

Michigan

Autism Spectrum Disorders

State Plan

Findings and Recommendations



December 2012

Acknowledgements

The Michigan Autism Spectrum Disorder State Plan Development Committee would like to thank everyone who contributed to the development of this plan. A special thanks to the families, professionals, service providers and community members who provided information, input and support to make this document credible and complete. Much appreciation goes to Rebecca Brinkley, Grand Valley State University Graduate Assistant, who spent many hours researching, coordinating, and formatting information for the plan. Additional thanks to the Center for Educational Networking (CEN) for the final design and layout of the document.

Michigan
Autism Spectrum Disorders
State Plan

Report to the Michigan Human Service Directors

November 26, 2012

To the Michigan Human Service Directors,

On behalf of the Michigan Autism Spectrum Disorder (ASD) State Plan Development Committee and Advisory Committee, we are submitting the Michigan ASD State Plan to the Department of Community Health, the Department of Human Services, the Department of Licensing and Regulatory Affairs, and the Michigan Department of Education. The focus of the state plan development committee was to study the national trends in ASD, review what is currently in place for individuals with ASD in Michigan, and make recommendations in the areas of system and service coordination, family involvement, early identification and intervention, educational services, adult services, healthcare, and training and professional development. The resulting plan is the product of a two year process that included representation of multiple perspectives from the ASD community to define key recommendations aimed at addressing unmet needs. The implementation of the plan recommendations provides the opportunity for both public service agencies and the private sector to coordinate efforts and focus not only on ASD but also broad issues that can benefit individuals with other developmental disabilities.

The committee members who dedicated many hours of service to the creation of this plan should be commended. They consistently demonstrated a passion to improve the availability of information and services for individuals with ASD and their families in Michigan. Many of these professionals and family members continue to serve as leaders in the community and will play important roles in ensuring that continual progress is made in meeting the recommendations put forth in the plan.

Information about the implementation of the Michigan ASD State Plan can be found on the Michigan Autism Council website.

Sincerely,

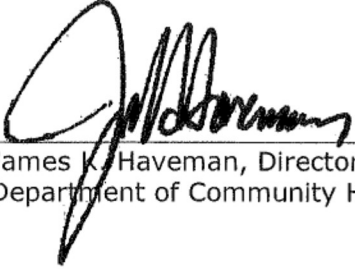


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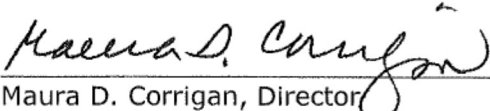
The following human service agencies have accepted the 2012 Michigan Autism Spectrum Disorder State Plan and agree to work collaboratively with the Michigan Autism Council to implement the plan.



James K. Haveman, Director
Department of Community Health

Feb 1, 2013

Date



Maura D. Corrigan, Director
Department of Human Services

Feb. 12, 2013

Date



Steve Arwood, Acting Director
Department of Licensing and Regulatory Affairs

2/6/13

Date



Michael Flanagan, State Superintendent
Michigan Department of Education

12-26-12

Date

Table of Contents

5

Executive Summary	6
Introduction	9
Background and Purpose	9
Autism Spectrum Disorders (ASD)	11
Evidence-based Practices (EBP)	12
Developing the State Plan	14
Focus Area: Infrastructure—System, Service, and Resource Coordination	16
Summary of Area	16
Key Findings in Michigan	18
Recommendations	19
Focus Area: Family Engagement and Involvement	22
Summary of Area	22
Key Findings in Michigan	23
Recommendations	25
Focus Area: Early Identification and Intervention Services	26
Summary of Area	26
Key Findings in Michigan	28
Recommendations	30
Focus Area: Educational Supports and Services	32
Summary of Area	32
Key Findings in Michigan	34
Recommendations	36
Focus Area: Adult Supports and Services	38
Summary of Area	38
Key Findings in Michigan	39
Recommendations	44
Focus Area: Physical, Mental, and Behavioral Health Care	46
Summary of Area	46
Key Findings in Michigan	47
Recommendations	49
Focus Area: Training and Professional Development	50
Summary of Area	50
Key Findings in Michigan	51
Recommendations	52
Fiscal Resources	54
Committees	55
Glossary	58
References	63
Appendix 1	
Appendix 2	

Overall Goal

Build the state infrastructure for comprehensive, lifespan supports to individuals with ASD and their families through access to information and resources, coordination of services, and implementation of evidence based practices.

This summary describes the major findings and recommendations for a plan to enhance the Michigan system of care for supporting individuals with an autism spectrum disorder (ASD) in their homes, schools, and communities. These findings and recommendations represent a synthesis and prioritization of goals with a primary focus on evidence-based practices and system and service coordination that brings together governmental agencies and private organizations. Expanding capacity to address the challenges presented by a rapidly growing ASD population does not mean the creation of a separate system of care specific to ASD but rather increasing the knowledge, coordination, and capacity of current systems in concert with focused attention on the specific needs of individuals with ASD.

The U.S. Centers for Disease Control and Prevention labeled ASD an "urgent public health concern" as the prevalence rate increased across the country to one in 88 children. It is imperative to understand the long-term implications of the identified needs of individuals with ASD given the major fiscal crisis if they do not receive adequate services. Lifetime costs for a person on the spectrum are estimated to be \$3.2 million, including costs for education, home and community-based services, and lost individual and family income (Ganz, 2007). However most important is the long-term impact on individual lives and the lives of family members if effective services and supports are not provided from a young age and throughout adulthood.

The state plan development committee believes that implementation of the recommendations will make a substantial difference in the lives of individuals with ASD and their families and will avert significant financial costs to the state. Gaps in services result from systemic challenges across service systems that affect a broader population of individuals with disabilities, and addressing these systemic challenges will benefit the broader populations served by the systems. Meeting the needs identified in this plan will require efforts at all levels of government and across public and private sectors. It is the hope of this committee that this plan will prompt further collaborative discussions and efforts to address the needs of all individuals with ASD in Michigan.

The recommendations outlined in the final state plan document:

1. reflect critical gaps and problems described by parents and professionals;
2. emphasize coordination of current systems of care;
3. promote increased access to knowledge, information, and skills;
4. promote greater awareness, availability, and implementation of evidence-based practices;
5. expand opportunities for individuals with ASD and their families to be fully engaged in their communities;
6. endorse systemic change that would benefit individuals with ASD as well as individuals with related disabilities.

Summary of Key Findings

Michigan currently lacks the following critical components for an effective state system of services and supports to individuals with ASD and their families:

- A state level Autism Council focused on ASD.
- A state center responsible for information dissemination, coordination of training and technical assistance efforts, and referral for services.
- Best practice guidelines for educators and service providers.
- Broad access to comprehensive diagnosis that is timely, affordable, and accurate.
- Service systems, including medical, human service, and educational systems, that demonstrate

effective coordination and communication so families can navigate between agencies and service providers.

- Consistent educational programming statewide that focuses on access to the least restrictive environment, the general education curriculum, and supplemental services that address the core deficits of ASD.
- Access to professionals, service providers, and community workers with training in evidence-based practices in all areas of the state.
- A sufficient number of service providers with experience and training in effective strategies to address significant behavior challenges and crisis situations.
- Availability of parent training and information focused on effective strategies for teaching and supporting a child with ASD.
- Sufficient access to employment, post-secondary education, housing options, leisure and community-based social activities, and transportation.
- A data system to assess the service needs and outcomes for individuals with ASD in the state.
- Adequate funding to support needed programs and services.

Recommendations for Immediate Action

The committee reviewed the recommendations from each section of the document and selected the following as the most critical issues that require immediate action:

- 1. Autism Council:** Michigan needs an Autism Council focused on the implementation, monitoring, and updating of the state plan to ensure that the key recommendations outlined in this document and future state plan updates become reality for individuals with ASD and their families. Therefore, the state plan recommendations will serve as the Autism Council's primary agenda. The Autism Council should be comprised of a broadly representative group of professionals, parents, and community stakeholders.
- 2. Autism Spectrum Disorders and Related Disabilities Resource Center for Michigan:** Establish a state center to serve as an information and resource clearinghouse for professionals and families and to assist in accessing and navigating programs and services related to ASD. The center would ensure that professionals, families, and individuals with ASD receive information about evidence-based and promising practices. The center should be linked to and integrated with existing resources.
- 3. Service Coordination and Statewide Infrastructure:** Improve service coordination and promote interagency agreements across all service systems. Establish standards of practice to be used by all agencies that function in a lead service coordination role. Individuals acting as service coordinators/case managers should be knowledgeable about ASD.
- 4. Regional Collaboratives:** Expand existing regional partnerships to promote communication, collaboration, and coordination efforts across all agencies, organizations, and key stakeholders. Regional collaboratives would serve as planning groups for training and resources within their catchment areas and as points of contact between the Autism Council, local service providers, families, and other stakeholders.
- 5. Early Screening, Evaluation, and Intervention for Young Children With ASD**
 - a. Increase screening by primary care providers, public health clinics, and early childhood providers such as Early Head Start.
 - b. Establish standards of practice and procedures for identification and referral.
 - c. Ensure that all young children with ASD receive systematic programming using evidence-based practices at a level of sufficient frequency and intensity to produce measurable gains.
 - d. Develop cross-agency, cross-program policies and procedures to coordinate available public and private resources to promote early screening and evaluation, referral to services, delivery of evidence-based interventions, and service coordination.

- e. Make high quality informational resources more readily accessible to families and providers.
 - f. Increase public awareness and available information related to the signs and symptoms of ASD, the importance of early identification on future outcomes, and procedures to access a medical diagnosis and special education eligibility evaluation.
- 6. Best Practice and Service Navigation Guidelines:** Develop and disseminate best practice guidelines for ASD identification and intervention across all age groups.
- 7. Crisis Intervention:** Address the shortage of both in-home and hospital/clinic-based crisis intervention services for children and adults with ASD in all areas of the state. This should include increasing the number of trained professionals and health care centers capable of implementing evidence-based interventions for addressing significant challenging behaviors.
- 8. Training and Professional Development:**
- a. Expand evidence-based, high quality pre-service and in-service professional development, technical assistance, and mentoring opportunities to ensure that Michigan has providers who are able to support individuals with ASD to be fully included in all aspects of their community.
 - b. Ensure that institutions of higher education and state sponsored trainings utilize the literature on evidence-based practice as the foundation for pre-service and in-service professional training.
 - c. Encourage universities to train more students in shortage areas, such as applied behavior analysis, to increase the number of these providers in schools, mental health settings, and adult service agencies.
 - d. Increase the availability of relevant training to key community members who encounter individuals with ASD such as first responders, bus drivers, and child and family service workers.
- 9. University Collaboration and Coordination:**
- a. *Research Coordination:* Plan a summit of university faculty conducting research in the area of ASD to discuss options for the coordination of research efforts and to seek federal grant funding that impacts both national and state efforts on behalf of individuals with ASD.
 - b. *Pre-service training for education and health care professionals:* Plan a summit of university faculty providing pre-service training to pre-professionals in education, health care, and the social sciences to discuss ways to infuse ASD specific information into pre-service curricula across education and the medical and social sciences.
- 10. Data system:** Create a centralized database for identifying the needs and outcomes of individuals with ASD in the state to assist state agencies in policy and service planning across the lifespan.
- 11. State Plan Review, Report, and Update:** The Michigan ASD State Plan should be reviewed and updated in three years to measure progress and establish future goals.

Background and Purpose

Historically, autism spectrum disorders (ASD) were misunderstood and rarely diagnosed, yet recently, the U.S. Centers for Disease Control and Prevention labeled ASD an “urgent public health concern” as the prevalence rate increased across the country to one in 88 children. As the number of people being diagnosed with ASD in Michigan continues to grow at rates consistent with national data, it is now essential that the medical, educational, and human services communities rethink and transform the way we serve this increasing population. Although changes have occurred on behalf of children and adults with ASD in Michigan, the pace and amount of change has been insufficient to meet the growing needs. In Michigan, we have no agency or organization charged with coordinating ASD services, collecting data specifically related to ASD, or assessing the needs of the numerous individuals with ASD in Michigan.

Based on statistics from the U.S. Department of Education and other governmental agencies, the number of individuals diagnosed with ASD has been estimated to be growing nationally at a rate of 10 to 17 percent a year. Data from the Michigan Department of Education indicates that in 1990, 1,203 children between the ages of birth to 26 identified with ASD were receiving special education services, whereas by January 2011, 15,976 children were receiving services under the ASD eligibility label (see Appendix 1). Given the absence of a comprehensive public registry, the true number of individuals with ASD in Michigan beyond the identified school population labeled with ASD is unknown.

The growing number of individuals with ASD poses a significant challenge to Michigan’s schools and human services providers. Most services for individuals with ASD are provided through schools, primarily in special education, and through various public local community mental health service programs. As the number of individuals with ASD has increased, some schools and agencies have developed their programs and expertise to meet the needs of individuals with ASD. However there is considerable variability around the state in the availability of effective programs and services. Despite the beneficial programs and services that some individuals with ASD in Michigan now receive, on the whole, Michigan is struggling with inadequate fiscal and other resources to serve individuals with ASD. The systems are overwhelmed by the magnitude of this growing population given the complexity, intensity, and economic costs of services needed throughout their lives. Across the state, families, providers in state service systems, and private providers report there are significant gaps in programs, services, and funding for individuals with ASD and their families. There is an urgent need for comprehensive planning, preparation, and resources across the service systems to meet the full range of needs that exist throughout the lives of individuals with ASD.

