with the general early intervention programs.

At this time, there are two Medicaid waivers that include individuals with ASD: the section 1915 (c) Developmental Disabilities (DD) waiver and the 1115 demonstration project waiver. The DD waiver covers individuals who have a diagnosis of mental retardation, and includes individuals with a co-occurring diagnosis of ASD. Connecticut also has a TEFRA/Katie Beckett HCBS waiver, which was designed to provide access to Medicaid coverage for children with disabilities or complex medical needs whose families are over the income eligibility cutoff for Medicaid. This waiver does include individuals with ASD.

Connecticut DDS is currently in the process of designing Medicaid waivers that will cover both children and adults who have ASD but no co-occurring diagnosis of intellectual disability. Children with an ASD diagnosis currently covered by DCF will be transferred to the Autism Division once the new waivers are in place if they meet the eligibility criteria. DDS will be the operating agency for the autism waivers. The State's Level of Need assessment and screening tool will be used to determine the range of supports the individual needs. This tool also identifies outcome areas on which to focus and helps case managers develop individual service plans (ISPs).

The Connecticut Autism Insurance Reform Act became effective as of January 1, 2010.⁶⁵ The Act requires private insurers to cover the cost of diagnostic assessments for ASD and services to individuals with ASD who are under age 15. Benefits can be capped at \$50,000 per year for children under age 9, at \$35,000 per year for children ages 9-12, and at \$25,000 per year for children ages 13-14. Insurers may not place higher copayments, deductibles, or other out-of-pocket expenses on care related to ASD than for any other medical, surgical, or physical health conditions. The Act requires coverage of the following kinds of services: behavioral therapy (including ABA), pharmacy care, direct psychiatric or consultative services, direct psychological or consultative services, physical therapy, and occupational therapy. These services must be medically necessary, prescribed by a licensed clinician or clinical social worker, and based on a treatment plan.

Adoption and Promotion of Evidence-Based Practices and Promising Practices in ASD

Connecticut's DDS and DOE promote the use of evidence-based/promising practices through policy, program, and financing initiatives. In its innovative State funded *Pilot Program for Young Adults with Autism Spectrum Disorders*, Connecticut implemented a two-year demonstration based on use

⁶⁵ Autism Votes. *Frequently Asked Questions About the Connecticut Autism Insurance Reform Act*. Available at http://www.autismvotes.org/atf/cf/%7B2A179B73-96E2-44C3-8816-1B1C0BE5334B%7D/Connecticut_FAQs.pdf

of evidence-based/promising practices applied to meeting a defined set of client needs determined through a comprehensive assessment process, and evaluated for effectiveness throughout the demonstration. Another example is the use of and coverage for evidence-based/promising practices embedded in the draft HCBS autism waiver. The waiver manual will contain a policy on these practices.

Connecticut uses the National Autism Center's National Standards Report (2009) and the Autism Spectrum Disorders (ASD) Services Final Report on Environmental Scan (2010) for guidance with regard to evidence-based practices for individuals with ASD. While committed to promoting sound practices, Connecticut agencies are also supportive of families' requests for services that may not meet an evidence standard.

In developing and implementing its proposed Autism Medicaid waivers, Connecticut will employ the Level of Need Assessment and Screening Tool mentioned above, a validated instrument developed in collaboration with the University of Connecticut. The tool identifies need, supports targeting services planning, and provides a baseline of need and functioning with utility in outcomes evaluation.

Connecticut will cover behavioral support services, which have the strongest scientific basis for treatment of ASD, as well as employment support services, which have a strong evidence base of effectiveness in meeting the needs of persons with developmental disabilities and mental disorders.

Lessons Learned

Connecticut State officials report the following lessons learned for building a care system and implementing promising ASD services:

- Successful implementation planning is conducted with a large State Advisory Council that included multiple stakeholders. It is important to include families, advocates, researchers, and providers when designing new services.
- Periodic clinical reviews are useful for fine-tuning HCBS.
- Developing a knowledgeable provider network was a significant challenge in implementing the *Pilot Program for Adults with Autism Spectrum Disorders*. Major workforce issues included the lack of specialized training in ASD among support staff, and a lack of experience that produces sound judgment and good instincts in serving persons with complex needs. Support staff persons receive targeted training in ASD, employing standardized training curricula and DVDs, followed by a competency test and routine supervision.
- Joint client and staff training is an innovative approach to providing the knowledge and skills, while building mutual understanding between consumers and their support staff.
- Monitoring is critical to assuring the accountability and appropriateness of care provided to persons with ASD. Connecticut conducts periodic clinical reviews, convening clients, their families, DDS staff, clinical experts, and all program or support staff in what is effectively a constructive "grand rounds". This affords all involved the opportunity to evaluate progress, make adjustments in the services plan, and reach agreement on next steps in providing tailored services to meet individual client needs.

Indiana

System Overview

The Indiana Family and Social Services Administration (FSSA) is the lead agency responsible for individuals with autism spectrum disorders (ASD) in Indiana. In addition, the Indiana Commission on Autism was established under Indiana Code 12-11-7. The Commission, consisting of 14 members designated by legislative leadership, was instructed to:

- Study the service delivery system for individuals with autism and their families, including statistics on the portion of the population with ASD, funding information, services and expenditures, interagency information, and residential treatment options for individuals with ASD;
- Study the need and effectiveness of programs for individuals with ASD; and
- Oversee and update the development of a comprehensive plan for services for individuals of all ages with ASD.⁶⁶

Indiana Code 12-11-7 requires that the comprehensive plan include an interagency cooperation agreement among the Department of Education, the Division of Mental Health and Addiction, the Division of Family Resources, the Department of Child Services, and any other appropriate agencies. In February 2007, the commission issued a report entitled *Indiana Comprehensive State Plan to Guide Services for Individuals with Autism Spectrum Disorders*, with an interagency cooperation agreement. Following submission of the report, the Indiana Interagency Coordinating Committee was established to oversee the implementation of the recommendations outlined in the State plan.⁶⁷

In addition to the changes enacted via Indiana Code 12-11-7, Indiana Code 12-11-8 authorized the Developmental Training Center at the Indiana University-Bloomington to establish a resource center for ASD. The resource center provides information on federal, state, and local services to families of a child with ASD. The resource center also offers training and technical system supports for individuals who work with individuals with ASD. Every three years, the resource center is expected to conduct a statewide assessment on the status of services provided to individuals with ASD and to identify additional needs for support services.⁶⁸

In addition to the services overseen by the FSSA, the Division of Mental Health and Addictions (DMHA) offers a community alternative to a residential services grant that serves individuals with ASD. Grant services are available to individuals ages 6-21.

⁶⁶ Indiana Code - Chapter 7: INDIANA COMMISSION ON AUTISM. Available at <http://codes.lp.findlaw.com/incode/12/11/7>

⁶⁷ Indiana General Assembly, Indiana Commission on Autism Home Page. Available at <http://www.ai.org/legislative/interim/committee/auti.html>

⁶⁸ Indiana Institute on Disability and Community. *Indiana Resource Center for Autism*. Available at <http://www.iidc.indiana.edu/index.php?pageid=32>

Coverage Summary

There are five Home and Community-Based Services (HCBS) waivers operated under Indiana's Medicaid program:

- Two waivers are designed to provide support and services to individuals who meet requirements for nursing facility level of care:
 - the Aged and Disabled waiver, and
 - the Traumatic Brain Injury waiver.
- Three waivers provide support and services to individuals who meet requirements for Intermediate Care Facility for the Mentally Retarded (ICF-MR) level of care:
 - the Developmental Disabilities waiver,
 - the Support Services waiver, and
 - the Autism waiver.

As of May 2010, these five HCBS waivers covered a total of 11,957 individuals of all ages and diagnoses. Indiana Medicaid does not have screening guidelines that are specific to the diagnosis of ASD. They have standard eligibility criteria for the waivers, which include a definition of developmental disabilities, standards regarding the level of care, and Medicaid eligibility criteria.

Within its approved capacity, the autism waiver serves Medicaid-eligible individuals of all ages who are diagnosed with autism. As with the other HCBS waivers offered by Indiana Medicaid, individuals are eligible for the waiver if the recipient would require institutionalization in the absence of the waiver and/or other home-based services. The autism waiver is intended to serve up to 530 individuals. It covers a broad range of services, soon to include evidence-based behavioral support services.

In the current fiscal climate, Indiana has attempted to preserve the total capacity of their service system by cutting provider rates rather than cutting programs and services. This does not appear to have reduced the hours available to consumers. In addition, the American Recovery and Reinvestment Act of 2009 (ARRA) led to an award of approximately \$8 million dollars to the First Steps program, Indiana's early intervention program. These funds are being put toward supportive services. This is timely, as the First Steps program has seen a recent increase in requests for early intervention services.

In 2001, Indiana Code 27-8-14.2, known as the "Autism Insurance Mandate," passed the 112th General Assembly. Under this section of the Indiana Code, group health insurance coverage is required for pervasive developmental disorders, which include autism and Asperger's syndrome. Individual health plans are required to provide an option offering coverage for ASD. Coverage is limited to treatment prescribed in accordance with a treatment plan prescribed by a qualified health care provider. Pervasive developmental disorders are defined as a neurological condition. Coinciding with the passage of Indiana Code 27-8-14.2, the Indiana General Assembly passed H.B. 1047, which defines autism as a neurological condition, consistent with the definition found in the

Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) of the American Psychiatric Association.⁶⁹

Adoption and Promotion of Evidence-Based/Promising Practices in ASD

Indiana's Medicaid program does not have a State definition for promising practice. The recently convened Indiana Autism Task Force has been looking at state-funded services and is developing a policy on best and promising practices that is currently pending completion.