The Costs of ASD

The age distribution of individuals with ASD has been studied in California, which has kept some of the most detailed epidemiology data on this disability. Studies show that 85 percent of those with “full spectrum autism” are under the age of 21, 78 percent are under the age of 18, and more than a quarter of children with ASD served by their state’s developmental services system are between the ages of 6 and 9 (California Dept. of Developmental Services, 2008). The CDC has found incidence rates, and therefore age distribution, to be relatively uniform across the country. Michigan, along with the rest of the nation, can expect a large surge in demand for services as each successive wave of children with ASD ages into adulthood.

Lifetime costs for a person on the spectrum are estimated to be \$3.2 million over the person’s life, including costs for education, home and community-based services, and lost individual and family income (Ganz, 2007). The costs of services for individuals with ASD and the role of private insurance in meeting those costs is a current public health policy issue that is fast evolving and national in scope. Many families report significant difficulty accessing ASD services through their private health insurance. However multiple research studies document that investment in intensive, early treatment will reduce more costly long-term expenses such as the level of need for school-funded special education services and long-term support including job training, Medicaid, and adult day programs.

Ganz (2007) indicates that most of the lifetime costs for an individual with ASD are incurred after the age of 21. Intensive early intervention has the potential to reduce long-range costs therefore we need to

prioritize intensive intervention in early childhood and allocate the necessary resources for implementation of effective interventions. Not only is this in keeping with what we know to be best practice, there is considerable evidence that early intervention is cost-effective as it reduces financial costs while improving the quality of life for individuals and their family. A 1998 study by Jacobson, Mulick, and Green estimated that a three-year investment in Early Intensive Behavioral Intervention would produce considerable savings by lowering support costs during adulthood. Similar findings were reported by Chasson, Harris, & Neely (2007) in their analysis of costs in Texas.

Services and Systems

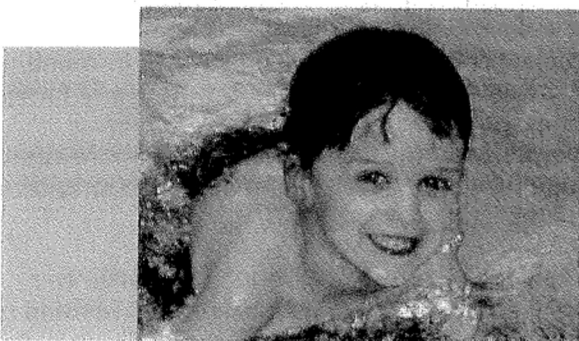
In seeking services for individuals with ASD, families experience problems with access to services, including inconsistent coordination of services across systems of care. Systems have different eligibility, assessment, and service requirements and practices, which can be difficult for families to navigate as they try to obtain comprehensive care. Families can experience difficult transitions across systems and programs many times during their child's life, such as when the child transitions from early childhood to elementary school and during transition to adulthood. While systems are expected to collaborate and plan ahead for achieving successful long-term outcomes for individuals across their life span, especially during times of major transition, more deliberate collaborative planning is needed.

One challenge is the degree to which treatment and support of those with ASD cuts across numerous service delivery systems, including health care, early intervention, education, vocational rehabilitation, and community services. In addition, there is no easily accessible mechanism by which providers from different systems can come together to create a coordinated plan of care. Michigan should look to primary prevention models that focus on early supports and ongoing monitoring as a means of avoiding costly, crisis-driven interventions. Additionally, the state must consider a cost effective means of bringing interdisciplinary teams together at the local and regional level to consider individual programming as well as service system coordination.

The gaps in service are often greatest for families and communities that are already impacted by various other challenges. In particular, families with cultural and language differences, families from low socioeconomic status, or those who have limited services available due to living in rural areas or distressed communities may experience significant gaps in service provision. A family facing such challenges is especially unprepared for the personal and economic crises involved in supporting a child with ASD and often lacks the resources for strong advocacy to obtain what they need. Needs of underserved populations must be met to ensure that no individuals, families, and communities are left without access.

Public Health Issues Across the Lifespan

Programs and services for adults with ASD face the greatest challenges. Existing programs and services across the systems of care must be expanded and reformulated to meet the unique needs of this population, particularly in light of the large number of persons with ASD who will enter adulthood in the upcoming years. The broad array of community services available to persons with disabilities often does not take into account the unique characteristics of people with ASD. Therefore developing appropriate models of service sensitive to the needs of people with ASD is critical. Like other complex public health issues, the exponential increase in ASD warrants a comprehensive public and private led public health



initiative and infrastructure to accomplish key goals to improve programs, services, and outcomes for all individuals with ASD in the state of Michigan.

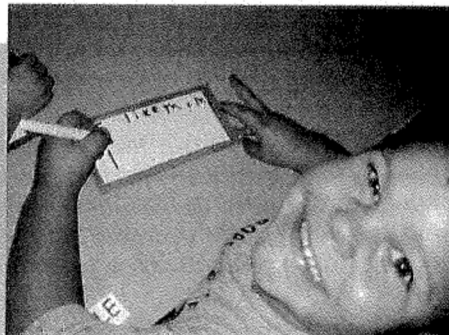
Autism Spectrum Disorders (ASD)

Autism Spectrum Disorders (ASD) are complex neurobiological disorders that present varying degrees of impairment in communication skills, social interactions, and restricted, repetitive, and stereotyped patterns of behavior, among other behavioral and physiological symptoms (CDC, 2011). ASD occurs in all racial, ethnic, and socioeconomic groups, and on average occurs four times more often in males than in females. The "autism spectrum" refers to the continuum of symptom severity and expression that individuals with ASD can experience. How ASD is manifested and how severely it affects one's life is distinct for each individual. As the word "spectrum" implies, individuals diagnosed with ASD are each unique. They may be extremely verbal or entirely nonverbal. Although everyone with an ASD has challenges in certain areas, some might be gifted in other areas. Although the exact cause of ASD remains unknown, research is revealing there may be multiple factors that contribute to the disorder, which would explain its variability. Scientists have uncovered a genetic basis for ASD including a higher risk for ASD among siblings (Ozonoff et al., 2011).

At present, there is no cure for ASD, and many individuals with ASD will need lifelong supports and services. Having an ASD significantly impacts a person's ability to function in his or her home, school, and community due to challenges in communication, learning, and forming relationships. Many individuals with ASD have other disabilities, such as intellectual impairment or emotional or behavioral disorders, which impair their overall level of functioning. Additionally, those with ASD frequently experience other chronic medical conditions, including immune system and gastrointestinal disorders, seizure disorders, and/or psychiatric conditions such as anxiety and depression. Any single individual with ASD will have a unique mix of symptoms within a complex array of ASD and coexisting conditions, which may change over time. Although there is no cure, educational programs and specialized interventions can lead to meaningful improvements for individuals with ASD (National Research Council Report, 2001).

There is no medical test for ASD. Typically, a medical diagnosis is made after a thorough evaluation by a qualified team of professionals. Such an evaluation might include clinical observations, parent interviews, developmental histories, psychological testing, speech and language assessments, and the use of one or more ASD diagnostic tests such as the Autism Diagnostic Observation Schedule (ADOS). Although symptoms can sometimes be recognizable at 18 months or even earlier, many children are not diagnosed with autism until a later age. Early identification should lead to early treatment, which is critical for optimal long-term outcome.

Access to appropriate screening, treatment, education, and life skills training is critical to the goal of ensuring that everyone with an ASD has the opportunity to live a full and productive life. However at this time the long-term outcome for individuals with ASD is often poor for those who do not receive adequate services. "A review of the current literature on outcomes for adults with ASD indicates that, independent of current ability levels, the vast majority of adults on the spectrum are either unemployed or underemployed and, further, that large numbers of adults with autism remain without any appropriate services" (Gerhardt & Lainer, 2011, p. 37). The Easter Seals study (2008) found that 79 percent of children with autism are living at home beyond age 18, and only 17 percent have friends in their community. Of the parents surveyed, 79 percent were extremely or very concerned about their child's



future independence. Individuals with ASD who are able to communicate their experiences report that it is difficult to find a job and live independently as an adult. And even adults with a college degree said they were unable to find employment. A number of adults reported having additional mental health problems such as depression or anxiety as a result of their challenges in life.

Research also confirms that ASD has a significant impact upon the lives of parents, siblings, and family systems as a whole. Families caring for their children with ASD experience significant stress. Caring for a child with ASD includes many extra responsibilities beyond typical child care including: more frequent medical/clinical appointments; frequent meetings with and training of school staff, specialists, care providers, and medical professionals; coordinating care with multiple providers; researching, applying for, and managing support services; ongoing advocacy; significant caregiving; direct teaching of their child; and supervision for safety. In contrast to parents of typical children, parents of children with ASD and other disabilities appear to be at greater risk for depression, anxiety, social isolation, fatigue, and frustration (Hastings & Beck, 2004). Some research also indicates that the presence of ASD places couples at risk of divorce (Hartley et al., 2010), which is, in turn, associated with a decline in the standard of living for one or both households.

Evidence-Based Practices (EBP)

Experts agree that treatment should be tailored to address the needs of the individual, and no single intervention is best for every person with ASD. Research indicates that some interventions have a high degree of efficacy for addressing the learning and behavior needs of individuals with ASD. An urgent concern is the lack of education and training on evidence-based practices (EBP) and promising approaches for ASD detection, education, and treatment to empower parents, educators, primary care providers, speech and language therapists, occupational therapist, behavior therapists, and other professionals and paraprofessionals to best serve this population. Evidence-based practices and cutting-edge research findings are utilized by specialists in ASD at leading medical centers, universities, and comprehensive educational programs. However, this information may not be widely available to or used by the vast majority of direct service providers who help most persons with ASD in the home, at school, and in other community settings.

A dramatic increase in the number of individuals diagnosed with autism spectrum disorders coupled with greater access to non-established treatment methods has created a critical need for better understanding and dissemination of EBP. The goal of the EBP movement is to provide families and service providers with clear, concise information about the strength of research supporting different treatment options. Effective interventions are based on sound theory and supported by empirical data. The research literature uses a variety of terms to refer to these practices, including Empirically-Supported Treatments, Empirically-Validated Treatments, and Evidence-Based Treatments. These terms all refer to interventions for which there is replicated research published in peer-reviewed scientific journals demonstrating their effectiveness. For the purposes of the Michigan ASD State Plan, the term EBP will be used to refer to these practices.

Professionals from a variety of scientific fields have repeatedly concluded that implementation of EBP is critical. Life and health in America has been profoundly improved over the past 50 years by the use of medical practices demonstrated effective in randomized controlled trials. These research-proven practices include vaccines for polio, interventions for hypertension, and cancer treatments that have dramatically increased survival rates from many types of cancer. Similarly, welfare policy has been remarkably successful in moving people from welfare into the workforce and has been guided to a large extent by scientifically-validated knowledge about effective practices. Interventions for individuals with ASD must be founded in the same quality of research that is expected from these other fields.

Within the field of education, the federal No Child Left Behind Act of 2001 set the stage for EBP by having K-12 educators use "scientifically-based research" to guide their decisions about the interventions they implement. Moving forward, continued efforts are needed to support the implementation of evidence-based practices within school systems. According to research, those teaching strategies that have been researched are often difficult for teachers to access and implement (CEC, 2011). So, while the educational

field is increasingly emphasizing the importance of research, policies and guidelines to facilitate the implementation of these practices are still emerging.

In the first decade of this century, the field of ASD saw a rapid growth in the number of reports and articles identifying EBP. In 2001, the National Research Council published a report examining the scientific, theoretical, and policy literature regarding young children with ASD. The final chapter of this report included recommendations for practice based on a review of the literature. Other more recent reports by the National Autism Center's (NAC) National Standards Project and the National Professional Development Center on ASD also identified effective, research-validated practices for individuals on the spectrum. The NAC website offers an extensive manual that outlines eleven EBPs, and the NPDC website provides module briefs and checklists that facilitate the implementation of 24 EBPs.

- National Autism Center's National Standards Project
www.nationalautismcenter.org/about/national.php
- National Professional Development Center on Autism Spectrum Disorders
<http://autismpdc.fpg.unc.edu>

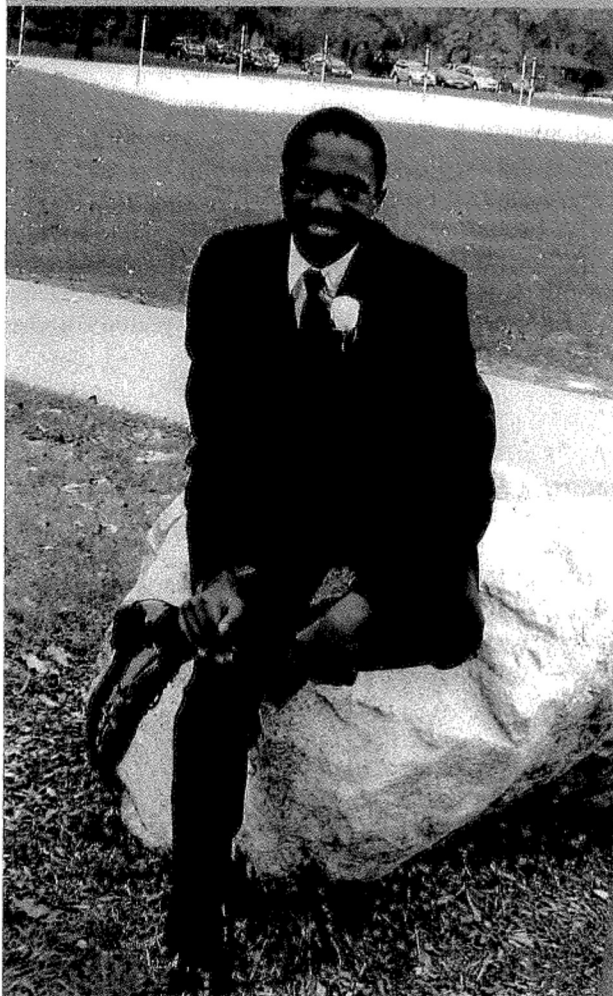
Other peer-reviewed journal articles provide similar reviews of EBP for practitioners and families who are interested in gaining information on this topic (Iovannone et al., 2003; Odom et al., 2003; Simpson, 2005), and recently, several books have also been published that examine evidence-based practices in the field of autism (Luiselli, Russo, Christian & Wilczynski, 2008; Reichow, Doehring, Cicchetti & Volkmar, 2011).

Determining Evidence-Based Practices

Determining EBP is a complicated process, and these complexities have been discussed at length by several authors (e.g. Shea & Mesibov, 2011; Reichow, Volkmar & Cicchetti, 2008). Nonetheless, there are many consistencies in the processes adopted in the reports cited above. In each, researchers reviewed a body of research on interventions for individuals with ASD and classified the individual studies based on quality indicators and outcomes. Many of these researchers distinguished between studies that used randomized controlled trials and those that used other types of experimental designs, such as single subject design. They also examined other criteria, such as the number of studies evaluating the practice, the number of participants involved, and whether studies were conducted by independent research groups. After accounting for outcome data, the result was the designation of practices that were "efficacious," "well-established," "promising," or "emerging" with particular terminology being dependent on the language adopted by the individual researchers. Although this process was fairly similar across research groups, many researchers used individualized criteria to determine the practices they identified as evidence-based in their reports and publications. Consequently, although there exist guidelines from a number of books, journal articles, and websites authored by national projects or associations (e.g., the National Standards Project, the National Professional Development Center on ASD, the American Psychological Association), there has not yet been universal adoption of a "gold standard" set of evidence-based practice guidelines for individuals with ASD. Furthermore, the guidelines that have been identified thus far often focus on particular age groups, for example, younger children, or practices implemented in particular settings, such as in schools. To date, there has been only limited attention directed toward the identification of EBP for adults on the autism spectrum.

Selection and Implementation of EBP

As our general knowledge about the practices that qualify as EBP continues to improve, the field must shift direction, focusing more carefully on the next crucial steps in the process. These include identifying the particular EBP that would most appropriately meet the needs of an individual student and evaluating the fidelity of implementation of EBP in schools, home, and community settings. Educators and service providers must carefully identify and implement EBP through balancing professional judgment, knowledge of the individual characteristics and strengths of the person with ASD, and evidence regarding the domains for which these practices have been supported. Decisions about EBP should be based not only on available evidence of what are effective practices, but also on knowledge of an individual's presenting symptoms



and personal and family preferences that might allow that practice to be most successfully implemented within his or her life context.

According to Odom (2009), implementation is the link between science and outcomes. As a field, we must rapidly focus beyond mere knowledge of EBP and emphasize implementation of EBP. This requires the understanding that randomized controlled trial research on interventions typically occurs under ideal conditions, with high levels of funding, clinical expertise, time, personnel, and material availability. These conditions are often not possible in the more natural context of traditional intervention settings. True implementation of EBP requires that consultation and support are available to families and practitioners in natural settings. This process also requires thoughtful and reasonable data collection practices that allow families and professionals to accurately evaluate the benefits of the practice for the individual. Although awareness and understanding of effective practices is critical, successful implementation is necessary to improve quality of life outcomes for individuals with ASD and their families.

Developing the State Plan

Based on the growing number of individuals with ASD in Michigan, it was determined that the state needed an ASD focused strategic plan to guide future planning, decision making, and resource allocation. In August 2009, the state human service directors approved the development of a Michigan ASD State Plan, and the Michigan ASD

State Plan Development Committee convened an initial meeting to outline the work of developing the state plan. The primary goal of the state plan was to identify current best practice in supporting individuals with ASD of all ages, review current practice in Michigan across key priorities areas, identify gaps between best practice and current practice, and make recommendations for improving services and outcomes for individuals with ASD and their families. The ultimate goal of this plan is to create a solid understanding of needs in order to identify, access, and coordinate resources for all individuals with ASD, birth through adulthood, across the state of Michigan. The final plan offers summaries, findings, and recommendations to parents, educators, legislators, professionals, and any other individual or group who has an interest in ASD.

The Michigan ASD State Plan Development Committee and the State Plan Advisory Committee together were comprised of 51 individuals including parents, adults on the autism spectrum, educators, agency/organization professionals, health care providers, university faculty, state grant project staff, and state government personnel. The Development Committee took the lead role in researching and writing the plan while an extensive group of parents and professionals were recruited to serve on subcommittees and as reviewers of the plan. Data used in the preparation of the plan were gathered from a variety of sources including literature reviews, other published reports and recommendations, parent and professional surveys designed and disseminated by the Development Committee, public input, and expert opinion. For the state plan survey, family members and school professionals were surveyed separately using Survey Monkey, an online survey tool. A total of 312 family surveys and 612 school professional surveys were completed. Key information from the survey is presented in appendix 2.

The Michigan ASD State Plan represents Michigan's first key step to establish an evidence-based focus on lifespan services for all individuals with ASD in Michigan. It is clear that much work remains to be done beyond the development of this initial plan. Given the large number of recommendations generated by this process, the committee had to prioritize issues for immediate action, leaving other issues for future work. Michigan must now begin to expand its capacity to address the challenges presented by a rapidly growing population of individuals with ASD. This does not mean the creation of a separate system of care specific to ASD, but rather increasing the capacity and the knowledge within our existing systems with more systematic coordination of efforts.

The findings and recommendations are divided into the following sections:

1. Infrastructure—System, Service, and Resource Coordination
2. Family Engagement and Involvement
3. Early Identification and Intervention Services
4. Educational Supports and Services
5. Adult Supports and Services
6. Physical, Mental, and Behavioral Health Care
7. Training and Professional Development

Focus Area: Infrastructure—System, Service, and Resource Coordination

Overall Goal

Build the state infrastructure for comprehensive supports that benefit individuals with ASD and their families by improving access to information and resources and increasing system coordination at the local and state level.

Summary of Area

The following systems are critical to establish an infrastructure leading to improved system coordination at the state level: 1) comprehensive planning and collaboration, 2) cross-agency service coordination, and 3) access to information and training based on assessment of needs.

State Level Coordination and Collaboration

Because of the rapid increase in the number of individuals being identified with an autism spectrum disorder (ASD), the complexity and diversity of their needs, and the pressure on the existing education and social service systems, a more thoughtful, coordinated approach to service delivery and funding is necessary. A systematic review of existing service systems is needed to identify ways to coordinate the delivery of services in schools, provider agencies, rehabilitation services, and all other key stakeholder organizations. Children who have been recently identified with ASD will become adults in the next 5 to 15 years and the current adult service systems are unprepared for the wave of young people who will require numerous supports to become engaged members of their communities. The successful implementation of any state plan hinges on a comprehensive state system with strong leadership, coordinated efforts at the state and local level, community focus, and a clear vision. Any model for system and service coordination must be inter-disciplinary and inclusive of individuals with ASD and their family members.

Currently, the majority of services available to individuals with ASD are provided through the school system, local community mental health service programs, and university or medically based programs. Service systems need to work together to address the needs of individuals with ASD. Otherwise, accessing services can become a complicated process for parents and professionals to navigate. Parents of children with ASD report that locating services, understanding service options and needs, and applying for services are difficult at best. Some families do not have the resources or knowledge to conduct searches for services and they may never access available resources or may experience confusion regarding which services are important. Even when services are identified, families may experience long waiting periods before services are started or may need to travel long distances to obtain them.

Systematic collaboration and coordination is important because the multifaceted needs of individuals with ASD often cannot be addressed entirely by one program or agency. Limited financial resources in most states necessitate true collaboration to make major changes and capitalize on existing systems. Greater awareness and coordination among agencies and stakeholders will result in appropriate and cost effective services. Collaboration changes the way organizations work. Collaboration leads to less competition and more consensus; less working in isolation and more inclusion of others; less thinking about specific activities, services, and programs and more thinking about larger results and strategies (Ray & Winer, 1994). Collaboration occurs when people are brought together to achieve common goals that could not be accomplished by a single individual or organization working independently. Without collaboration, states cannot take full advantage of the expertise and skill currently available, leading to unnecessary redundancy.

One model by which higher level collaboration can occur is through the development of regional partnerships or collaboratives that create opportunities for stakeholders to connect. A state with established regional partnerships or collaboratives creates opportunities for stakeholders to share information, resources, ideas, and training, which allows for a synergistic growth of possibilities. Numerous small initiatives being implemented around the state can be shared, expanded, and scaled up to the state level through regional collaboratives. A number of other states have reorganized their

systems and developed collaborative networks to better coordinate services and share information and resources.

Service Coordination

Many individuals with ASD require lifelong services and supports in order to live and prosper in community settings. How ASD is manifested and how severely it affects a person's life is unique for each individual and will change across the lifespan. This complexity and variability poses challenges for service coordination. For each individual with ASD there is a need to develop a coordinated plan of care that cuts across the lifespan and home and community environments. Service coordination is a foundation of family-centered care in child disability services because integrated and coordinated support services to children and families are integral to effective service provision (Bruder, 2005; Dunst & Bruder, 2002). Typically, there isn't a single lead agency to provide service coordination across the lifespan for individuals with ASD. In Michigan, the lead agency for services, and thus the service coordinator, is associated most often with the age of the individual: infants and toddlers are served through *Early On*[®] programs, school age children are served by education, and adults are served through the mental health system or rehabilitation services. In reality, while there is an age-specific lead agency, multiple agencies may provide services at the same time, depending on the needs of the child and family. Because of confidentiality/*Health Insurance Portability and Accountability Act* (HIPAA) regulations, health care services are often provided independent of education and community services resulting in confusion for individuals and families. Many families experience difficulties in identifying the services and supports they need, determining where they can find these resources, and accessing them easily (McLennan et al. 2003).

While the individual and family may have a coordinator or a case manager through the age-specific lead agency, often there is limited or no integration of services across agencies when individuals and families are served by multiple agencies and programs. Each of these programs has different criteria for assessment, determination of eligibility, services, and funding. The complexity of today's service systems makes it necessary to provide high quality service coordination as an option for families. The primary goals of service coordination are: 1) to assist families in gaining ready access to information and resources and 2) to locate services to address current needs (Halfon et al. 1993). Access to coordinated and comprehensive care is associated with higher satisfaction with services, reduced stress, and better emotional well-being on the part of parents, particularly for children who have chronic conditions (King, King, & Rosenbaum, 1996).

We need a state autism task force so we can address and **solve issues** that plague the ASD community.

—Response from ASD
State Plan Survey

A disjointed service delivery system does not result in an efficient and cost effective utilization of resources. A lack of service coordination can cause gaps and duplication of supports and lost opportunities to deliver a seamless continuum of services. This lack of coordination also results in wasted time and money needed to meet the complex needs of individuals with ASD.

Centralized System to Access Information

To help families make informed decisions about needed services and how to access existing programs, they need a centralized, comprehensive, and accurate source of information. In particular, resources should include general information about ASD, research about various evidence-based treatment methods, guidance about available programs, and contact information for service providers and support groups. Other mechanisms to disseminate key information include best practice guidelines, service navigation manuals, a centralized website, and access to knowledgeable professionals and parents to provide information and answer questions. While these resources can be useful to all families, at times of transition such as at diagnosis and transition to adulthood, additional support may be needed such as a "Family or Systems Navigator." A Systems Navigator is a knowledgeable and unbiased individual who offers information, support, and assistance to families of individuals with ASD to identify resources, access services, and develop plans of action based on informed decisions. The Navigator model comes from other service systems such as the Patient Navigator in the medical system and numerous parent-to-parent

support systems available for children with various medical conditions or disabilities. A Navigator may be a professional or a parent with specific training necessary to support individuals and families. They help families not only overcome barriers to receiving services, but they also model effective advocacy within systems. Thus, families are taught and mentored to become advocates for their own services and supports.

An important element of accessing information is knowledge of what information is needed by families. At this time, families have few avenues for communicating their needs for information, programming, and service coordination. State-level data is needed to identify gaps in information and services to help pinpoint areas for further development.

Key Findings in Michigan

What Is Currently in Place?