Maine

System Overview

In 1984, Maine passed the Autism Act, which improved access to care for both children and adults with autism spectrum disorders (ASD) and Pervasive Developmental Disorders (PDD). The Act also required that the Maine Department of Health and Human Services (DHHS) report back to the legislature on the state of services for individuals with ASD and any associated issues, challenges, or initiatives.⁷⁰

Children with ASD are covered under the Division of Children's Behavioral Health Services (CBHS), which is part of the Office of Child and Family Services (OCFS). Adults with ASD fall under the purview of the Office of Adults with Cognitive and Physical Disabilities (OACPD). These offices contract with private community agencies for provision of all services. State employees provide some adult case management services and also the statewide crisis services (e.g., mobile outreach & crisis residential services).

As with many other states with large rural regions, Maine struggles to make available some services for families living at a distance from the population centers. In the example case of early intervention services, families living in Aroostook County, which is in the northernmost portion of the state, sometimes have to choose between local but perhaps less effective services and traveling up to 4 hours for out-of-district care. In contrast, York County children have a greater number of available providers, and out-of-district placements are only about 20 minutes' drive away.

Coverage Summary

Maine has two waiver programs that serve individuals 18 years and older who have a diagnosis of intellectual disability/autism and meet the eligibility requirements for an ICF-MR level of care.

⁶⁹ Easter Seals (2010). *2010 State Autism Profiles: Indiana*. Available at http://www.easterseals.com/site/DocServer/2010_Autism_Indiana.pdf?docID=140773

⁷⁰ Maine Department of Health and Human Services (DHHS). (2009). *Autistic Spectrum Disorders Report*. Available at <http://www.maineddc.org/documents/Autism-Spectrum-DisordersFeb-2009.pdf> (accessed 12/13/10).

The Community Supports waiver (Section 29) provides services primarily to people living with their families. Services in this waiver include:

- Community supports
- Respite care
- Employment specialists services
- Supported employment
- Home accessibility adaptations
- Communication aids
- Speech therapy
- Physical therapy
- Transportation
- Specialized medical equipment

The Home and Community Based Services (HCBS) waiver program (Section 21) is the primary program for supporting people outside their family home. This is a comprehensive waiver providing a wide range of residential options as well as additional supports including:

- Independent living supports
- Shared living
- Traditional group home settings of up to four people
- Community supports
- Employment
- Transportation
- Crisis intervention
- Therapies
- Home adaptations

The CBHS system of care provides a full continuum of services for children & youth with cognitive disabilities and ASD. Services include:

- Respite services
- Therapeutic recreation funds
- Case management services
- Medication management
- Family education & support services
- Crisis services (crisis phone supports, mobile outreach assessments & crisis stabilization Residential units)
- Outpatient treatment services

- Early intervention services
- Home & community treatment services (HCT)
- Individual planning funds (flex funds)
- Community rehabilitation services (CRS)
- Residential treatment services
- Children’s assertive community treatment (ACT)
- Information & referral services

Children’s Behavioral Health Services recently received CMS approval for Maine’s first exclusive HCBS waiver program (Section 32) designed for children and youth.

There are currently 4 crisis teams statewide and 4 “crisis homes” for adults with a full range of developmental disabilities. Reportedly, many adults with ASD have access to employment supports.

Adoption and Promotion of Evidence-Based/Promising Practices in ASD

As part of its effort to adopt evidence-based practices, DHHS, Department of Education, and the Department of Labor implemented a systems change initiative. This initiative utilized an evaluation and planning process called LEAN to improve services for individuals with ASD. During the LEAN process, individuals with ASD or PDD and their families were asked about their opinions and experiences with the process of accessing services. Providers and State employees were also queried and an accessibility map was developed. Based on feedback from 30-40 families and providers, the State determined that it took an average of 32 months after the parent(s) first voiced concern for a child to receive a diagnosis of an ASD. Children often received multiple referrals for a variety of assessments but these were not coordinated.

The LEAN process took four intensely structured days to determine the location of problems in the system of care. The results were reported back to the commissioners of the various State agencies involved and a system improvement plan was adopted. Based on family and provider concerns, two areas were targeted for improvement: early identification and early intervention.

Because State agencies recognized that change is more successful with multiple points of input, Maine brought together medical providers such as pediatricians, family practitioners, and nurse practitioners and others to improve Maine’s rate of early identification. They determined that developmental screening should be conducted using the PEDS at 9, 18, and 24 months and ASD screening using the M-CHAT at 18 and 24 months. The State conducted a pilot screening program in 6 practices across the state. Pilot funds paid for screenings and program evaluation. Approximately 3500 children were screened during the pilot. Providers liked how easy the PEDS was to administer but disliked the ongoing cost of the tool and found that it could not be easily integrated into electronic medical records (EMRs). All of the providers liked the M-Chat and committed to continue using it after the pilot ended. Based on the pilot, MaineCare added screenings to their “Bright Future” well-child forms.

Maine's Center for Disease Control is currently conducting grand rounds with other physicians across the State to promote universal screening of children for ASD. In these rounds they are presenting Medicaid data and information about incorporating screening tools into physician practices to make the case for early screening. There are 17 more grand rounds are scheduled.

The next step after a positive screening for ASD is how to assure children receive a thorough evaluation in a timely fashion. The LEAN process identified that families had been going to different providers and receiving different diagnoses, because there was no standard for who can diagnose and what components should be included in evaluations. The medical provider workgroup conferred and drafted competencies professionals must have and identified guidelines for evaluations.

The Initiative sent the recommendations to a larger group of clinicians and found 30 clinicians who felt capable of providing ASD diagnoses. They are in the process of formalizing the policy and distributing it to physicians across the state. To further improve the connection between formal diagnostic processes, they piloted an approach for diagnosticians to work with early intervention professionals so evaluations only occur once. Then the group will work to create an initial, coordinated plan of care.

A second LEAN process was conducted to evaluate and improve collaboration among early intervention providers. Maine has found that a typical child with ASD might have early intervention services via IDEA while receiving other services such as in-home supports from MaineCare. The LEAN process discovered that a child and family can have two or more different care plans which are coordinated or communicated among professionals to varying degrees. In the best case scenario, the plans may have the same goals, but in the worst case the plans could include contradicting components.

Maine has chosen to pilot the Waisman Center medical home template that was created as part of the national medical home autism initiatives. This enhanced medical home would not only provide screening, referral, and ongoing medical care but would also coordinate all plans of care for children with ASD. They are funding two pediatric offices to staff a coordinator that will assist the physician in providing this enhanced medical home. One concern that Maine is in the process of mitigating is how Maine's managed care system will impact this enhanced medical home model.

DHHS/Children's Behavioral Health Services, in collaboration with the Maine Department of Education, providers, parents, and an individual with ASD recently released a report entitled *Interventions for Autism Spectrum Disorders: State of the Evidence*.⁷¹ This report explored the evidence associated with the following practices:

- Applied behavior analysis (ABA)
- Augmentative and alternative communication

⁷¹ Maine Department of Health and Human Services (DHHS) and Maine Department of Education. (2009). *Interventions for Autism Spectrum Disorders: State of the Evidence*. Available at www.maine.gov/dhhs/ocfs/cbhs/ebpac/asd-report.doc

- Developmental, social-pragmatic models
- Diet & nutritional approaches
- Pharmacological approaches
- Psychotherapy
- Sensory integration therapy
- Social skills training

The Children’s Evidence-Based Services Committee, which developed the report, advises providers to work with families to educate them about evidence-based practices, their availability, and the need for more research and trained clinicians to foster the growth of evidence-based practices.

Throughout the state, there are many programs based on ABA grounded in an evidence-base. The vast majority of these programs and providers are not certified in ABA, however, and there is a great deal of variation in services between programs. As of the 2009 State of the Evidence report, there were only 26 Board Certified Behavior Analyst (BCBA) practitioners, most of whom were located in the southern counties. Only a few schools have providers trained in ABA.

DHHS has determined that there were not enough qualified clinicians to address the emerging behavioral health needs of newly identified children and their families. However, Maine is making steady gains through such avenues as the University of Southern Maine’s training program that results in becoming a BCBA. In the past 2 years, BCBA’s have been added to the Medicaid State Plan as eligible providers in the development and oversight of individual treatment plans and the provision of program consultation services. In order to foster the utilization of evidence-based practices for children, CBHS was successful in developing an enhanced rate for providers of community rehabilitative services. Providers must apply for consideration and continue to perform with fidelity to the evidence-based practice model.

In addition, the State has found that many physical health care practitioners, who might otherwise provide care for individuals with ASD in the course of their work, often refer them out to primary care practices with behavioral specialties, because they are concerned about their capacity to adequately treat an individual with ASD; even cases of strep throat or ear infections are referred out to behavioral pediatricians.

Maine, along with several other states, has been awarded an Autism Implementation grant in order to implement an existing State plan to improve the system of services for children and youth with special health care needs who have ASD and other developmental disabilities, as defined by the following components:

- Partnerships between professionals and families of children and youth with ASD
- Access to a culturally competent family-centered medical home which coordinates care with pediatric subspecialties and community-based services
- Access to adequate health insurance and financing of services

- Early and continuous screening for ASD and other developmental disabilities
- Community services organized for easy use by families
- Transition to adult health care

The Maine Developmental Disabilities Council provided funding for the development and delivery of a curriculum to general practitioners regarding strategies to improve routine care for children with ASD. Building on this work, the funds provided by the Autism Implementation grant will expand the training to increase the capacity of primary care physicians by training additional developmental pediatricians so that they can go out to train physical health practitioners and provide technical assistance when practitioners feel they need support. DHHS hopes that this will reduce the wait time to see behavioral pediatricians in the state, which at this time is over a year. In response to the fact that clinicians are not the only staff involved in interactions with individuals with ASD, DHHS is also developing an online training for office staff, which will provide guidance about how to interact with individuals with ASD.