- Many professionals and families in Michigan are committed to improving the lives of individuals with ASD as demonstrated through their efforts on committees, workgroups, associations, societies, and teams, as well as through their advocacy and leadership on policy and practice issues. In coordination with state-level agencies, professionals and parents are capable of implementing a comprehensive state plan to improve the state's services for individuals with ASD.
- Currently, information about ASD is available on Michigan-based websites such as the Michigan Alliance for Families, Autism Alliance of Michigan, the Statewide Autism Resources and Training Project (START), and various school district websites among others.
- The Developmental Disabilities Institute at Wayne State University is Michigan's University Center of Excellence in Developmental Disabilities. The Institute is federally mandated to serve families and individuals with disabilities statewide through education, community support, research, and information dissemination.
- The Michigan Developmental Disabilities Council is a Governor-appointed board whose mission is to support people with developmental disabilities to achieve life dreams. The Council achieves its mission through policy development as facilitated by community grants.
- Professionals function as service coordinators within systems such as *Early On*, school systems, community mental health, and Michigan Rehabilitation Services (MRS) although a standard of practice across systems is not in place. Through the Michigan Alliance for Families, many parents serve as mentors or navigators to other families in need of support.
- Regional Collaborative Networks (RCN) are established in every region of the state through the START Project. Each RCN links with the START Project to identify and expand the use of evidence-based practices, create training opportunities, and establishing local resources. Although the founding members of each RCN are school personnel, many have added other stakeholders such as parents and community partners to their membership. Members of the RCN meet on a monthly or quarterly basis to plan, train, and share. The representative members of the RCN then share information with their local district, agency, or parent group to implement systemic changes in how services are delivered to individuals with ASD. Each RCN has developed to meet the unique needs of their region and community, however all RCN share common key components, which could be expanded to include new activities.
- Recommendations for practice with young children with ASD were developed through a Michigan ASD workgroup comprised of state agency representatives, parents, and various public and private stakeholders. The ASD Planning Workgroup provided recommendations in five areas: Results/Outcomes and Indicators, Screening and Assessment Processes and Tools, Intervention Models and Processes, Fiscal Resources, and Training and Technical Assistance. Although these recommendations were released in 2007, many providers and parents are not aware of them.
- The state has several university and medically-based autism research and treatment centers. Many university faculty members in Michigan are conducting research related to ASD that has been beneficial to individuals with ASD both within and outside the state. Increased collaborative efforts amongst universities could help the state become more competitive for federal grant funding and achieve statewide scale up of research based practices.
- The Department of Health and Human Services and the Michigan Academy of Pediatrics have engaged

in efforts to promote the Medical Home model. Although Michigan currently has some medical homes, families could benefit from the addition of new medical home sites along with more training and preparation for existing medical homes serving individuals with ASD.

What Are the Gaps?

- In the Michigan State Plan Family Survey and the Michigan State Plan School Professional Survey, coordination and collaboration among families, schools, and service providers was identified as one of the top five priorities for the state.
- There is no centralized, sanctioned autism council, advisory body, or agency responsible for creating and managing a strategic plan or working to coordinate state activities for individuals with ASD and their families on an ongoing basis.
- Individuals with ASD and their families have difficulty in accessing and navigating programs and services because there is not a state center responsible for information dissemination, coordination of training and technical assistance efforts, and service navigation.
- Service systems, including medical, behavioral health, and education systems need better coordination and communication so families can navigate between various agencies and service providers. Eligibility requirements and services differ greatly depending on the system being accessed.
- *Early On*, the school system, medical homes, community mental health, and rehabilitation services act as service coordinators for their consumers. However each system defines their own roles and responsibilities in this function. A standard of practice and common roles and responsibilities are not defined for these lead agencies that coordinate and implement a system of care for people with ASD.
- Michigan lacks coordinated practice guidelines and service navigation manuals to guide parents, educators, and service providers in accessing information, identifying and implementing best practices, and locating services. Systems often overlap, creating duplication and sometimes conflicting information between agencies.
- Currently, Michigan does not collect complete data and information about individuals with ASD. A statewide system would assist in planning for needs and making policy decisions to formulate and deliver new services and guide the state plan for ASD. Without these data, it is difficult to determine funding needs or plan for services.
- State agencies are attempting to address the needs of a growing number of individuals with ASD and their families without adequate funding.

Recommendations

1. **Autism Council:** Michigan needs an Autism Council focused on the implementation, monitoring, and updating of the Michigan ASD State Plan to ensure that the key recommendations outlined in this document and future state plan updates become reality for individuals with ASD and their families. Therefore, the state plan recommendations will serve as the Autism Council's primary agenda. The Autism Council should be comprised of a broadly representative group of professionals, parents, and community stakeholders.

The structure of the Autism Council would include an executive committee, a council coordinator, and subgroups focusing on: early identification and intervention, adult services, family support, school based intervention and supports, health care, pre-service preparation, training and technical assistance, and research. The State ASD Autism Council should include representation from many

As a new to Michigan parent of a child with ASD, I am **continually lost** when trying to find resources for my child.

—Response from ASD State Plan Survey

stakeholder groups including: individuals with ASD; family members of individuals with ASD; state agencies including Michigan Department of Education (MDE), Department of Community Health (DCH), Department of Human Services (DHS), and the Department of Licensing and Regulatory Affairs (LARA); school systems including intermediate school district and local school district administration and personnel; *Early On* (Part C); transition coordinators; adult service providers; state funded projects serving individuals with ASD; health care providers; disability organizations; universities; medical centers; non-profits serving individuals with ASD; and policy makers.

The coordinator of the Autism Council would be associated with a state agency. The job description and selection would be coordinated between the funding agency and the Autism Council. A coordinator of the Autism Council would be responsible for working with the other members of the Autism Council toward the goal of implementation of the state plan to ensure that individuals with ASD and their families are provided services in a coordinated, comprehensive, and effective manner.

- 2. Autism Resources and Information Center of Michigan:** Establish a state center to serve as an information and resource clearinghouse for professionals and families and to assist in accessing and navigating programs and services related to ASD. The center would ensure that professionals, families and individuals with ASD receive information about evidence-based and promising practices. The key activities of the state center would include:

Resource and information dissemination

- Clearinghouse of information
- Information guides
- Calendar of state events
- Newsletter
- Research dissemination

Service access and support

- Service provider database
- Systems navigator

Outreach, training, and technical assistance through coaching

Establish training, technical assistance, and other support to families, providers and community members as well as regional collaboratives so they can inform, train, assist, and empower families in their region to access and navigate services.

- Conferences, workshops, webinars
- Intensive team training
- Training series
- Technical assistance for implementation of evidence-based practices
- Family to family mentoring

Provider/stakeholder communication network

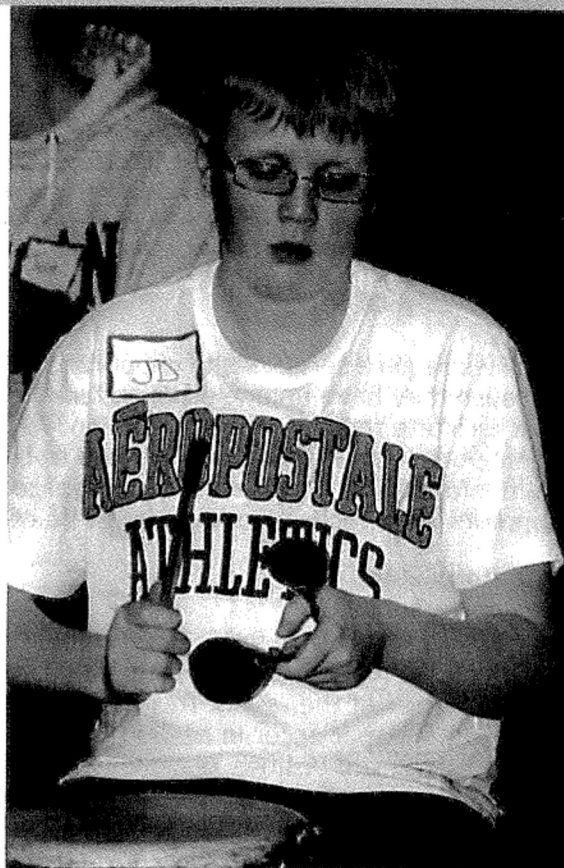
Facilitate a communication system to keep apprised of initiatives, activities, research projects and collaboration opportunities related to ASD in Michigan.

- 3. Regional collaboratives:** Create regional partnerships that promote communication, collaboration, and coordination efforts across stakeholders. Expand current START RCN to include greater representation from schools, provider agencies, community mental health, early childhood education services, Michigan Rehabilitation Services, health care providers, other relevant public and private agencies, and family support and advocacy organizations. Regional collaboratives will serve as planning groups for services within their catchment areas and as points of contact between the Autism Council,

I would like to see a collaborative community of parents and health and education professionals working together to provide **a continuum of services** and resources that ALL families can access to support their child with ASD.

—Response from ASD State Plan Survey

local service providers, families, and other stakeholders. Regional collaboratives will be charged with promoting a coordinated approach to service delivery, sharing information about successful practices, and working to address gaps in the service system. As part of a statewide network, these collaborative networks will be able to share information, maximize training and professional development opportunities, and coordinate efforts across regions.



4. Service coordination:

- Promote interagency agreements, collaborative planning time, training opportunities and other activities necessary to ensure collaboration and coordination of services and efficient use of funding.
- Clearly establish service coordination responsibilities to be used by all agencies functioning in a lead service coordination role such as *Early On*[®], special education teachers, medical home service coordinators, CMHSP providers, and MRS coordinators.
- Provide further training to professionals currently acting as service coordinators/case managers to expand knowledge of other programs and resources.
- Encourage the growth of the medical home model, especially in larger practices with multiple primary care providers.
- Train individuals with ASD and family members to become advocates and effective case managers.
- Improve service coordination in the adult service system by clarifying the roles and responsibilities of each public service agency such that services can be provided more consistently, efficiently, and in a coordinated manner both within agencies, and across agencies.
- Create an information system, such as e-portfolios, that allow family members and service providers working with an individual to share information.

5. Develop best practice and service navigation guidelines:

- Develop best practice guidelines for ASD identification and intervention.
- Develop a road map to navigating services for children age birth to 6.
- Develop a transition to adulthood road map (age 16 through transition to adulthood).
- Develop a lifespan community service and system guide.

6. University collaboration and coordination:

- *Research coordination:* Plan a summit of university faculty in Michigan who are conducting research in the area of ASD to discuss options for the coordination of research efforts and to seek federal grant funding that impacts both national and state efforts on behalf of individuals with ASD.
- *Pre-service training for educational and health care professionals:* Plan a summit of university faculty in Michigan who are providing pre-service training to pre-professionals in education, health care and the social sciences to discuss ways to infuse ASD specific information into pre-service curricula across education and the medical and social sciences.

7. Data system for identifying the number and needs of individuals with ASD in the state:

Create a centralized database for individuals with ASD to assist state agencies in developing policies and planning for services across the lifespan. Relevant areas of data collection might include: early childhood placements and outcomes, educational placements and outcomes, and adult outcomes in the areas of employment, post-secondary education, housing, social/leisure/recreation, and medical/physical health.

Overall Goal

Families will have easy access to comprehensive, relevant information and resources to address the needs of their child with ASD across the lifespan. Coordinated services will be available to meet the needs of the family and the child with ASD in order to promote the health and quality of life of the entire family.

Summary of Area

Families require services and supports that meet their needs throughout the life of their child with ASD. Because they have unique profiles, families benefit from supports that are individualized, and interventions that facilitate their active participation. At different points in the lifespan, families require different forms of supports, some of which may need to be provided in an overlapping fashion. These supports may range from informational resources, to specialized services, to financial and emotional supports. To ensure that supports are effective, services must be coordinated and integrated in the family context.

Family Needs

Families need services and programs that work within family lifestyles and include parents as active participants. Interventions must be evidence-based, and should accommodate the unique culture and character of the family. Researchers have found that parents who collaboratively participate in interventions that occur in natural environments, such as during mealtimes at home or in the local grocery store, show more positive responses and affect in their interactions with their children (Koegel, Bimbela & Schreibman, 1996). They also show increased self-confidence, and lower levels of observed stress when parents and clinicians collaborated to identify target behaviors and implement intervention strategies (Brookman-Frazee & Koegel, 2004).

Research has also highlighted other family needs, including practical and emotional concerns. Since there are many direct and indirect economic consequences of raising a child with a disability, practical needs, such as limited financial resources, may result in limited access to interventions such that family functioning may be impacted. Parents may also require relief from care-giving. Respite options that are both short-term (e.g., 2-3 hours in the evening), and more lengthy (overnight or week-long), may be beneficial (Hare, Pratt, Burton, Bromley, & Emerson, 2004). Additional research indicates that parents need programs that teach them to successfully manage challenging child behaviors in their homes and communities (Benson & Karlof, 2009), since reducing child behavior problems may reduce parent stress. Families might benefit from availability of services to address marital relationships (Brobst, Clopton, & Hendrick, 2009) and sibling relationships (Hare et al., 2004). Several researchers have proposed the need for even broader services that address psychological variables that families might experience, including parental depression and parental cognitions that might contribute to stressful emotions (Benson & Karlof, 2009; Hill & Rose, 2009; Kayfitz, Gragg & Orr, 2010). To foster better outcomes for their child with autism and maintain their own mental health, it is important to provide families with opportunities to enhance their confidence and competence.

Family Experiences

Parents are essential in the lives of their children and they have the greatest influence on their child's health, development, and well-being. However families with children with ASD often experience increased levels of stress in their daily lives, which can impact their child's progress and outcome (Hastings 2003; Lecavalier, Leone & Wiltz, 2006). Many issues, beginning with the process of diagnosis and continuing through the lifespan of the child with ASD may contribute to this outcome. For example, Brobst, Clopton and Hendrick (2009) found that couples with a child with ASD reported more child behavior problems, and identified lower levels of social support and relationship satisfaction than couples who did not have a child with ASD. In an interview study with 26 families of adults with ASD, parents reported that they felt their lives were restricted by the needs of their son or daughter with ASD, as manifested by reduced social opportunities or even considerations such as the location of the family residence (Hare, Pratt, Burton, Bromley, & Emerson, 2004). These parents generally expressed concerns about the future for their

children, citing anxiety about who would care for their children as they aged. Because of these significant stressors, parents of children with ASD may also experience negative psychological outcomes, including depression and anxiety (Bromley, Hare, Davison, & Emerson, 2004; Emerson, 2003; Hastings, 2003). In fact, recent data has suggested that parents may be at higher risk for depression if their child with ASD has co-occurring sleep problems (Meltzer, 2011), which is a commonly reported concern for many children on the spectrum (Wiggs & Stores, 2004). Consequently, parenting stress is an important area to consider in planning for the needs of individuals with ASD and their families.