Also with the funds provided by the Autism Implementation Grant,⁷² Maine will focus on further improvements to the early screening process, as well as doing “grand rounds” with behavioral specialists to train clinicians. In addition, they will work to integrate DHHS services with the Public Health nursing and home visiting services already available to new mothers. These public health services are currently available to all new mothers, regardless of whether or not they are Medicaid clients. The grant will fund training for public health nurses, home visitors, Head Start staff and Special Supplemental Nutrition Program for Women, Infants and Children (WIC) nurses about developmental screening and ASD. DHHS, in partnership with the Maine Developmental Disabilities Council and the evaluating company Altarum, will develop a home visiting screening protocol, early referral forms, and streamline the referral process.

To further this effort, DHHS will:

- Develop a single health access system to connect the various electronic medical records systems these individuals are included in, such as:
 - MaineCare billing system;
 - Immunization database;
 - Behavioral health EIS system;
 - IDEA (education) tracking database; and
 - Blood screening database, will be expanded to facilitate referrals.
- Build the capacity of diagnosticians, clinicians, and office staff with regard to ASD.
- Communicate with primary care physicians and families about the screening and diagnostic process.

⁷² U.S. DHHS, Health Resources and Services Administration (HRSA). (2010). *State Implementation Grants for Improving Services for Children and Youth with Autism Spectrum Disorder (ASD) and other Developmental Disabilities*. Grant Information available at <http://www.grants.gov/search/search.do?mode=VIEW&oppld=54579>

- Develop and pilot the national autism initiative’s medical home model for children with ASD.
- Increase parent ability to actively participate with their medical home via training and resource development.
- Provide research and educational materials on treating children and adults with ASD, including information about co-morbid disabilities, the provision of basic medical care to individuals with sensory and communicative issues, hospitalization, and how to care for individuals with ASD in a way which takes pain and communication challenges into account for nonverbal individuals.

At this time, DHHS is in the planning year of the grant.

Lessons Learned

Informants from Maine stressed several lessons learned that would be helpful for other states:

- Don’t build systems based on one disability. You will spend more money and be less efficient if you build an ASD-specific system.
- Quality improvement processes are useful but they are just a first step to improving services.
- It’s crucial to have a coordinator/boundary spanner who understands the system and how to collect and use data. This person needs to have access to the commissioners who can authorize work.

Missouri

System Overview

Missouri provides a range of services to children and adults with autism spectrum disorders (ASD) and their families. State services for persons enrolled with the Missouri Division of Developmental Disabilities (DD) fall under that Division’s purview. The Office of Autism Services is part of the Missouri Division of Developmental Disabilities within Missouri’s Department of Mental Health.

In recent years, Missouri’s statewide autism system and services have been shaped by recommendations developed by the Missouri Blue Ribbon Panel on Autism in 2007. The panel included legislators, State agency representatives, health care providers, and other professionals with autism interests. The panel submitted a final report in December 2007 with legislative recommendations to improve services for persons with autism.⁷³

In 2008, legislation (SB 768) established two important components of the Missouri system. The Office of Autism Services within the Missouri Department of Mental Health, Missouri Division of Developmental Disabilities was charged with providing leadership in program development for

⁷³ Easter Seals. (2010). *State Autism Profiles: Missouri*. Available at http://www.easterseals.com/site/DocServer/2010_Autism_Missouri.pdf?docID=140008

children and adults with ASD, to include establishment of program standards and coordination of program capacity. This legislation also established a Missouri Commission on Autism Spectrum Disorders that is supported by the Missouri Department of Mental Health. The Commission meets quarterly to review and make statewide recommendations on autism support services, training, and treatment for individuals with autism. The 24-member commission is composed of seven State departments, majority and minority members of Missouri's house and senate, clinicians, educators, community service providers, parents of individuals with ASD, and individuals with ASD.

In the early 1990s, five regional autism projects were established to serve persons with autism and their families. In 2010, these were codified into Missouri statute, providing that the Division of Developmental Disabilities work with regional Parent Advisory Committees and a State parent advisory committee on autism, for the purpose of establishing programs and services for individuals with autism.⁷⁴

Education

The Missouri Department of Elementary & Secondary Education, Office of Special Education offers programs and services to support students with autism and oversees the administration of special education services according to the IDEA and State special education regulations. Through Project ACCESS and the Professional Development in Autism (PDA) Center, professional development programs and training are available to support instructors who work with students with autism.

Services Delivery

The State DD serves individuals with developmental disabilities, including autism, mental retardation, cerebral palsy, head injuries, epilepsy, and select learning disabilities. To be eligible for developmental disabilities services, individuals who have the aforementioned disabilities must be "substantially limited in their ability to function independently".⁷⁵ Onset of these conditions must have occurred before age 22 and must also be expected to continue. Service eligibility is determined by 11 regional offices throughout Missouri, which also provide service coordination and work with individuals, families, and providers. The regional offices are the primary points of entry into the system, and provide assessment and case management services, which include coordination of each Individual Service Plan (ISP).

Eligible children under 3 years are served through the Missouri First Steps Program, an early intervention program designed to serve children from birth to age 3 who have developmental delays. Children over age 3 are evaluated through their public school district's special services department.

⁷⁴ Easter Seals. (2010). *State Autism Profiles: Missouri*. Available at http://www.easterseals.com/site/DocServer/2010_Autism_Missouri.pdf?docID=140008

⁷⁵ Missouri Department of Mental Health Division of Developmental Disabilities. *About Us*. Available at <http://dmh.mo.gov/dd/about.htm>

In-Home and Out-of-Home Services

DD funds many in-home and out-of-home services.⁷⁶ In-home services may include, but are not limited to: speech therapy, physical therapy, occupational therapy, behavior therapy, crisis intervention services and respite care. Also, medical and behavioral assistance can be provided in a person's home or during other activities in the community. DD supports out-of-home services to individuals in residential or community settings.

Self-Directed Services

DD strives to improve the lives of persons it serves through programs and services that support living independently and productively. It helps individuals with disabilities and their families gain greater independence through Self-Directed Support (SDS) services.⁷⁷ The Missouri Department of Mental Health website offers information for persons considering SDS to determine if it is appropriate. Enrollment in these services is organized by the regional offices.

As outlined in the *Missouri Department of Mental Health Self-Directed Supports Employer Manual*, individuals who use SDS have control over hiring and firing employees as needed, training employees to deliver services at their direction, creating an optimal work schedule and determining employees' earnings (within State guidelines).⁷⁸ Responsibilities include oversight, such as assurance that employees' work is completed and based on an individual service plan (ISP), as well as monitoring and approval of employees' schedules and timesheets. Service coordinators are available to create a budget based on an individual's needs but the responsibility to manage services within the budget lies with the individual. DD contracts with ASIWorks, Inc., an organization that serves as the fiscal management service for administrative functions such as payroll, taxes, and Workers Compensation insurance.

Advocacy

Missouri's history of providing autism services shows a broad practice of engaging various sectors of State agencies and sectors of society in projects, initiatives, and policies that affect the lives of persons with ASD in the state. Since 1991, consumer- and family- driven autism projects have been part of the statewide service landscape and coordinated and funded by the state. Family involvement in State services and decision making is exemplified by the Missouri Autism Coalition (MAC) and Missouri Families for Effective Autism Treatment (MO-FEAT).

⁷⁶ Office of Autism Services. *Navigating Autism Services: A Community Guide for Missouri*. Available at http://www.mofeat.org/files/MO_NavGuide_Web_June09.pdf

⁷⁷ Missouri Division of Developmental Disabilities. MoDMH Self-Directed Services. Available at <https://modmhselfdirected.com/>

⁷⁸ ASIWorks, Inc. *Employer Manual*. ASIWorks, Inc., *Fiscal Management Services for Missouri DD Self-Directed Supports*. Available at <https://modmhselfdirected.com/pdf/administrative/EmployerManual.pdf>

Coverage Summary

Medicaid

The Missouri Department of Mental Health's Division of Developmental Disabilities administers 5 HCBS waiver programs for persons with developmental disabilities. These HCBS waivers provide the main source of funding for people with developmental disabilities who live in the community in various settings.⁷⁹ Regional offices determine individuals' eligibility for 4 of the 5 waivers. Four also require eligibility for the State's Medicaid program (MO Healthnet). Medicaid eligibility is determined by the Missouri Department of Social Services' Family Support Division.

Autism Waiver

As of July 2009, Missouri has had an autism waiver in place to provide services for individuals with autism ages 3-18 who live with their family in the community. Eligibility for autism waiver services requires that a qualified professional make one of the following diagnoses:

- Autistic disorder
- Asperger's syndrome
- Pervasive developmental disorder-not otherwise specified
- Childhood disintegrative disorder
- Rett Syndrome⁸⁰

Additional criteria for eligibility include requirements that the child experiences behavioral, and/or social or communication deficits that meet DD requirements and interfere with the child's participation in community activities. The child must also meet ICF-MR level of care as determined by a regional office. Finally, the regional office must also determine that the individual's needs for services can be met within the annual limit of \$22,000.

The Missouri autism waiver includes coverage for the following services for persons ages 3-18:

- In-home respite
- Personal assistant
- Behavior analysis
- Environmental accessibility adaptations
- Out-of-home respite
- Specialized medical equipment (adaptive equipment) and other supplies

⁷⁹ Office of Autism Services. *Navigating Autism Services: A Community Guide for Missouri*. Retrieved January 7, 2011 from: http://www.mofeat.org/files/MO_NavGuide_Web_June09.pdf

⁸⁰ AUTISM WAIVER IMPLEMENTATION. September 4, 2009 (Revised). Available at: http://www.mofeat.org/files/DMH_Autism_Waiver%20FAQ.pdf

- Support broker
- Transportation

There are annual limits on services supported by the autism waiver. Up to \$22,000 per child per year is allowed and there can be no more than 150 persons receiving services under the waiver at any time.⁸¹

Private Insurance Mandates

In the 2010 legislation session, Missouri became the 21st state to approve autism insurance legislation. The law (HB 1311) requires private insurance companies operating in the State to provide coverage under group health insurance policies for the following types of care:⁸²

- Psychiatric care
- Psychological care
- Habilitative or rehabilitative care (including ABA therapy)
- Therapeutic and pharmacy care for children who have been diagnosed with autism ASD

Individuals with an individual health benefit plan may add this coverage; however, there may be additional costs. This law also establishes licensure requirements for therapists who provide ABA therapy for children with ASD.

Adoption and Promotion of Evidence-Based/Promising Practices in ASD

For guidance on evidence-based interventions for children, Missouri State officials look to the National Autism Center and its National Standards Project, which is a major initiative to develop a set of standards for effective, research-validated education and behavioral interventions for children with ASD.⁸³ In addition, Missouri officials refer to the definitions of evidence-based and promising practices put forth by CMS's *Autism Spectrum Disorders (ASDs) Services Final Report on Environmental Scan*. These sources were found to be useful. Missouri State officials also maintain regular communication with researchers from universities throughout Missouri to stay current on new study findings.⁸⁴ Further, DD has endorsed best practices for screening, diagnosis, and assessment of ASD as evidenced by its co-sponsorship of the Best Practice Guidelines published in

⁸¹ Missouri Department of Mental Health. *Autism Waiver*. Available at: <http://dmh.mo.gov/dd/progs/waiver/autism.htm>

⁸² Missouri Department of Insurance, Financial Institutions and Professional Registration (DIFP). *Autism and related insurance resources*. Available at: <http://insurance.mo.gov/consumer/autismFAQ/>

⁸³ Retrieved January 12, 2011 from: <http://www.nationalautismcenter.org/about/national.php>

⁸⁴ Young J, Corea C, Kimani J, and Mandell D. (2010). *Autism Spectrum Disorders (ASDs) Services Final Report on Environmental Scan*. Available at <http://www.impaqint.com/files/4-content/1-6-publications/1-6-2-project-reports/finalasdreport.pdf>

April of 2010. Missouri officials appreciate these types of projects and reports and will continue to reference and utilize them in the future.

Missouri offers guidance for clinicians, service providers, educators, and families on its website and in print. This practice of developing and disseminating service-related materials with and for multiple stakeholders of the autism system is considered one of the State's strengths according to State officials. Several are described below:

- *The Autism Spectrum Disorders: Missouri Best Practice Guidelines for Screening, Diagnosis, and Assessment* was developed after over a year of work by a group of 42 professionals and parents who collaborated to formulate these guidelines. Based on the understanding that children's outcomes are greatly improved with earlier diagnosis and treatment of ASDs, the group's goal was to work from the most current research to facilitate these critical first steps.⁸⁵ The guidelines' dissemination was funded by various private and public partners.
- The brochure titled *Could my Child have Autism* was developed by the Central Missouri Rapid Response Initiative. The group included parents, teachers, child care licensing staff, State agencies, provider organizations, and university representatives. The brochure is unique because it is based on early activity, it is tri-fold, easy to understand, and gives information on where one can seek assistance throughout the state. These materials were not costly to produce once the information and formatting were established.

Missouri officials report the following lessons learned for building a care system and implementing promising ASD services.

To improve the system, the Mid-Missouri Rapid Response Initiative was designed to:

- Increase the number of children who are routinely screened for ASD
- Improve access to timely and accurate diagnosis for individuals at risk for ASD
- Improve access to timely and effective interventions for individuals with ASD
- Provide family members with education and supports

This group produced "Understanding Autism" (in young children) training videos hosted on the University of Missouri Extension website and accessible free of charge through both the Thompson Center for Autism and Neurodevelopmental Disorders website and the university extension's website.⁸⁶

The State raised one consideration regarding the terminology for best practices. In some instances, challenges have been encountered when using terms like "best practices" because of the different

⁸⁵ Missouri Autism Guidelines Initiative. Available at: <http://www.autismguidelines.dmh.missouri.gov/>

⁸⁶ Department of Elementary and Secondary Education. Special Education Listserv. Subject: Autism/Understanding Autism/Training Module. Available at: <http://dese.mo.gov/divspeced/LS10.21.10.htm>

connotations of multiple stakeholders – both positive and negative. State officials will continue to provide guidance and materials supporting the implementation of evidence-based practices.

When asked what factors influence the State’s decisions about which evidence-based, best, or promising practices/services to offer to persons with ASD, representatives shared the following insights:

- *Family involvement.* Missouri officials cited families’ interests and requests among the most influential forces in the development of the care system.
- *Access is a key issue in autism services delivery.* One question that the State often asks is: Given defined best practices and standards, how can the State support increasing provider capacity to develop and then maintain fidelity to treatment approaches? These are critical statewide issues for movement toward the adoption and implementation of evidence-based practices.
- *Resources and Requests.* One challenge the State faces is that the needs and desires put forth by families can’t always be met. In some instances, families may advocate for the State to provide therapies that the State simply cannot provide for a number of reasons, such as having limited resources and /or a limited evidence base to justify support for some therapies.
- *Gaps in services and delays in obtaining timely treatment.* Awareness and increased screening campaigns have been successful at increasing the demand for services. There are more places throughout the State where diagnoses can be made. After diagnoses are made, some individuals and families may not be able to access needed services immediately. Missouri has faced challenges with ensuring consistency in offering contemporary practices delivered by qualified providers. This situation can be complicated when families have longstanding relationships with their preferred providers who may not meet standards for practice. The lack of access to services or qualified practitioners can be especially problematic in rural areas of the state.

The community collaborative known as the Central Missouri Rapid Response Initiative became the impetus for a HRSA State Implementation grant facilitated by the University of Missouri Thompson Center for Autism and Neurodevelopmental Disorders. The purpose of this grant is to expand the model throughout Missouri and to support improvements in the system of care.

When asked for recommended future directions for research on ASD services, the following suggestions were offered:

- Longitudinal research is needed on intervention effects, as well as comparative effectiveness of interventions, to assess services across the spectrum and across the lifespan.
- Technology and telemedicine have shown promise as methods to make costly resources available across the State and to reach rural areas. These methods should be further studied.

Advocacy initiatives

With regard to advocacy initiatives in Missouri, the State’s historical and ongoing engagement of family members, service providers, clinicians, and multiple State agencies is noteworthy. This practice of seeking multiple and diverse sources of input appears to have been present throughout the shaping of the current autism system in Missouri.

New Mexico

System Overview

The Developmental Disabilities Support Division (DDSD) of the New Mexico Department of Health is responsible for the policy, planning, and administration of services and supports to persons with developmental disabilities, including autism and autism spectrum disorders (ASD) in New Mexico. New Mexico currently serves more than 4,000 individuals under its Developmental Disabilities (DD) HCBS waiver, approximately 200 under its Medicaid Medically Fragile HCBS waiver, and more than 100 under its HCBS Self-Directed waiver. State General Fund Services and Family Infant Toddler services cover more than 13,000 individuals statewide.⁸⁷ It is unknown how many of these individuals have ASD.

Autism is at the forefront of the State’s health and human services agenda. DDSD funds most non-school related autism services to all age groups, with the New Mexico Public Education Department providing funding for special education services to children from pre-school through age 21. In addition to Public Education Department, DDSD collaborates with the Human Services Department, Children Youth and Families Department, the Aging and Long Term Services Department, and the Developmental Disabilities Planning Council.

DDSD administers an array of contracted services for individuals with autism and their families through its policy, financing, and regulatory framework. The Center for Development and Disability (CDD) at the University of New Mexico is a leading DDSD partner in providing training, clinical consultation, and technical support to providers and family caregivers throughout the care system. CDD is also the leading diagnostic center in the state, screening individuals for ASD services eligibility, with the final determination made by DDSD. While the Division does not require individual providers to hold an ASD related license or degree, the State does require completion of the University of New Mexico’s 40 hours of autism-specific course work, as well as approved functional behavioral analysis training, for ASD service delivery. In addition, DDSD offers targeted ASD training and technical assistance to individual and program providers.

In addition to services available to individuals through the DD Waiver Program, New Mexico offers a variety of ASD services through its State General Funds for those who either don’t qualify for the

⁸⁷ New Mexico Department of Health Developmental Disabilities Supports Division. *Funds, Programs, and Services*. Available at <http://www.health.state.nm.us/ddsd//programswaiversandstatefunding/programswaiversandservicespg2.htm>

Waiver or who are still waiting for an opening in the Waiver program. State officials highlighted the following services as promising practices:

- Adaptive skill building program (children age five through eighteen)
- Parent home training (children age birth to five)
- Family and community education (FACE) provider training
- Recreational respite

The greatest challenge to system development is the lack of expertise in autism found among New Mexico's health and disability providers. This poses difficulties in staffing programs throughout the state, a challenge most notable in efforts to implement screening, evaluation, and treatment services for young children. The biggest service delivery challenge is the lack of services for young adults ages 19-21.