Key Findings in Michigan

What Is Currently in Place?

- Michigan has numerous agencies that support families of individuals with ASD. These include state and federal parent support initiatives (e.g., Michigan Alliance for Families), universities, and medical centers responsible for diagnostic or treatment services, and local service providers from non-profit and private agencies. Additional services are provided through school systems and other government agencies. The frequency and intensity with which these providers directly support families varies. Furthermore, although a range of services are available, supports may be different based on geographic region, and families may not always know how to locate and access the specific supports that they require. In many instances, families have financial limitations that limit their ability to access necessary services.
- The Family Support Subsidy (FSS) program was established in statute in 1984 and is currently funded by federal monies. The FSS is accessed through the local community mental health service program and provides a monthly payment of \$222.11 to families with net incomes of less than \$60,000 who have children living with them who have severe developmental disabilities. Of the current recipients of FSS funds in Michigan, 4,695 families have children with ASD. Two particular issues seem to be impacting whether families of children with ASD are able to access these funds: 1) awareness of the program, and 2) eligibility based on school placement.
- The Supplemental Security Income (SSI) program for children is a financial program for families with low incomes and limited resources who have a child under the age of 18 with a disability that meets the Social Security Administration definition. Qualifying families may receive up to \$674 per month. Families who receive this income may also be eligible for Medicaid.
- Medicaid is a federally-funded, state-run form of health insurance that provides access to medical providers for individuals and families with limited incomes and resources. This program pays for health care costs, including doctor's visits and eye-care. Families can obtain Medicaid applications at their local Michigan Department of Human Services (MDHS) office and staff from MDHS will assist families to complete the application, if requested.
- MICHild is a health insurance program for uninsured children in Michigan. HMOs and other health care plans throughout Michigan provide MICHild services. Qualifying families pay a \$10 monthly premium without copays or deductibles. Information and application materials can be found at www.michigan.gov/michild or by calling 1-888-988-6300.
- Autism insurance legislation was passed in Michigan in April 2012, which will allow most families with insurance coverage to access services such as speech and language therapy, occupational therapy, applied behavior analysis, and diagnostic evaluations starting in October 2012.

We need more **ASD friendly activities** for kids, so they can enjoy things others do without being overwhelmed.

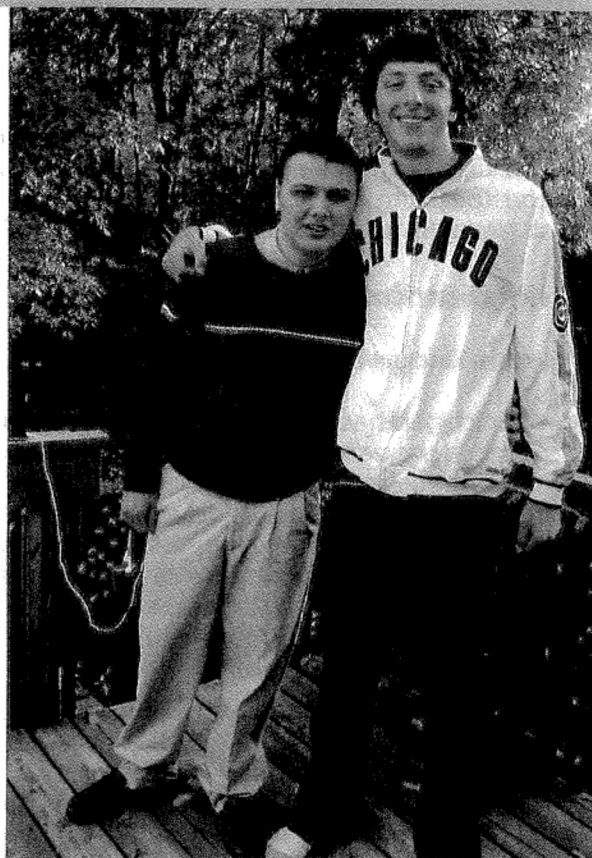
—Response from ASD State Plan Survey

What Are the Gaps?

- Families need information regarding diagnostic and evaluation services. Currently, families receive these services through a variety of sources, including local school districts, professionals in their local

communities, or staff in universities/medical centers. Given that there is no single point of entry, families may receive different recommendations regarding the evaluation process and subsequent services.

- Once their children are diagnosed, families need information and education regarding EBP for children with ASD, as well as high-quality, affordable intervention services in their area. Families may not always be able to identify providers implementing EBP in their region.
- Service providers may not take into account family needs and preferences when designing and implementing interventions. Consequently, families do not always actively participate in the process, limiting the likelihood that interventions will be implemented effectively in home and community environments.
- Service coordination is often limited, especially when multiple service providers are involved, such as when school-based, medical, and private service providers work with the same family.
- Providers and services that meet a range of family needs can be difficult to identify and are inconsistently available across the state (e.g., sibling supports, respite care, mental health services, community recreational opportunities, advocacy, etc.). The ability of families to access such supports may be limited by financial barriers or a lack of family awareness regarding local resources. Even when families are able to identify local providers who offer these critical services, the providers may not have specific training in ASD.
- Services for individuals with ASD who have significant behavioral challenges are in short supply. In some geographic regions, families may be able to hire behavioral consultants who develop behavioral intervention plans, but there may not be support and coaching to help implement these plans in natural settings. Short-term crisis placement services can be difficult to access. Professionals in hospital emergency rooms, law enforcement agencies, mental health settings, and psychiatric hospitals who encounter individuals with severe challenging behaviors are generally insufficiently prepared to handle the crisis needs of individuals on the spectrum.
- State Plan Family Survey Results:
 - » To determine family needs in Michigan, 312 parents, grandparents, and other caregivers of children with ASD responded to the ASD State Plan survey. The ages of the children with ASD described by the caregivers ranged from 2 years old to 40 years old. In the ASD State Plan Family Survey, families indicated that they had a variety of needs. Parents and caregivers were asked to identify up to six state priorities that would improve services for individuals with ASD and improve quality of life. Sixty-seven percent of parent respondents reported that they desired greater education and training for the school personnel who worked with their child, and sixty-three percent of parents felt that insurance coverage for ASD services was a critical area. Forty-nine percent indicated that the development of peer support programs was an important goal. Additionally, 49 percent of parents indicated that coordination and collaboration among families, schools, and service providers was a critical area of need in the state. Other topics endorsed by parents included: inclusion and access to general education (37 percent) and earlier diagnosis and referral (37 percent).
 - » Family survey participants were also asked to indicate their top three most challenging aspects of life with their child with ASD. Seventy-seven percent of respondents reported emotional challenges, and 63 percent indicated financial challenges. Thirty-three percent reported challenges in finding time to work on teaching skills to their son or daughter with ASD.



- » Families also identified a number of services for which they desired to have greater access. The specific priority areas of services differed depending on the age of their child and the region of the state in which they lived. The primary services needed by parents of children ages 3-5 were recreational/extracurricular activities and non-school based summer program opportunities. The services desired by parents of children ages 6 to 12 were peer-supported social opportunities, and social skills instruction. For parents of children ages 13-18 and 19-25, the services they required were transition to adulthood services and peer-supported social opportunities. The dominant theme across all ages was social and recreational opportunities, which arguably lead to a more fulfilling life and connection with the community.

Recommendations

1. Create a comprehensive and accessible information clearinghouse that provides guidance to families regarding EBP and local and state-level ASD services. This resource clearinghouse should provide comprehensive information regarding the range of services available through local providers, as well as through statewide activities and initiatives. Lifespan issues from infancy through adulthood should be represented. Additionally, services that target the social, emotional, and practical needs of families should be provided. These include sibling supports, respite care, mental health services, social and peer supports, community recreational opportunities, and advocacy services. In particular, the Michigan ASD State Plan family survey results indicated two particularly strong needs in the state: transition to adulthood services, and greater social opportunities with peers and the community.
2. Implement the concept of a "family navigator" or "systems navigator" to serve as a guide to families at critical times, such as at diagnosis and transition to adulthood. Trained navigators could be professionals and parents working together to help families navigate and select from the myriad of services that are available, while modeling effective advocacy strategies.
3. Identify and fund model programs that involve families as active and collaborative partners in providing intervention to their child with ASD. Develop and implement these models across the state.
4. Explore revisions to the Family Support Subsidy program to make sure that qualifying caregivers have access to these financial resources.
5. Explore models that would improve service coordination in the state of Michigan. The Medical Home Model is one such model, implemented in other states and currently being piloted in Michigan. Other models and processes that can improve coordination among agencies might also be explored, such as the adoption of an e-portfolio system.
6. Identify and expand supports that specifically address the significant behavioral challenges families may face in parenting a child with ASD. Across the state, a continuum of services should be available to address behavioral concerns that may include: crisis placement and crisis intervention services for acute, severe challenging behaviors; individualized assistance in implementing behavioral intervention plans; and group-based parent training programs with a strong foundation in Positive Behavioral Interventions and Supports (PBIS). Professionals who develop behavioral intervention plans should have an understanding of the Functional Behavior Assessment process.
7. Ensure that all professionals working with families and individuals with ASD have knowledge about evidence-based practices, so that families are supported to implement effective strategies to teach their child skills and manage challenging behaviors.

Focus Area: Early Identification and Intervention Services

Overall Goal

All Michigan children will be screened for Autism Spectrum Disorders (ASD) before age two and any children suspected of having ASD will be referred for evaluation and services immediately. All children with a diagnosis or educational eligibility of ASD will have timely access to a structured, intensive program of evidence-based intervention.

Summary of Area

Early Identification and Long-term Outcomes

According to the Centers for Disease Control, ASD affects one in 88 children in the United States (CDC, 2012). Among Michigan's 120,000 annual births, over 1,200 children per year may be identified with an autism spectrum disorder (ASD). Tools are emerging that will allow many of these children to be identified by age two and thus referred for early intervention to ensure a future with greater opportunities. The average age of diagnosis across all ASD is 5 1/2 years (Shattuck, et al., 2009) and even older in racially diverse and under-served populations (Mandell, et al., 2002). Children of low socioeconomic status, children living in rural areas, Latino children, and African American children are often diagnosed later than other children and are less likely to access early intervention services.

Evidence indicates that when children with ASD are identified early and receive intensive, evidence-based intervention services, it improves the odds of both positive short- and long-term outcomes. In 2004 the Centers for Disease Control and Prevention reported that "children with ASD identified early and enrolled in early intervention programs show significant improvements in their language, cognitive, social, and motor skills, as well as in their future educational placement" (CDC, 2004). Another report published by the National Institutes of Health (NIH) concluded that "evidence over the last 15 years indicates that intensive early intervention in optimal educational settings for at least two years during the preschool years results in improved outcomes in most young children with ASD" (NIH, 2004).

As more research has become available about critical learning periods and long-term outcomes, there is an increased sense of urgency to provide young children with access to intervention programs that meet the recommendations of the National Research Council (2001).

"Educational services should include a minimum of 25 hours a week, 12 months a year in which the child is engaged in systematically planned, developmentally appropriate educational activity aimed toward identified objectives" (NRC, 2001, p. 220).

Addressing learning needs and improving outcomes for children with ASD will significantly impact their future and the lives of their family as well as substantially reduce the cost of lifelong care. While the positive effects of early identification and intervention are well-established, ongoing work is needed to implement the NRC recommendations.

Early Signs and Screening

The first signs and symptoms of ASD may be noticed in the setting where a child spends the most time, typically in the home and in early childcare and educational environments. Primary care practitioners may also notice signs of ASD during a well-baby or well-child examination. When professionals or family members are not aware of the early warning signs, when screening does not occur with all children, or when concerns are not communicated, precious time may be lost. To increase identification, parents, early childcare providers, and primary care providers need to have an understanding of the signs and symptoms of the disorder, and understand the steps to getting an evaluation.

Primary care providers are on the front lines of early identification because they are in regular contact with infants and toddlers. In 2008, the American Academy of Pediatrics (AAP) published new guidelines



for primary care providers and other clinicians. The guidelines involve a more intense and explicit process of developmental screening during well-child visits, including specific screening for ASD at the 18 and 24 months visits (AAP, 2008). Screening is a quick, simple and inexpensive process to identify children who have symptoms that could indicate a disorder. Universal screening of children at well-child exams is recommended to ensure that children with ASD are identified as early as possible. The M-CHAT is a 23-question, parent-completed survey that can be used at well-child check-ups and is valid for children between the ages of 16 and 36 months. Once a child is identified through screening as having indicators of ASD, the child should be referred for a comprehensive diagnostic ASD evaluation or school evaluation for eligibility.

Data from a survey of pediatricians indicate that many primary care providers are not using screening tools to conduct early screening of young children with only eight percent of pediatricians routinely screening for ASD (Dosreis et al., 2006). Lack of training regarding the use of appropriate screening tools and lack of guidance regarding reimbursement for these screening services have been reported as primary reasons for the limited use of screening tools. When screening suggests possible ASD, direct primary care providers need to make an immediate early intervention referral.

Medical and Educational Evaluation

Because there are no medical tests for ASD, diagnosis involves a series of assessments across multiple domains of functioning to differentiate ASD from other disorders. Professionals from multiple disciplines are needed to conduct a complete assessment (e.g., psychologist, physician, speech-language pathologist, occupational therapist, social worker). The comprehensive assessment leads not only to diagnosis, but also to a plan of intervention and services for the child and family. Families need information and referral to health, educational, financial, and family support resources.