There is currently an interagency pilot project underway to bring youth nearing age 18 back to their home communities from Residential Treatment Centers. It is hoped that by planning and arranging "wrap around" services for this challenging group of youth, New Mexico can learn how to strengthen our service system for youth and young adults with ASD. This effort is collaboration between DDSD, CDD, the Behavioral Health Single Entity, Children Youth and Families Department, Medicaid and the relevant local public school districts.

The New Mexico Autism Taskforce was formed in 2007 after Governor Bill Richardson publicized the need for a comprehensive system of services and supports for individuals with ASD.⁸⁸ The Autism Task Force comprises parent stakeholders, the Department of Public Education, the New Mexico Children, Youth and Families Department, the University of New Mexico, and the New Mexico Autism Society. The Autism Taskforce developed guiding principles and program recommendations for autism services and supports. Beginning in 2008, the New Mexico legislature allocated funds to implement Taskforce recommendations to DDSD and will continue to appropriate funds through at least 2011.

DDSD has been working closely with the Medical Assistance Division of the Human Service Department, as well as several provider and statewide advocacy agencies, to reorganize and leverage Medicaid to offer more services and options to individuals with ASD.⁸⁹ Advocates pursued legislation in 2009 that was never enacted, authorizing the New Mexico Department of Human Services to apply for an HBCS waiver for adaptive skill building services targeted at children ages 0-5 with autism, Rett Syndrome, and PDD. The State instead established adaptive skill building services for children with ASD in this age group through the Medicaid State plan.

⁸⁸ NM Department of Health. *Developmental Disabilities Supports Division*. Available <http://www.health.state.nm.us/DDSD>

⁸⁹ New Mexico Department of Health Developmental Disabilities Supports Division. *An Overview of Changes to the New Mexico Developmental Disabilities Medicaid Waiver*. Fall 2010. Available at <http://www.health.state.nm.us/ddsd//resourcesupportbureaupublications/DDW/DDWaiverRenewalUpdate.htm>

Coverage Summary

New Mexico's Medicaid program covers eligible individuals with developmental disabilities under mandatory, optional, and waiver service provisions. State Medicaid waivers include:

- Medically Fragile waiver
- Developmental Disabilities waiver
- The "Mi Via" (My Way) Self-Directed waiver
 - The Mi Via waiver is co-administered with the Department of Health and the Aging and Long Term Care Services Department.

In order for New Mexico residents to qualify for the DD HCBS waiver, individuals must present a confirmed diagnosis of an intellectual disability, mental retardation, or a specific related condition.⁹⁰ Once the diagnosis is confirmed by the state, individuals are placed in the Central Registry database to await opening in the DD Waiver program. There are currently over 5,000 individuals on the Central Registry; it is unknown how many of those individuals have an autism spectrum disorder. Adults with ASD are only eligible to receive targeted autism services once they are allocated to the DD waiver. Many adults with ASD do not meet these requirements and must rely instead on non-specialized developmental disability and mental health services.

Several agencies in New Mexico support ASD services for individuals and their families. The Public Education Department offers special education services for children and transition-age youth with developmental disabilities. For individuals with ASD who have a co-occurring severe mental illness, the Behavioral Health system is their primary resource beyond the services provided by Special Education. While New Mexico is actively attempting to meet the growing needs of ASD supports and services, the State has limited financial resources with which to treat all individuals with ASD. Fiscal stress has resulted in the State's current cap on ASD services. For instance, the state-funded Adapted Skill Building program now has a waiting list.

Adoption and Promotion of Evidence-Based Practices and Promising Practices in ASD

New Mexico does not employ a formal definition of evidence-based or promising practices; however DDSD is in the process of developing written guidelines and definitions of evidence-based practice for individuals with ASD. Services for individuals with ASD are family-driven, and family members have been influential in defining the criteria for the State's promising autism programs. Family members have requested that State services follow certain guidelines in contracting for ASD services; services must (1) target and support family needs, (2) be generalized across settings, (3) be scientifically proven, and (4) be fiscally responsible. CDD has been instrumental in developing and implementing promising practices for individuals with ASD. In 2009, DDSD created an evaluation project to examine New Mexico's evidence-based/promising practices for individuals with ASD and

⁹⁰ New Mexico Department of Health. *Developmental Disabilities Supports Division: Program Eligibility Criteria*. Available at <http://www.health.state.nm.us/DDSD/eligibility/eligibilitypg3.htm>

their families. The State recently completed a report on the evaluation and implications for further system improvements.

State law SB 39, passed in 2009, mandates private insurance coverage for individuals with ASD who are age 19 or below, and up to age 22 if they remain in high school. The mandate requires coverage for diagnostic and treatment services, including the evidence-based practice of ABA, speech therapy, and occupational therapy up to a benefit cap of \$36,000 per year and \$200,000 over a lifetime.⁹¹

A bill is currently before the New Mexico Legislature which, if passed, will require public school IEP teams to review and consider a specified list of factors when preparing IEPs for children with ASD. The list of factors contained in the bill is based upon best practice; advocates believe this will promote better quality of special education services for this population.

Lessons Learned

New Mexico State officials report the following lessons learned for building a care system and implementing promising ASD services:

- State and community stakeholder leadership is crucial for moving a system to embrace change.
- Enlist valued academic, clinical, and program partners in building ASD care system capacity and expertise.
- Traditional Medicaid State Plan and waiver LTSS is insufficient to meet the needs of transition-age youth. Make investments in system infrastructure to serve as a platform for implementation of new models and expanded ASD service capacity.

Pennsylvania

System Overview

In response to the dramatic rise in the prevalence of autism spectrum disorders (ASD) over the last decade, Pennsylvania has taken great strides to become a national leader in meeting the needs of the autism community.

As a result of recommendations by the Pennsylvania Autism Task Force (2004), the Bureau of Autism Services (BAS), one of the first autism-specific State offices in the nation, was established in Pennsylvania in 2007. Organizationally, BAS is part of the Pennsylvania Department of Public Welfare's Office of Developmental Programs (ODP). Its mission is to develop and manage services and supports to enhance the quality of life of Pennsylvanians with autism and to support their

⁹¹ National Conference of State Legislatures. *Autism and Insurance Coverage State Laws*. Available at <http://www.ncsl.org/?tabid=18246>

families and caregivers. BAS primarily carries out its mission through the development and administration of direct services for adults with autism. In addition, it supports people with autism of all ages through the ASERT regional collaboratives; the development of crisis programs to support individuals in need of acute intervention; family support programs; training programs to increase provider capacity; and by providing technical assistance and autism expertise to other DPW offices and government agencies.

BAS works to align policy and program initiatives, promote innovation and evidence-based services, and fill gaps in care for individuals with ASD by interacting with and offering technical assistance to other State agencies with a responsibility for providing care for persons with ASD, including:

- Pennsylvania Office of Child Development and Early Learning (OCDEL) for early intervention services to children ages 0-3
- Office of Mental Health and Substance Abuse Services (OMHSAS) for behavioral health services to Medicaid and Medical Assistance eligible children with ASD who use, for example, behavioral health rehabilitation services (BHRS)
- Pennsylvania Department of Education (DOE) for services provided through age 21
- ODP for services under the Consolidated and PFDS Intellectual Disability waivers
- Pennsylvania's Medicaid program, known as HealthChoices, covers managed care plans and waiver programs that provide developmental, medical, and behavioral health services

Coverage Summary

Children

Services for children through age 21 fall under the purview of the State's Department of Education or the Department of Public Welfare's Office of Mental Health & Substance Abuse Services (OMHSAS). In addition to early intervention services, children who are exhibiting developmental delays or signs of autism may be evaluated by credentialed developmental specialists to determine a diagnosis of ASD. Medicaid and Medical Assistance eligible children with ASD receive targeted therapeutic, individual and family support services under BHRS. These HCBS are delivered by credentialed providers who participate in the behavioral health managed care program networks.

For school-age children, State laws and regulations include several provisions for children with ASD. The State requires, for example, that a certified school psychologist be included when a child is being evaluated for autism and other types of disabilities. Further, autism or other pervasive developmental disorders are included as factors when determining if a student is eligible for an extended school year at the student's Individualized Education Program (IEP) meeting. Year round, consistent service interventions are essential to promoting optimal development and mitigating risk of disability in children with ASD.

Adults

The 2004 Pennsylvania Autism Task Force described an urgent need to establish HCBS for adults with ASD. Specifically, the Medicaid waiver subcommittee of the task force emphasized the importance of beginning eligibility at 21 – the age at which entitlements to services end.

In response to these gaps, BAS designed two innovative programs for adults with ASD: the Adult Autism HCBS waiver and the Adult Community Autism program (ACAP).

In 2008, the BAS application for an adult autism Medicaid waiver, which is a traditional Medicaid FFS HCBS waiver, was approved and became the first program in the country to specifically support adults over 21 with ASD. The waiver is approved to serve up to 300 adults statewide from age 21 who meet the following criteria: US citizenship or qualified alien, residence in Pennsylvania (or plan to be a resident upon enrollment), have a diagnosis of an ASD,⁹² and meet federal functional eligibility. The program is structured to give priority to those not receiving any State funded or State and federally funded HCBS.

Providers who deliver care under the waiver must receive training specific to supporting adults with an ASD. Services covered by the waiver include a broad range of therapeutic day and residential services, as well as community and family support services.

This waiver does not include a cost limit or capitation. However, service limitations for a number of specific waiver services are outlined in the Participant Handbook. This waiver, as currently approved, is set to expire on June 30, 2011⁹³ and a renewal is expected to be approved with some modifications, effective July 1, 2011.

To create an additional service option for adults with ASD, BAS was also approved for a second innovative program for adults called ACAP, the Adult Community Autism Program (2009).

ACAP serves adults with ASD age 21 or older in 4 Pennsylvania counties using a prepaid inpatient health plan model. The program provides integrated physical, behavioral, and community services to adults with ASD. The contractor and its network of providers offer medical, dental, behavioral health, and HCBS. Like the adult autism waiver, ACAP providers must receive training specific to supporting adults with ASD.⁹⁴ A summary of the ACAP program, including eligibility criteria and covered services, is found in Section 4.8 of this report.

⁹² Adult Autism Waiver diagnostic criteria: Must have a diagnosis of an autism spectrum disorder, which includes: Autism, Pervasive Development Disorder-Not Otherwise Specified (PDD-NOS), Asperger Syndrome, Childhood Disintegrative Disorder, or Rett Syndrome. (IQ score is not considered)

⁹³ Pennsylvania Department of Public Welfare. *Adult Autism Waiver: Eligibility Questions*. Available at <http://www.dpw.state.pa.us/foradults/autismservices/adultautismwaiver/eligibilityquestions/index.htm>

⁹⁴ Pennsylvania Department of Public Welfare. *Comparison of Medicaid Programs that Serve Adults with Autism Spectrum Disorders (ASD)*.

Private Insurance Mandates

In July 2008, Pennsylvania passed a law (Act 62 Statute) that addresses insurance coverage, requirements, and treatment for children and youth under age 21 who have a diagnosis of an autism spectrum disorder. The Autism Insurance Act covers children or young adults below age 21 who are covered by specific types of employer group health insurance policies or Medical Assistance or Pennsylvania's Children's Health Insurance Program (CHIP), or AdultBasic.

Overseen by the State's Department of Insurance, the Act involves several important entities in the autism system. Under this law, many private health insurance companies are required to cover the costs of diagnostic assessment and treatment of ASD and services for the covered population up to a total of \$36,000 per year. In addition, the DPW must cover the cost of services for persons who are enrolled in the Medical Assistance program and do not have private insurance coverage, or for individuals whose costs surpass \$36,000 per year. Further, the law also requires the State to license professional behavior specialists who provide services to children.⁹⁵

The Act allows for coverage of: diagnostic assessment services and treatment of ASD, including prescription drugs and blood level tests, and services provided by a psychiatrist and/or psychologist; applied behavioral analysis (ABA); and other rehabilitative care and therapies.

Treatment provided under the Act must meet certain requirements, including that they are:

- For an ASD
- Medically necessary
- Identified in a treatment plan
- Prescribed, ordered, or provided by a licensed physician, licensed physician assistant, licensed psychologist, licensed clinical social worker or certified registered nurse practitioner
- Provided by an autism service provider or a person, entity, or group that works under the direction of an autism service provider

Adoption and Promotion of Evidence-Based/Promising Practices in ASD

Science-based treatment models, such as ABA and positive behavioral support, are emphasized in the State's service documents for persons with ASD. Pennsylvania officials have not published specific policies and definitions of evidence-based or promising practices for ASD services. However, ABA is a Pennsylvania standard in meeting the needs of individuals with ASD who are behaviorally complex.

Available at

http://www.dpw.state.pa.us/ucmprd/groups/webcontent/documents/communication/s_000918.pdf

⁹⁵ Pennsylvania Department of Public Welfare. *Autism Insurance Act Fact Sheet*. Available at

<http://www.dpw.state.pa.us/foradults/autismservices/paautisminsuranceact62/autisminsuranceactfactsheet/index.htm>

Lessons Learned

State officials report the following lessons learned for building LTSS system and implementing promising ASD services:

- *Focus on Outcomes:* For adult services that are under the State’s purview, both the ACAP and adult autism waiver models were designed based on the notion that attention to outcomes was critical. This focus on outcomes was largely informed by concerns about the use of aversive techniques such as restraints and medication, crisis management, and involvement with the criminal justice system among persons with ASD. With these factors in mind, adult autism services were designed to address the importance of quality of life and meaningful outcomes that would be desirable for families and adults with ASD. They also emphasized the prerequisites to successful outcomes, such as assessments that would “drive support planning”. These elements formed the foundation for modeling the design.
- *Manualized Standards and Training:* Those who designed the services provided under the Pennsylvania autism services waiver recognized the need for standards and training to strengthen the orientation of service providers to the role and methods of outcomes assessment. Pennsylvania offers such training for providers. Accompanying manuals and protocols have been developed and are included in the package of materials associated with the autism waiver, many of which are also available online.

Use of Data and Documentation: In order to better understand and meet the needs of Pennsylvanians with ASD, BAS initiated two projects designed to gather data with respect to the number of Pennsylvanians living with ASD, their experiences, and their needs.

In October 2009, BAS released the Pennsylvania Autism Census Project Final Report. This was the first study to estimate the number of individuals living with ASD in the Commonwealth. The intention was to reveal the scope of need for ASD-specific services and programs and to inform policy development and the design of effective services. Results of the census show that, as of late 2009, the number of children and adults with ASD in Pennsylvania was approximately 25,000. The report also illustrates that the number of adults with autism will increase dramatically in the future, growing by 170% to more than 3,800 in 2010 and by 621% to more than 10,000 by 2015.

Pennsylvania is faced with the task of ensuring that appropriate supports and services are available to this growing number of individuals with ASD, so that they may become productive and contributing members of our society. It is therefore important to have a deeper understanding of the extent to which current public systems are meeting the service needs of children and adults with ASD and their families.

In 2009, BAS conducted an assessment in order to gauge how well public systems are meeting the service needs of individuals with ASD and their families. With over 3,500 responses, the survey is believed to be the largest of its kind to date. The data are intended to inform changes in policy and practice that can guide the distribution of resources and result in more effective and efficient program planning at the state, regional, and county levels. An in-depth series of reports will be issued. The initial report is a statewide snapshot that examines trends by age group and broad themes, including co-occurring disorders, the diagnosis process, occurrence of problem behavior, follow-up services, hospital use, caregiver education and workforce participation, and long-term

planning. Subsequent reports will explore the geographic differences among the regions and counties of Pennsylvania by specific topic areas, including unmet needs, barriers and limitations to accessing services, diagnostic process, police contact, employment, caregiver burden, hospitalizations and residential facilities, and effectiveness of services.

Participation in State and National Dialogue: In addition to documenting the lessons that have been learned in Pennsylvania, there is a need to connect with others and have a dialogue at the national level. As policymakers, Pennsylvania officials would find it helpful to have a more formalized way for states to be engaged and to exchange information about what they are doing to serve individuals with ASD, their families, and the professionals who support them. This mechanism would reduce redundancies and prevent others from “reinventing the wheel” when states have limited time and resources. Pennsylvania has hosted two national policy conferences toward this purpose, and believes that on-going opportunities for engagement would be beneficial.

Knowledge Dissemination: Another recommendation of the 2004 Task Force was to create regional autism centers. As a result, three regional Autism Services, Education, Research, and Training (ASERT) collaboratives were developed and funded by BAS. These innovative partnerships between universities, hospitals, and autism service providers are enhancing the lives of Pennsylvanians with ASD by improving regional access to quality services and interventions; providing information and support to families; training professionals in best practices; and facilitating partnerships among providers of services throughout the Commonwealth.

Innovation and Adaptation: Children and adults with autism have complex needs and as a result are served by many systems. This results in many systemic challenges in supporting this growing sector of the Commonwealth. Therefore, it is critically important that State health, human service, and education agencies continue to identify innovative ways to get appropriate services and resources in place. One of the most important avenues open to leaders and advocates in Pennsylvania is building on their successful BAS initiative to develop and strengthen effective collaborations between systems and leverage existing resources and expertise.

Co-Occurring Disorders: Another challenge lies in how to address the needs of persons with ASD and co-occurring mental disorders. The Pennsylvania Autism Needs Assessment found that co-occurring disorders are common among individuals with ASD, who were most often diagnosed with attention deficit/hyperactivity disorder, anxiety disorder, or intellectual disability/mental retardation. However, many mental health professionals do not have the training and expertise necessary to provide effective interventions to individuals with ASD who have co-occurring mental health conditions.

Some participants in Pennsylvania’s adult autism programs have a co-occurring mental health diagnosis that may challenge providers who may not have the skills to effectively support that participant. Training specific to these diagnoses is provided in an effort to enhance the provider’s support repertoire. Further, at times there are multiple systems involved in supporting an individual who has a dual diagnosis. Coordination and collaboration within these systems can be cumbersome and difficult given the varied backgrounds and disciplines of staff; however, Pennsylvania informants

indicated that successful collaboration will enable each system to benefit from the others' expertise, supporting better individualized services and supports for service users.

Wisconsin

System Overview

In Wisconsin, the primary agency responsible for the care of individuals with autism spectrum disorders (ASD) is the Division of Long Term Care (DLTC) - Department of Health Services (DHS). DHS is the State Medicaid Agency, and DHS defines HCBW procedures and processes for implementing and accessing HCBWs. DHS contracts with all counties in Wisconsin to implement HCBW services. DHS provides technical support and guidance to each county waiver agency (CWA) and has a state-level quality assurance system. The State psychiatric hospitals and intermediate care facilities for the mentally retarded (ICF-MR) are the only state-funded and operated institutional providers.

Wisconsin counties have statutory obligations to the various State departments. Thus, State contracted waiver agencies are a constitutional extension of the State governmental structure. CWAs must follow State Medicaid waiver agency process and procedures, including eligibility requirements, allowable services, financial accountability, qualified providers, consumer health and safety, and consumer choice responsibilities. CWAs contract with providers of waiver services in accordance with all waiver requirements. All providers must sign a provider agreement with Medicaid. Emergency services for individuals with ASD are provided by county mental health systems. DHS holds monthly teleconferences and meets quarterly with county human service departments and waiver staff on many issues related to ASD. These meetings are focused on the provision of services to children in the home HCBS, other Medicaid services, and educational services.