A diagnosis of an ASD by a medical provider, *Early On* identification, and Michigan special education eligibility determination are separate processes and result in access to different services. A medical diagnosis of ASD for a young child has several benefits such as possible qualification for research projects focused on children with ASD, private provider services focused on ASD, and Medicaid (along with income qualifications). For states that have passed legislation requiring insurance coverage for autism, such as Michigan, a medical diagnosis will lead to insurance coverage of specific services. Even with a medical diagnosis of ASD, school eligibility determination is required by the *Individuals with Disabilities Education Act* (IDEA) in order to access educational supports and services. *Early On* eligibility provides service coordination and access to infant-toddler programming. Starting at birth, Michigan special education eligibility of ASD can provide the child with special education services and possible eligibility for the Family Support Subsidy (see Family section). The educational services and supports section of this document provides a further description of school eligibility determination. Although these systems may support one another, they are often non-overlapping with minimal communication between the medical system and the educational system. This results in confusion for families when determining the best approach to evaluation in order to access services for their child.

Although children should begin receiving early intervention services as soon as they are suspected of having an ASD, many do not begin services until they receive a definitive ASD diagnosis or school eligibility for ASD or early childhood developmental delay. When a child has an atypical ASD screening, best practices, according to the AAP, call for the child to be simultaneously referred for further evaluation

and to early intervention services. However, an average of one year elapses between the time when caregivers first seek professional help and the time when services are initiated (Mandell et al., 2005). An issue that may affect caregivers' ability or inclination to initiate services may be the level of direction they receive from medical professionals. Physicians generally agree that they lack the knowledge, information, and contacts necessary to address the varied needs of families (Carbone et al., 2010) and a medical home approach that includes care coordination could be beneficial.

Intensive, Evidence-Based Intervention

Systematic instruction using evidence-based practices, structured teaching, and strategies for active engagement must be provided at a level of sufficient frequency and intensity to produce gains in social-communication, play, cognitive, and pre-academic skills. The ultimate goals for all children with ASD are skills that will lead to independence, social opportunities, and quality of life. The intensity of early intervention for children with ASD varies widely across the country. In many states, services are insufficient and underfunded, and many early childhood providers are not trained in evidence-based practices for young children with ASD. Frequently, funding and training barriers make it difficult to deliver the necessary level of services that will lead to an optimal outcome. In the long run, the expense of comprehensive early intervention services is significantly less than the cost of potential future services and long-term care required if early services are not provided (Jacobson & Mulick, 2000). According to Ganz (2006), 90 percent of children with ASD who are deprived of effective early intervention will require special or custodial care throughout their lives, and this is estimated to cost the United States \$35 billion dollars a year.

I cannot emphasize enough how **early intervention** helped my son learn to communicate and blend into his peer group.

—Response from ASD State Plan Survey

Key Findings in Michigan

What Is Currently in Place?

- Project Find focuses on identifying children with disabilities and is responsible for outreach activities to locate, identify, and evaluate individuals, from age 3 through 25, who may be eligible for special education in Michigan. To reach eligible children, and fulfill regulatory requirements, Project Find Michigan targets specific audiences, including the homeless, migrants, wards of the court, those advancing from grade to grade who may have a suspected disability, high school drop outs, and Native Americans, as well as primary referral sources. Parents and primary referral sources contact Project Find through the toll-free number and through the online referral process available at www.projectfindmichigan.org.
- *Early On* Michigan is the state's system of early intervention services, which is federally funded through Part C of IDEA. *Early On* coordinates services for infants and toddlers, birth to age 3, with developmental delays and/or established conditions, and their families. Funding is awarded from the U.S. Department of Education to the Michigan Department of Education where it is allocated, based on a formula, to intermediate school districts who administer local systems of services. *Early On* provides support for families so that they may enhance the development of their children within their daily routines and activities. Depending on the child, services may include: occupational therapy, speech therapy, physical therapy, nursing, family training and counseling, among others.
- Michigan Department of Education, Office of Special Education (OSE) provides funding to Intermediate School Districts and Local School Districts for the education of young children age birth to 26 and may include programming in early childhood special education classrooms, preschool classrooms for children with ASD, and inclusive classrooms. Early childhood special education services are often provided by special educators and related service providers. Some children might also receive services through Head Start and private or public preschool programs.

- Michigan's Act Early Team applied for and received a one year AMCHP grant in December 2010 to focus on improving the identification and delivery of evidence-based services to young children with ASD through the coordination of schools, service agencies, health care providers, and families. This project includes the development of a road map of services for families and providers to scale up a system of care collaboration and coordination between pediatricians and educators to reduce the time to intervention, and assist all stakeholders, including parents, in navigating the service delivery system.
- In 2004, the Michigan human service agency directors approved the development of an interagency workgroup, including parents, which systematically examined EBP for children with ASD ages birth to 6 years in the areas of screening, assessment, and intervention. A set of recommendations resulted from the work along with two pilot projects that worked to implement the recommendations of the group.
- Professional development and training opportunities are available around the state through school systems, state grant projects, hospital based clinics, private service providers, and parent organizations among others.
- Diagnostic and service centers exist around the state housed in university and hospital settings. Additionally, there are many private service providers throughout the state. Most sites are located in urban or suburban areas of the state.

What Are the Gaps?

- In 2007, the American Academy of Pediatrics (AAP) issued a policy statement recommending physicians and other primary care providers screen all children for ASD twice before a child's second birthday. However, not every young child in Michigan receives an ASD screening at the recommended times even though some efforts have been made to provide information and materials to primary care providers. Many primary care providers are not aware of the early signs of ASD or the process for ASD screening.
- The number of specialized diagnosticians and diagnostic clinics is insufficient or not accessible by all families due to cost or geography. Additionally, some comprehensive medical centers have extensive wait lists to receive an evaluation for a medical diagnosis, resulting in delays in identification that limits access to timely intervention services.
- A difference exists between a medical diagnosis of ASD and an education eligibility determination for ASD services. This difference sometimes causes confusion to families and providers and information about how a medical diagnosis and an educational eligibility serve the needs of a child is not readily available to families or providers. For example, a medical diagnosis of ASD does not guarantee special education services since a school based multidisciplinary evaluation team must determine eligibility for special education services (R 340.1721a). Alternately, a young child with ASD can receive special education services through their local school district with an *early childhood developmental delay* through age 7, and thus not receive an eligibility of ASD until elementary age. The Michigan ASD State Plan Survey of Families indicated that 21 percent of children were given an ASD eligibility between the ages of birth to 2 while 51 percent of children were given an ASD school eligibility of ASD between the ages of 3-6 years. Families indicated that 27 percent were given a medical diagnosis between ages birth to 2 years with 46 percent receiving the medical diagnosis between ages 3-6.
- When families suspect ASD or receive a diagnosis or eligibility determination of ASD, the process for accessing services and support is unclear. Families must rely on providers, schools, and the internet to locate information and figure out next steps. Providers struggle with the same challenges when attempting to locate information and services for children and families.
- Many children with ASD are not receiving the recommended minimum 25 hours of structured, intensive programming per week including active engagement; repeated, planned teaching opportunities;

More needs to be done to allow parents to get an **early diagnosis** to start helping their child ASAP.

—Response from ASD State Plan Survey

instruction to meet individualized goals; low teacher-to-student ratios; ongoing program evaluation and assessments; and parent training, as recommended by the National Research Council (2001) report titled *Educating Children with Autism*. In particular, intensive services with highly trained staff are even more difficult to access outside of metropolitan areas.

- Care and service coordination among families, the primary care office/medical home, specialists, early intervention services, and school districts is limited, and this contributes to poor communication and inefficient use of time and resources. In the Michigan ASD State Survey of school professionals, 73 percent of respondents indicated that coordination and collaboration among families, schools, and service providers was a top priority; 48 percent of families completing the Michigan ASD State Survey for Families rated this item as a top priority.
- The general public is not sufficiently informed that early identification and intensive, evidence-based interventions substantially improve outcomes for children with ASD and reduce the intensity of intervention they will need later in life. This is most problematic for parents of young children, particularly those of first children who have limited information about developmental and behavioral expectations in their young children as well as child care providers and preschool programs who have access to large numbers of children around the state.
- According to the Michigan ASD State Plan Survey of Families, the primary services families of young children would like to have more access to include summer and recreational activities, full year schooling, social and peer support, applied behavior analysis, and parent support.

Recommendations

- 1. Screening and evaluation:** Increase screening by primary care providers, public health clinics, and early childhood providers such as Early Head Start.
 - Work with the Michigan Chapter of the American Academy of Pediatrics to advocate for the implementation of the recommendations set forth by the American Academy of Pediatrics that prioritize universal screening for ASD and other disabilities by age two, using a tool such as the Modified Checklist for Autism in Toddlers (M-CHAT) with a systematic referral for a comprehensive assessment for children with positive screens.
 - Provide education/training for primary care providers and other health care providers on ASD screening and follow-up.
 - Examine fiscal and practice barriers to early screening and evaluation.
 - Expand the number of people performing screenings by training non-medical personnel, such as daycare workers, preschool teachers, early intervention specialists, or social workers.
 - Coordinate ASD screening with efforts to screen for other developmental delays.
- 2. Guidelines for assessment, diagnosis, and intervention:** University, hospital, and outpatient diagnostic evaluation clinics, along with school systems, should collaborate to coordinate evaluation procedures and promote the use of evidence-based evaluation procedures.
- 3. Intervention services:** Young children with ASD should receive systematic programming using evidence-based practices at a level of sufficient frequency and intensity to produce measurable gains. These services should lead to successful transition to and participation in K-12 education and community involvement.
 - Expand training in evidence-based practices for early intervention and preschool program staff to enhance implementation of practices and demonstration of student progress toward goals in social-communication, behavioral, and cognitive skill development.
 - Increase family involvement in intervention programming including training in practices as well as program decision making.
 - The National Research Council report (2001) recommendations support increasing the amount and quality of structured programming based on individual student need. In an effort to align with these

recommendations, early intervention should be coordinated among families, service agencies, medical providers, and schools to coordinate intensive, collaborative programming.

- Seek innovative models for increasing intensity of services through partnerships between schools, universities, hospital-based programs, and private service providers.

4. Service coordination:

- Develop cross-agency, cross-program policies and procedures to coordinate available public and private resources to promote early screening and evaluation, referral to services, delivery of evidence-based interventions, and service coordination.
- Improve communication and sharing of information between health care providers and community-based programs, service providers, local education agencies, and families such as developing an e-portfolio for children that compiles information to be shared across providers and family that follows the requirements of *Family Educational Rights and Privacy Act (FERPA)* and *Health Insurance Portability and Accountability Act (HIPAA)*.

5. Information and resource accessibility:

- Make high quality informational resources more easily accessible to families and providers.
- Create a directory of providers who are skilled at providing high quality diagnostic and intervention services and make it available to primary care providers, early childhood centers, educators, and families.
- Develop a road map for families to navigate the process of identification to intervention, including the critical information needed by families during the early identification process. Review and update the road map on a regular basis.
- Develop a road map for providers to follow a system for effective screening, assessment, referral, and service provision. Review and update the road map on a regular basis.

6. Public awareness:

- Increase public awareness statewide and available information related to the signs and symptoms of ASD, the importance of early identification and future outcomes, and how to access a medical diagnosis and special education eligibility evaluation.



Overall Goal

All Michigan students with ASD will have access to effective, integrated learning environments and highly trained school staff in order to make progress toward academic, social, communication, behavior, and adaptive skill development. Michigan students with ASD will transition into adulthood with high levels of independence, and will be prepared for post-secondary education and employment opportunities that lead to positive outcomes and quality of life.

Summary of Area

It is critical that all students with an autism spectrum disorder (ASD) have access to high quality, evidence-based educational services regardless of geography, severity of disability, age, or socioeconomic status. Instruction should be based on the general education curriculum with appropriate accommodations and modifications delivered by qualified professionals and paraprofessionals. Additional instruction and programming is often necessary to address the deficits of ASD, including social, communication, and adaptive skill needs. Structured learning environments and visual supports can allow optimal learning to occur, and instructional delivery must be considered for individual students to maximize rate of learning. All educational services and supports should be evaluated and monitored on a regular basis to ensure progress toward goals, with awareness that the long-term success of educational programming may be best measured by evaluating adult outcomes. Transition planning is essential for individuals with ASD and their families in preparation for life beyond graduation from the educational system.

Least Restrictive Environment

The federal regulations of IDEA define the right of students with disabilities to be placed in the least restrictive environment (LRE). According to the findings in IDEA, "almost 30 years of research and experience has demonstrated that the education of children with disabilities can be made more effective by...having high expectations for such children and ensuring their access to the general education curriculum in the regular classroom, to the maximum extent possible" (20 U.S.C. 1400 (c)(5)(A)). Therefore students with disabilities, including ASD, should have access to educational services in schools where peers without disabilities attend, and participate in general education programs under the supervision of general education teachers, with special education support and assistance as determined appropriate. Individualized Education Program (IEP) teams must address the issue of LRE at each IEP team meeting.