Wisconsin began a system transformation in the mid 1990's by decreasing the reliance on ICF-MRs, using the resulting cost savings to support increased community-based services, resulting in decreased waitlists. Wisconsin has been providing intensive in-home autism treatment services for children with ASD since 2004 under two children's Medicaid HCBS waivers serving children up to age 22. These two waivers are not autism-specific and serve all children who meet the appropriate eligibility requirements.

The entry point for eligibility determination and access to the Children's HCBS waivers is through the CWA. Aging and Disability Resource Centers (ADRCs) were introduced beginning in 1997 and continue to roll out statewide. These centers provide benefits counseling and support services to adults at the county level. ADRCs begin operation in the region a minimum of three months before the regional transition process begins; and while they are not specifically aimed at individuals with ASD, they play a key role in an ASD family's ability to access care.

Coverage Summary

Screening and diagnosis are reimbursed as a Medicaid State plan fee-for-service for Medicaid eligible children. Educational efforts for providers and families are targeted to ensure that children with ASD are identified early. In order for families in Wisconsin to receive early intensive treatment services, DLTC requires a differential diagnosis of autism, Asperger's, or PDD-NOS.

There are three section 1915(c) Children's Long Term Support (CLTS) HCBS waivers in Wisconsin for children from birth to age 22: The Children's Serious Emotional Disturbances (SED) waiver, the Developmental Disabilities (DD) waiver, and the Physical Disabilities (PD) waiver. Children with a diagnosis of an ASD may receive services through the SED or DD Waivers. Currently, there are approximately \$42 million in all funds dedicated to intensive in-home autism treatment services each biennium. Each child's intensive treatment plan costs approximately \$41,000/year. The CLTS intensive autism treatment service is focused on the development of social, learning, and communication skills.

There is collaboration with IDEA-related planning as part of an Interagency Collaborative Agreement, and transition planning is defined. Most individuals with an ASD already have a family and child service support coordinator who attends their IEP planning meetings. This support and service coordination helps to shape and coordinate the transition process with all the staff and services involved. When the individual with an ASD resides in a long-term support reform county and reaches age 17 years and six months, he/she can be referred to their regional Aging and Disability Resource Center (ADRC) for adult waiver eligibility determination as well as counseling for long-term support waiver planning when they turn 18. When the individual resides in a county that operates the legacy adult HCBW, the person transitions into adult services when he/she is ages 18-21.

For individuals who have aged out of children's services, Wisconsin offers a variety of LTSS. Wisconsin provides both a fully-integrated managed care model known as Family Care, as well as a self-directed HCBS waiver, IRIS (Include, Respect, I Self-Direct) waiver. There are about 16 counties (of the total 72 in Wisconsin) that have yet to transition to the Family Care and IRIS Programs.

In 1997, five counties began to transition adult long-term care service provisions using the Family Care managed care waiver. The Family Care waiver is funded by through Medicaid and is managed by the DHS using a managed care delivery system, and increases traditional care management in order to increase quality and reduce costs. The cost savings from this process are reinvested in the system to eliminate waiting lists.

The Family Care waivers are a fully integrated managed care model. Individuals enrolled in Family Care have access to a multi-disciplinary team. In addition, person-centered, self-directed components are available and can be added according to the wants and needs of the individual and their family. For example, some individuals prefer to be able to choose who assists them.

Individuals using the IRIS waiver also have the ability to realize cost savings. Individuals in IRIS receive a budget allocation based on an actuarial model and then are assisted in forming their care

plan and budgeting their funds. They have the opportunity to purchase services and supports that best suit their needs within their support system. For IRIS services, individuals use the “circle of support” concept, which is a strengths-based approach that allows individuals to capture their own cost savings for self-directed services. Wisconsin’s self-directed plans (SDPs) must meet the same requirements of the regular Medicaid HBCS services plan, including assuring health and safety, qualified providers, and allowable services.

The IRIS self-directed supports waiver began operations in 2008. Consumers and families choose the waiver that best suits their needs. The Family Care, IRIS, and Legacy waivers provide an option for behavioral consultation, during which the individual, family, and consultant come up with strategies to address assessed needs and to develop a service plan to maximize success.

The IRIS waiver is currently in the process of being renewed. While many individuals want self-directed care, initially DHS has found that many people need more support. Consequently, the proposed waiver includes a more in-depth IRIS consultant/coordinator option so that people who require additional training to use self-directed services are able to access this support.

Wisconsin provides vocational and future-planning services to look at ways to build the individual’s background and experience in their chosen field. One way this occurs is through the provision of pre-vocational services, with the intent to teach specific skills that will enable the individual to meet goals set at the beginning of the service so that they can eventually transition to a community-based option. These services are intended to be time-limited, and the State is working to emphasize more self-directed approaches. Wisconsin also has a “Customized Goods and Services” option within the IRIS waiver, which allows individuals to develop more individualized approaches to vocational support.

Adoption and Promotion of Evidence-Based/Promising Practices in ASD

Wisconsin continues to work on identifying and clarifying evidence-based and promising treatment practices for children with ASD. There are currently 22 intensive in-home autism treatment service providers in Wisconsin, of which approximately three-quarters self-identify as implementing ABA or “ABA-based” models. The others use the Denver Model, the Social Communication, Emotional Regulation and Transactional Support (SCERTS) Model, as well as other treatment models.

The DHS follows the Medicaid definition of evidence-based practices for intensive autism treatment services. In instances when family caregivers request treatment services that do not meet the State’s criteria for evidence-based services, DHS investigates the work done in other states and from other national entities (e.g., the National Autism Center, and IMPAQ) to determine whether or not these services meet its standards.

The DHS works collaboratively with the Waisman Center at the University of Wisconsin-Madison, which is one of the National Professional Development Center (NPDC) pilot sites. DHS also uses the NPDC’s research to support and guide their policy development.

Wisconsin has an insurance mandate, which covers many children and adults with ASD through private insurance policies. It was enacted in the fall of 2010. The mandate is specific to treatment for ASD; other services are not covered by the mandate, and it covers only evidence-based behavioral and psychological interventions. The mandate distinguished between early, intensive treatment, and ongoing intervention. Intensive services for children through the insurance mandate have a time limit of 4 years and the child must be ages 2-9 when starting services. There is no time or age limit allowed for other treatments.

The insurance mandate spurred a successful statewide effort to license behavior analysts, which, over time, is hoped will increase the number of available qualified providers. The Wisconsin Department of Regulation and Licensing has approved the licensing guidelines and issues the license for these professionals

Lessons Learned

Informants from Wisconsin reported the following lessons learned:

- Individuals and families need support and education in ways to enact successful self-directed services.
- Periodic reviews of assessments and individual services assists in monitoring the quality of services.
- Other states can provide useful support and guidance in service development.
- Close collaboration between State agencies can improve coordination of services.

Appendix 2: Discussion Guide

Review of States' Evidence-Based Practices, Best Practices, and Promising Practices in Services for Individuals with Autism Spectrum Disorders Discussion Guide (April 5, 2010)			
Date:	Start time:	End time:	Abt staff first & last name:
Discussant's current full name, degrees, title, affiliation, and State:			

[This introduction will be read aloud by Abt staff member. It will not be included in the discussion guide but is included for your reference.]

Thank you for reviewing this discussion guide that we developed for your State. We appreciate your time in talking with us about the following topics that were designed to provide us a fuller picture of your State's best services for persons with Autism Spectrum Disorders and the implementation conditions to be considered for replication. Over the next 45 minutes, we'll discuss four main areas of interest:

- *Evidence-based practices, best practices and promising practices;*
- *Service-related topics;*
- *Policy and fiscal issues; and*
- *Lessons learned and future directions*

I. Evidence-based Practices, Best Practices and Promising Practices

As you know, the purpose of this review of states is to understand the best practices and promising approaches used by nine states. Criteria have been developed by CMS for promising practices. In addition, several initiatives conducted through national research centers have generated scientifically established criteria for evidence-based practices for ASD.

CMS Definition of Promising Practices:

CMS provides a definition and criteria (found on the CMS website⁹⁶) for promising practices.

A "promising practice"must:

- *Be related to the improvement of quality of care and/or life for Medicaid and/or CHIP beneficiaries*
- *Address a significant problem in health status or functioning based on trends in mortality, morbidity, quality of life, utilization and/or costs*
- *Reflect an innovative approach to meeting a common problem*

⁹⁶ Centers for Medicare and Medicaid Services. *Medicaid/CHIP Quality Promising Practice Nomination*. Retrieved December 3, 2009 from: <http://www.cms.hhs.gov/MedicaidCHIPQualPrac/Downloads/prompracnomform.pdf>

- Have been in operation for a sufficient period of time to demonstrate effectiveness (e.g., minimum 12 months)
- Have demonstrated success through tangible results (e.g., improvements in beneficiary physical or mental well-being, savings)
- Comply with Federal Medicaid statute and regulations and CMS policy direction

To what extent do you use the CMS definition of Promising Practices? If used in your State, please describe how it gets used.

Notes...

What guidelines, criteria, principles or definitions of “best practices” and “promising approaches” in services for individuals with ASD are used by your State? Were these guidelines, criteria, principles or definitions developed by your State?

REFER TO EVIDENCE-BASED PRACTICES DEFINITIONS IN APPENDIX

If yes, describe how and why they were developed.

Notes...

Does your State use guidance developed by other entities?

If so, which ones and why?

II. Service-related topics:

We’d like to understand the larger context for evidence-based practices, best practices and promising practices in autism services in your State.