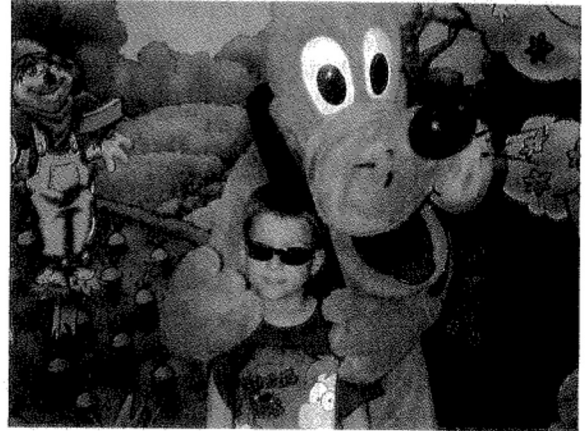
Inclusion of students with ASD is associated with improved outcomes, including higher achievement scores, increased participation in the core general education curriculum, and development of IEP goals reflecting higher order and applied thinking skills (Ferraioli & Harris, 2011). Other researchers have noted that social competence, communication skills, and other developmental skills of students with disabilities improve in inclusive settings (Hart & Whalon, 2011; Bennett, Deluca & Bruns, 1997).

Implementation of Evidence-Based Practices

Students with ASD often require supplemental instruction in the social, communication, and adaptive behavior domains, therefore educators require information about evidence-based practices (EBP) to help address these needs. For example, clinical data supports the idea that academic outcomes for students with ASD are impeded by social skill deficiencies (White, et al, 2007), yet effective social skill intervention often prevails as an unmet need in schools. Implementation of peer-mediated intervention, an evidence-based practice, can improve social competence. Educators need information and support to ensure that this, and other evidence-based practices are implemented to benefit students. With the increasing availability of information about evidence-based practices, schools are better able to access critical information about strategies that are effective; however, implementation of these practices requires using effective instructional delivery methods, as well as progress monitoring processes and tools.

Training for All Staff who Support Students with ASD

According to the National Research Council (2001), “personnel preparation remains one of the weakest elements of effective programming for children with autistic spectrum disorders and their families” (p. 225). The unique needs of students with ASD necessitate specialized training for the educational professionals who work with them, and multidisciplinary training is essential, since students with ASD are served by a variety of professionals who work together to address a range of needs (Scheurmann, Webber, Boutot & Goodwin, 2003). Paraprofessional training is another area that requires attention. Paraprofessionals are the least trained and qualified, yet they often educate children with the most complex disabilities; they are under-trained, underpaid and feel they lack skills and supervision (Giangreco, Edelman Broer & Doyle 2001). In a study that surveyed professionals from six states, school teams reported concerns about how paraprofessionals were used and expressed additional concerns about how this impacted students with developmental disabilities (Giangreco & Broer, 2007). According to Broer, Doyle, and Giangreco (2005), paraprofessionals may impede inclusion experiences as children may look to them as “friends” and this may deter natural relationships from developing. In some cases, children who are supported by a paraprofessional have reported feeling socially stigmatized and disconnected from the classroom teacher. Paraprofessionals are often relied on to provide primary educational support as evidenced by the fact that 70 percent of surveyed paraprofessionals indicated they were making curricular and instructional decisions without oversight by a special or general education teacher (Giangreco & Broer, 2005). While paraprofessionals will continue to have a vital role in special education, it is important that they have specific training, supervision, and direction. This is becoming increasingly difficult as special education teachers address more complex student and classroom issues and subsequently paraprofessionals take on more student support tasks without increased training.



Educating with a Focus on Lifelong Outcomes

Transition planning is essential for individuals with ASD and their families, and this involves preparing the student for life beyond graduation from high school. Young adults preparing to transition from high school should have many choices and options for higher education, technical training, employment, community living, and community-based socialization and recreation. However, the lack of availability of options in each of these areas weighs heavily on the families of individuals with ASD. An Easter Seals study released in 2008 indicated that 80 percent of parents of children with autism reported that they were extremely or very concerned about their child’s future independence across multiple domains. Since ASD is a lifelong condition, skills for independent living, including socialization, must be taught early to enable a more successful transition and maximize quality of life. Personal relationships can be particularly complicated for young adults with ASD (Sperry & Mesibov, 2005), and the inability to form and maintain social relationships can negatively impact adult experiences. The failure to engage in typical social exchanges can result in the individual being unable to understand and follow social rules and expectations, avoiding social situations, or experiencing overt social rejection (Cotugno, 2009). Planning for transition, with a strong focus on social skill development must begin well ahead of high school graduation, even as early as the first IEP meeting.

Special Education Evaluation and Identification

According to *Michigan’s Administrative Rule for Special Education* R 340.1715, ASD is considered a lifelong developmental disability that adversely affects a student’s educational performance in one or more of the following performance areas: (a) academic, (b) behavioral, or (c) social domains. An evaluation by a multidisciplinary team, consisting of a psychologist or psychiatrist, a provider of speech and language therapy, and a school social worker is required to determine educational eligibility. This contrasts with medical diagnoses of Autistic Disorder, Asperger Syndrome, and Pervasive Developmental Disorder, each

of which has specific criteria which are similar, but not exactly the same, as those required for school identification. Whereas Federal regulations require a multidisciplinary evaluation for special education eligibility, medical diagnosis does not. Practitioners such as physicians and psychologists can, and do, make diagnoses independently even though a multidisciplinary medical evaluation is ideal.

Key Findings in Michigan

What Is Currently in Place?

Least Restrictive Environment

- The 2011-2012 Indicator 5 target for the Michigan State Performance Plan is that 63.0 percent of students with disabilities ages 6 to 21 should be in the general education setting at least 80 percent of the time. As of November 2010, 62.8 percent of all students with disabilities ages 6 to 21 in Michigan are in the general education setting 80 percent or more of the time, while 45.4 percent of students with ASD are in the general education setting 80 percent or more of the time.
- In Michigan, the Pupil Accounting Manual now includes specific provisions for implementation of Peer to Peer Support programs, including details regarding credit attainment, curriculum, funding, and grading processes. Many districts throughout the state have received local Board of Education approval for implementation of Peer to Peer Support programs. These programs are designed to support students with ASD across school environments including general education.

EBP Implementation

- According to the Michigan ASD State Plan School Professional Survey, school professionals indicated *significant* knowledge in Positive Behavior Interventions and Supports (PBIS) and Functional Behavior Assessment; and *moderate* knowledge in Applied Behavior Analysis, Asperger Syndrome, and data collection and progress monitoring.
- In 2009, the Statewide Autism Resources and Training (START) project, a Michigan Department of Education funded grant project, received a collaborative partnership award from the National Professional Development Center on Autism Spectrum Disorders (NPDC). The primary focus of this partnership was to establish model sites of evidence-based practice in schools throughout Michigan. To date, eight districts have worked with START on this project. Although the grant partnership with NPDC is complete, START is continuing to expand onsite technical assistance for EBP implementation through continued identification and support of new model sites each year.
- According to Michigan State University's ASD-Michigan Project, the five most highly reported practices used by educators for students with ASD were visual supports, structured teaching, direct instruction, applied behavior analysis, and social stories. Four of these five practices have been identified as evidence-based practices by the National Professional Development Center (NPDC) and the National Standards Project (NSP). The fifth practice, direct instruction, although not reported in NPDC or NSP standards, is considered to be an effective practice in special education, with components that are consistent with an applied behavior analysis approach (e.g., frequent opportunities to respond, error correction, and reinforcement of correct responding).

Training

- According to the Michigan ASD State Plan School Professional Survey, the majority of respondents indicated that teaching and support of children with ASD in their building, district, or ISD was *somewhat effective or highly effective* in the following areas: IEP development and implementation,

We have been very pleased with the help we have received from my son's school. He seems to be **progressing more rapidly** since he has been a part of the inclusion program.

—Response from ASD State Plan Survey

social development, communication development, behavior support, and academic support, including accommodations and modifications. Survey responders reported that they received specialized training or learning opportunities primarily through Conference and Workshops, Self-Study, and START Intensive Team Training. Time and cost were significant barriers to accessing more training.

- Since 2001, staff from the START project has provided year-long Intensive Training for school teams who work with students with ASD. Training modules include: Foundations in ASD, Positive Behavior Intervention and Supports, Educational Strategies, Peer to Peer Support, Teaming Process and Meeting Mechanics, IEP Development and Implementation, and Systems Change through Coaching. Additional modules focus on Asperger Syndrome and the evaluation process. To date, over 400 teams comprised of more than 2,100 educators and school professionals have participated in the START Intensive Team-based Training. Educators have participated in many other forms of training through START as well.
- Over the past five years, more options for obtaining an ASD teaching endorsement have become available. Eight Michigan universities are approved to offer an ASD teaching endorsement. An endorsement is also available through the Autism Collaborative Endorsement (ACE) program, which is a collaborative partnership among four universities. As of 2012, more than 850 teachers in the state of Michigan have an ASD endorsement on their teaching certificate.
- The Interdisciplinary Certificate in Autism (ICA) is a special recognition awarded by the Michigan Department of Education and Oakland University to professionals who have advanced their expertise in the area of autism through education and professional experiences. At this time, 27 professionals in the state have an ICA.
- Over the past several years, the state of Michigan has gradually increased the number of teacher consultants for ASD employed by public schools. Michigan criteria for teacher consultant approval includes a valid Michigan teaching certificate with special education endorsement in autism, an earned master's degree in education or a field related to special education, and completion of a minimum of three years of satisfactory teaching experience, two years of which must be teaching students with disabilities in a special education classroom. However, many counties and local districts utilize other highly competent professional staff, such as school psychologists, school social workers, and occupational therapists, in a consultant/ASD specialist role.

Transition

- School professionals from preschool through post-high school support students with ASD as they prepare for transition. Services provided by school professionals are gradually becoming better linked with those of Transition Coordinators funded through the Michigan Department of Education, as well as those provided by public service agencies (i.e., Community Mental Health, Michigan Rehabilitation Services).

Special Education Evaluation and Identification

- According to the Michigan Department of Education December 2011 count, 15,976 students are receiving special education services under the ASD eligibility classification in Michigan (7.3 percent of Michigan's special education student population).
- The START project provides training in the Centralized Evaluation Team process, which is designed to support school-based teams in the multidisciplinary process of school eligibility determination for ASD.

What Are the Gaps?

Least Restrictive Environment

- Data needs to be used consistently to make informed decisions about classroom placements that align with least restrictive environment, and educators need more training to learn how to collect and use data to make placement decisions.
- Programs that support access to least restrictive environments need to be promoted and supported. For example, peer support programs (e.g., LINKS) require staff expertise, time to set up, and ongoing technical assistance to ensure that these programs are implemented effectively.

EBP Implementation

- Currently, a mechanism to measure professional competency with regard to knowledge of ASD and EBP is

not established across most disciplines. Special education teachers working specifically with students with ASD must pass the Autism Michigan Test for Teacher Certification (MTTC) to receive an endorsement in ASD.

Training

- According to the Michigan ASD State Plan School Professional Survey, school professionals indicated *minimal to no* knowledge regarding specific methodologies such as Pivotal Response Teaching, Discrete Trial Teaching, and Functional Communication Training.
- On the Michigan ASD State Plan Family survey, parents reported a desire for better training of educational professionals. Sixty-seven percent of parent respondents reported that they desired greater education and training for the school personnel who worked with their child. These results were consistent with Michigan State University's ASD-Michigan Project findings that suggested a need for better educator training at undergraduate, graduate, and in-service levels.
- Within Michigan, there is no specific model for paraprofessional training in the state, resulting in a wide range in knowledge and skill sets, depending on the training structure of the district.
- Interpretation of the rules and use of Personal Curriculum varies from county to county and local Boards of Education, as does the determination of whether a student should receive a high school diploma or certificate of completion.
- Teachers are expected to provide differentiated instruction for all of their students, as well as targeted and intensive interventions for students with ASD, when necessary. More training and support related to modification of curriculum and differentiation of instruction is needed especially for general education teachers however teachers are finding it increasingly more difficult to get approval for out of building professional development.
- Training and support for general education and special education teachers as well as other educational professionals are not always provided in the most effective manner. For example, single-session in-service training is not associated with positive implementation (Lang & Fox, 2004). Training opportunities with follow-up, coaching, and, in some cases, onsite technical assistance may be necessary to improve outcomes.

Transition

- The approach to post-high school programming for students with ASD is inconsistent across the state. For example, in some districts, students with ASD have been dual-enrolled in college and high school/post-high school with funding and support provided through the school system, but this option is not provided in other school districts. Job supports and participation in community work settings also varies widely across the state.
- There is a lack of clarity regarding the transition from school-based services to adult service options. Additionally, there is confusion regarding when this transition should occur and how overlapping services might be provided to best support individuals with ASD to achieve successful adult outcomes.

Special Education Evaluation and Identification

- The dual system of school eligibility/clinical diagnosis can be confusing for families and often redundant. If a child receives a clinical diagnosis of ASD from a physician or psychologist, evaluation by a multidisciplinary school team is still mandated by IDEA to consider special education eligibility under ASD. Even though the school evaluation team can consider information obtained from a clinical evaluation, the school team will still need to evaluate whether the disability has an impact on educational performance, and if the child is eligible for special education services.

Recommendations

1. All educational staff, including paraprofessionals, should be provided with quality professional development, mentorship, and ongoing consultation on best practices for educating and supporting individuals with ASD. Because implementation is the goal of training, certain critical factors associated with implementation should be incorporated into training practices such as multidisciplinary, team-based, intensive training with follow-up coaching and support. Team members should receive training in critical content areas, including ASD, systems variables (e.g., teaming process), and EBP. Because education in general education settings is critical, it is also important to provide training

in Individualized Education Program (IEP) development and implementation, accommodations/modifications, grading practices, and peer supports. Best practice recommends that each school building serving students with ASD should have a trained team in place, including one professional staff member who has dedicated time to serve as an ASD coach.