Please give a brief description of the range of services offered to children, transition age youth and adults with ASD.

Notes...

Next, I’d like to hear more about services that are considered evidence-based practices, best practices and promising practices in your State.

Because services are often targeted by age or developmental level when serving persons with ASD, we are asking if you can distinguish for us those services provided to the following three groups: children, transition age youth and adults. We ask about the same list of “Service Elements” for each age group, which we are using in an effort to gather a standard set of information for CMS. We understand that you may not have this level of detail on the promising practices and best practices in your State. Please provide us what you can and we will follow-up with others at your direction, which we’ll ask about at the end of this discussion.

<input type="checkbox"/> Screening guidelines	<input type="checkbox"/> Supported Employment
<input type="checkbox"/> Diagnosis guidelines	<input type="checkbox"/> Care/Service Coordination
<input type="checkbox"/> Functional Assessment	<input type="checkbox"/> Education for parents
<input type="checkbox"/> Intervention and Treatment	<input type="checkbox"/> Respite care
<input type="checkbox"/> Behavioral Support	<input type="checkbox"/> Dental care
<input type="checkbox"/> Applied Behavior Analysis (ABA) – based treatments	<input type="checkbox"/> Other specialized services (e.g. programs for people with Asperger’s Syndrome (specify): _____
<input type="checkbox"/> Day Programs	<input type="checkbox"/> Other (specify): _____
<input type="checkbox"/> Self-directed Service Delivery Models	<input type="checkbox"/> Other (specify): _____
<input type="checkbox"/> Independent Living Skills Acquisition	<input type="checkbox"/> Other (specify): _____
<input type="checkbox"/> Supported Housing	

Defining the Elements of Your State’s Promising or Best Practices			
	Children	Transition Age Youth	Adults
1. Program Name			
a. Open-ended description			
2. Target Population or Subpopulation Served			
a. Age group (children, transition aged youth, adults)			
b. Diagnosis (autism, ASD, other developmental disabilities)			
c. Service setting (in schools, families, communities, other)			
3. Description of Service			
a. Program concept (consumer needs being addressed, goals, objectives)			
b. Core program components (functions of the program designed to align with client need)			
c. Use of Individual Service Plan, frequency of evaluation and updating			
d. Options for tailoring the program to meet individual, linguistic and cultural needs			
e. Options for intensity, duration and continuity of care/services			
f. Structure, consistency and skill orientation of program			
g. Use of developmental and/or behavioral motivators			
4. Client Eligibility & Selection			
a. Screening, diagnostic and/or functional evaluation requirements			
b. Financial or program eligibility requirements			
5. Staffing Requirements			
a. Numbers and types of personnel			
b. Credentials and/or training			
c. Supervision and evaluation			
6. Innovation and Outcomes			

Defining the Elements of Your State's Promising or Best Practices			
	Children	Transition Age Youth	Adults
a. Program methods			
b. Client results (clinical, functional, quality of life, satisfaction)			
c. System results (improved access, better quality, cost efficiency)			
7. Funding			
a. Medicaid (mandated, optional and/or waiver)			
b. State appropriations			
8. Geographic/Siting			
a. Urban			
b. Rural			
9. Other			
a. Specify			

III. Policy and fiscal issues:

Does your State have a written policy currently in place regarding the provision of EBP, BP, PP Medicaid services to individuals with ASD?

If so, may we have a copy?

In general, how is your State meeting growing needs for ASD services in a time of fiscal stress?

Notes...

How have the American Recovery and Reinvestment Act of 2009 (ARRA) rules influenced providers, rates, and service offerings?

NOTE TO STAFF: HAVE ARRA RULES HANDY FOR REFERENCE DURING DISCUSSION.

Notes...

Are there unique conditions, innovative programs, and/or executive/judicial/legislative developments you wish to note at this point?

Notes...

Next, I'd like to understand which Medicaid or other financing programs your State uses to cover these EBPs, BPs or PPs for persons with ASD. Can you confirm which agency or agencies in State government currently administer the Medicaid-covered evidence-based practices, best practices, or promising practices?

Typical Agencies include... [PROBE FOR AGENCIES LISTED IN TABLE BELOW]

EBP, BP, and PP services/coverage	Medicaid	DMH	DMR/DD	DOE	Other (specify)
--	-----------------	------------	---------------	------------	------------------------

Mandatory	<input type="checkbox"/>	_____				
Optional	<input type="checkbox"/>	_____				
DD 1915(c) waiver	<input type="checkbox"/>	_____				
Autism 1915(c) waiver	<input type="checkbox"/>	_____				
1115 waiver	<input type="checkbox"/>	_____				
Other 1915(c) waivers	<input type="checkbox"/>	_____				
School Based Services (Medicaid services, that can be delivered in school settings)	<input type="checkbox"/>	_____				
TEFRA	<input type="checkbox"/>	_____				
1915(a) contracts	<input type="checkbox"/>	_____				

Now I'd like to ask you about non-Medicaid-funded EBP, BP, and PP in ASD services in your State.
If Medicaid doesn't fund these services, which agencies do?

<i>EBP, BP, and PP services/coverage</i>	<i>DMR/DD</i>	<i>DMH</i>	<i>DSS</i>	<i>DOE</i>	<i>Other (specify)</i>
State Funded Services	<input type="checkbox"/> _____				
Children	<input type="checkbox"/> _____				
Transition Aged Youth	<input type="checkbox"/> _____				
Adults	<input type="checkbox"/> _____				
Community Based	<input type="checkbox"/> _____				
Family Based	<input type="checkbox"/> _____				
School Based Services (Medicaid services, that can be delivered in school settings)	<input type="checkbox"/> _____				
Other	<input type="checkbox"/> _____				

In addition to funding, do these agencies have other roles regarding EBP, BP, PP ASD services in your State?

<i>ASD Role of Other Agencies</i>						
<i>Agency</i>	<i>Policy Role</i>	<i>Funding Role</i>	<i>Regulatory Role</i>	<i>Provider Role</i>	<i>Health Home</i>	<i>Other : specify</i>
DMH	<input type="checkbox"/> _____	<input type="checkbox"/> _____				
DMR/DD	<input type="checkbox"/> _____	<input type="checkbox"/> _____				
DSS	<input type="checkbox"/> _____	<input type="checkbox"/> _____				
DPH	<input type="checkbox"/> _____	<input type="checkbox"/> _____				

DOE	<input type="checkbox"/> _____	<input type="checkbox"/> _____				
Bureau or Office of Autism within another agency	<input type="checkbox"/> _____	<input type="checkbox"/> _____				
Emergency services	<input type="checkbox"/> _____	<input type="checkbox"/> _____				
Criminal justice system	<input type="checkbox"/> _____	<input type="checkbox"/> _____				
Specialized ASD Support Infrastructure	<input type="checkbox"/> _____	<input type="checkbox"/> _____				
Other: Specify						

Notes...

Services Implementation Considerations:

When implementing or providing the Promising or Best Practices we just discussed – what are some of the implementation considerations you take into account?

1. Planning	
2. Client Eligibility and Recruitment	
3. Provider Organization	
4. Facility and/or Community Site Requirements	
5. Staffing and Workforce Issues	
6. Licensing and Accreditation	
7. System of Care/Services Context for Program/Linkages	
8. Financing for Capital and Operations Costs	
9. Evaluation and/or Research– process or outcome	
10. Sustainability Plans	
11. Quality or Performance Standards	

What factors influence (d) your State’s decisions about which EBP, BP, or PP services to offer to persons with ASD?

Notes.....

What additional considerations should States take into account?

- Funding
- Workforce
- Training
- Prevalence of ASD in your State

That was the last question regarding policy, fiscal and organizational issues. Is there anything you’d like to add – anything I didn’t ask that you think is important to understand?

Notes.....

IV. Lessons learned & future directions

The next set of questions has to do with lessons learned, recommendations, and future directions. We understand that Medicaid may not be implementing these EBPs, BPs, or PPs but that Medicaid is involved with other aspects of the provision of these services (e.g., client eligibility and reimbursement).

Were there any notable lessons learned about implementation of EBP, BP, or PP in your State?

Notes.....

PROBE: For states that have used self-directed services, how is that working?

Notes.....

Is there any other information on adoption and implementation of EBP, BP, and PP for ASD services that can help to guide other states?

Notes.....

Do you have any recommendations on how to provide:

- **The highest quality services at the lowest cost possible?**

Notes.....

- **Recommended future directions for research on ASD services?**

Notes.....

Has your State conducted any research or developed any reports targeted to the use of best or promising practices or evidence-based practices for persons with autism or ASD diagnoses, or other aspects of these services? Would you be willing to share the resulting information with us?

Notes.....

Does your State make information about ASD, ASD services and/or research findings available to the public? Do you use written materials (e.g., brochures), telephone, hotline, and/or a website?

Notes.....

Finally, we would also like your recommendation for others whom we could follow-up with to get their perspective on some of the topics we discussed today. Who else could we follow-up with from

- Program or disability agency staff?
- Top performing provider?
- Others?

Please provide their contact information....

	Program or disability agency staff	Top performing provider	Other contact
Name			
Agency			
Title			
Phone			
Email			

V. Wrap-up

THANK YOU VERY MUCH for your time and willingness to participate in this discussion. This input will help us refine our description of your State’s services for individuals with ASD.

If you have any questions or further comments, please do not hesitate to contact me at (phone #) or (email).

For your information, CMS provides guidance on nominating programs to be considered Medicaid/CHIP Quality Promising Practices. If you are interested in learning more about this program, visit

http://www.cms.hhs.gov/MedicaidCHIPQualPrac/10_PromisingPracticesConceptNominationProcess.asp#TopOfPage