2. School professionals should be encouraged to use a systematic assessment process or tool regularly to measure whether EBP are being implemented within their school buildings (e.g., Universal Supports Assessment and Planning Tool).
3. Knowledge of EBP should be included in the competency criteria for professionals and paraprofessionals who work with students with ASD.
4. Given that peer mediated interventions are an evidence-based practice with significant, broad impact, school systems should be encouraged to develop a peer support program at the elementary and secondary level for students with ASD. A key component of these programs includes identification of a building-level peer support coordinator who receives additional training in order to ensure effective implementation of the program.
5. Best practice guidelines for the implementation of evidence-based practices in the school setting should be created in order to specify the practices and systems that are most effective for students with ASD.
6. Multidisciplinary evaluation team (MET) members (psychologists, school social workers, speech/language pathologists) should have access to ASD eligibility determination training to improve the consistency of evaluation practices across districts. One example is the START Project's Centralized Evaluation Team training. Eligibility determination for children with Asperger Syndrome and highly verbal students with ASD may need to be a particular focus of training, given that pragmatic language impairments are common in these individuals despite adequate vocabulary, syntax, and grammar.
7. Medical professionals should be encouraged to participate in multidisciplinary evaluations when making an ASD diagnosis.
8. Transition planning should begin earlier, with an emphasis on key skills such as independence, interpersonal interactions, self-management and self-advocacy. A discovery process should be used to identify the student's strengths, skills and talents to prepare the student for successful employment. A range of options should be available to students including college, vocational/technical school, supported employment, and customized employment that will allow them to become active, contributing members of their community.
9. Educators need access to an online resource center that allows them to easily access local, regional, and national information and resources to increase their knowledge and improve their ability to implement practices deemed effective for students with ASD. Once educators can access more resources, they can help link families and local agencies to relevant information.

General education
teachers need
training on ASD.

—Response from ASD State
Plan Survey

Overall Goal

All adults with ASD will have opportunities to be active participants in meaningful relationships, will experience inclusion and membership in their communities, and will have opportunities to work and contribute to society.

Summary of Area

Transition from School to Post-School Life

The transition process begins during the school-years, with the ultimate goals of this process being the same as the goals for students without disabilities, independence and social competence (Hendricks & Wehman, 2009). To prepare students with ASD for adult life, skills taught while in school should include academic, socialization, communication, self-management, self-advocacy, employment, and daily living skills. These skills must be taught and encouraged in a variety of environments by families and educators to ensure that, as adults, individuals with ASD fully and meaningfully participate in their communities. However, research suggests that young adults with ASD frequently have poor outcomes on a number of measures related to community integration and quality of life (Gerhardt & Lainer, 2011; Hart, Grigal & Weir, 2010; Hendricks, 2010; Hendricks & Wehman, 2009; McDonough & Revell, 2010). In order to prepare students for the broad and critical skills they require to live successfully as adults, professionals must carefully address transition needs, beginning during early childhood and continuing into adulthood.

Employment

Many researchers report a high unemployment rate for individuals with ASD (Gerhardt & Lainer, 2011; Hendricks, 2010). In the Easter Seals Living with Autism Study conducted in the U.S. between 2007 and 2008, researchers surveyed more than 1,600 parents of children with ASD, and more than 900 parents of children without any special needs. All parents had children aged 30 or younger. Whereas 75 percent of non-disabled adults ages 16 and older were working in paid employment settings, less than 25 percent of adults with ASD from this same age group were employed in paid positions. Similarly, in findings from their ten-year study with a national sample of transitioning students, researchers from the National Longitudinal Transition Study 2 (NLTS2) (www.nlts2.org/) suggested that only 32.5 percent of young adults with ASD worked for pay as compared with an average of 59 percent for all other disability groups. Even when individuals with ASD are able to find employment, they are more likely than their peers with other disabilities to work fewer hours per week and to earn a lower hourly wage (McDonough & Revell, 2010). In many instances, a lack of social skills and social understanding is cited as a primary cause of unemployment or under-employment for these otherwise skilled individuals on the autism spectrum. These data suggest that further research and attention must be directed toward improved employment options, through better assessment of student strengths, as well as a more thorough understanding of their sensory/environmental and social needs. By expanding social and job-based skills and matching individual interests, more meaningful, paid work experiences can be identified. The customized employment approach is one way to expand work opportunities for adults on the spectrum (Griffin, Hammis, Geary & Sullivan, 2008).

Living Arrangements

Decision-making about where an individual with ASD will live in adulthood is one of the many challenging issues that families with young adults with ASD might experience. While most high school graduates are expected to begin to make steps toward independent living arrangements, this outcome does not always occur for individuals with ASD. In the NLTS2 study, only 11.1 percent of surveyed individuals with ASD lived independently in adulthood. In the Easter Seals Living with Autism Study, survey results indicated that more than 96 percent of individuals with autism or PDD-NOS under age 30 resided with their parents or guardians. Less than 1 percent lived independently, either with or without a spouse or partner. Additionally, only 4 percent of students with Asperger Syndrome under age 30 lived independently, either with or without a spouse or partner, despite their average or higher IQ scores. To meet the needs of



individuals with ASD in adulthood, it is critical that a variety of living arrangements are available, including independent living, supported living, and family-style small group living options. However, it is also necessary to facilitate transition of individuals with ASD to these and other community living options while still maintaining the central role of their families in their lives.

Post-Secondary Education

While college is not the best match for every individual leaving high school, it should be a choice that is available for students, including students with ASD. We do not know how many people with ASD attend college or graduate; however, we do know that most do not participate in post-secondary education (Briel & Getziel, 2009), which can make it difficult for them to achieve career and life goals. College attendance is often another step in attaining independence, and can provide opportunities for individuals with ASD to achieve career goals, improve social skills, and increase self-advocacy and communication skills. Students with ASD can choose to participate in traditional postsecondary options, such as completing college level courses with accommodations, or nontraditional college options, such as auditing courses or participating in a separate curriculum program (Hart, Grigal & Weir, 2010). Some students with ASD may benefit from participation in the college community, through campus work experiences or student clubs or campus activities, even without being enrolled. Other students with ASD may benefit from enrollment in technical schools. Unfortunately, this range of options is not always available to, or accessed by, individuals with ASD. For those who do attend college, there are often struggles related to social interactions, academics, time management, organization, and studying (Adreon & Durocher, 2007). In addition, self-advocacy skills are crucial since, without a request from the young adult with ASD, universities and colleges are unable to provide disability support services. In order to facilitate active college participation, it is important to have better planning for post-secondary education during high school, advocacy from families and individuals with ASD, and consistent supports available in college, university, and technical school settings.

Adult Service System

The transition from mandated school services to the adult service system, which includes Community Mental Health Programs, the Department of Human Services, Michigan Rehabilitation Services, and Medicaid, is a complicated one, and can result in confusion and difficulties understanding the roles and responsibilities of varied service providers. In some cases, individuals with ASD receive services from multiple adult service agencies simultaneously. In other cases, individuals with ASD do not receive services as they move into adulthood. This may be due to confusing eligibility requirements or lack of knowledge of resources that these programs provide (e.g., job coaching, transportation, community integration supports, respite care). It is often unclear which agency or agencies might provide these supports to families. Some families of adult children without Medicaid choose not to become involved with their local community mental health agencies due to co-pay requirements or the perception that the process is too difficult for the support that's received. In one recent nationwide study, the authors found that 40 percent of young adults with ASD (ages 19 to 23 years of age) who had previously received services in secondary schools no longer received services upon graduation (Shattuck et al., 2011). Without a single point of entry and given that there is no consistent process for case management across agencies, the adult service provider system may be under-utilized, and services may be delayed or provided differently depending on one's geographic location. To ensure that the adult service provider system is maximally effective, it needs to be navigable and accessible to families, and service providers need to have an understanding of the characteristics of ASD and how it impacts individuals in their homes, work environments, and communities.

Key Findings in Michigan

What Is Currently in Place?

- Public mental health services are provided through the Managed Specialty Supports and Services Plan (MSSSP) for individuals with Medicaid who have a serious mental illness, developmental disability, or a substance use disorder. Michigan Department of Community Health (MDCH) contracts with 18 Prepaid Inpatient Health Plans (PIHPs) to deliver mental health services to Medicaid beneficiaries. The PIHPs are comprised of single or multiple Community Mental Health Services Programs (CMHSPs) for

services to children and adults with developmental disabilities. Each PIHP is required to have an array of specialty services and supports to both children and adults who have Medicaid that includes services such as community living supports, medication administration, occupational therapy, physical therapy, play therapy, speech, hearing and language, case management, supports coordination, respite care, family support and training. In adulthood, individuals on the spectrum may obtain services from the PIHP/CMHSP and other state agencies as they attempt to negotiate the variety of supported living arrangements available to them, as well as support services for accomplishing activities of daily living, transportation, employment and recreational activities. For children and adults who do not have Medicaid, a CMHSP must prioritize who receives public mental health services, and when it cannot address all local needs, establish a waiting list process that ensure systematic access into services. Without Medicaid and a priority need, a person with ASD is unlikely to get services from CMHSP.

- In 2010, 1,996 adults with ASD in Michigan were served through the Department of Community Health/Community Mental Health Service Program (DCH/CMHSP) system. Nearly half of the individuals in the DCH/CMHSP system were between the ages of 18 and 26 and most of them were still receiving school supports. These figures do not include individuals who do not receive any DCH/CMHSP supports, but may have been receiving services through another public service agency. Michigan data suggests an increasing number of students are receiving special education services under ASD eligibility; specifically, in 2011, there were more than 15,976 students with ASD from birth to 26 receiving services. As this population ages, the adult service system will need to plan for a significant increase in the number of young adults with ASD who are eligible for services. The significant number of students with ASD who will be entering adulthood in the next 5-10 years presents urgent challenges for the state of Michigan (see Appendix 1, graph 2).

Access to Adult Services and Supports

- Medicaid and Social Security benefits are the primary funding mechanisms for individuals with ASD with few or no other forms of support.
- Typically, individuals with ASD who have Medicaid and who meet criteria for developmental disability are eligible to receive public mental health services.
- The depth and range of services varies across the state. Various public resources are available to adults with ASD, but they are scattered and assistance is required in order to navigate them. Each organization has certain eligibility requirements that must be met, financial or disability related, before services can be delivered. The public service options available at the current time are regulated by the various state agencies, and the availability of private services for adults with ASD in the state is difficult to determine.
- Services provided through the public mental health system are based on a culture of gentleness, which is the premise that individuals should feel safe and valued as an alternative to relying on restraint, restrictions, and punishment. Statewide training and consultation is currently occurring related to this topic.
- As of September 2009, the last institution serving adults with developmental disabilities, Mt. Pleasant Center, closed. As of November 2010, all individuals from Mt. Pleasant Center have moved to community settings. Michigan is the largest state to have closed all large and small institutions for individuals with developmental disabilities.
- Public service providers have adopted a focus on understanding and diagnosing co-occurring disorders for individuals with ASD. With an emphasis on functional behavior assessment, it is easier to determine whether behavioral symptoms are the result of a true comorbid disorder such as mental illness or the result of other environmental or relationship concerns. Individuals with disabilities who may have undergone trauma or who may be experiencing depression and anxiety are more readily identified.
- EBP are observed in some interventions provided to adults with ASD across the state. Some of these include, but are not limited to, the following interventions identified in the National Autism Center's (2009) National Standards Project: antecedent package, behavioral package, modeling, naturalistic teaching strategies, visual schedules and support strategies, self-management and story-based intervention package.
- Person Centered Planning (PCP) is a process for planning and supporting the individual while building on his or her capacity to engage in activities that promote community life. This process honors the individual's preferences, choices and abilities, and involves families, friends, and professionals

consistent with the needs and desires of the individual. While the process may vary somewhat across the state, PCP is required in the Michigan Mental Health Code for all individuals served by the public mental health system.

- In conjunction with PCP, self-determination is an option for individuals served by the public mental health system. Self-determination is based on the premise that all individuals should have the freedom to live life the way they want, and they should have the authority to control the way they receive services and resources.

Public Adult Service Options

- Adults with Medicaid who meet eligibility requirements receive their services through PIHPs with funding from DCH. The MSSSP offers a variety of medically necessary services that focus on supporting adults with ASD and their families. The Habilitation Supports Waiver, which operates concurrently with the MSSSP, has additional enrollment requirements and is designed to provide home and community based services and supports for Medicaid beneficiaries with developmental disabilities who would otherwise require an institutional level of care. Some examples of services may include:
 - a. Work and day time options through promoting micro-enterprises and identifying specific employment opportunities that match the strengths and needs of individuals with ASD while reducing day programs and sheltered workshops.
 - b. Respite care is available for families with adult children with ASD who reside at home.
 - c. Supported living opportunities for individuals with ASD whose families have sought out-of-home placements, including staff to provide assistance.
 - d. Community living support (CLS) staff to assist individuals with disabilities as determined in their plan of service, or person-centered plan, and may include transportation to community activities.
 - e. Supports coordination or targeted case management may be able to link, coordinate, and assist the individual and family to navigate the various systems and programs.
 - f. Peer-to-peer supports may be helpful in linking and coordinating services and advocacy.
- Adults with ASD who do not qualify for Medicaid may be eligible for mental health services through the CMHSP; however, the CMHSP must prioritize who receives public mental health services, and when it cannot address all local needs, establish a waiting list process that ensure systematic access into services. Without Medicaid and a priority need, a person with ASD is unlikely to get services from CMHSP.
- A variety of services are offered through the Michigan Department of Human Services (DHS) including Supplemental Security Income (SSI), Medicaid, Food Stamps, Personal Care Services for Medicaid beneficiaries living in their own homes or the home of a family member (Adult Home Help Services), Medical Transportation (to and from medical appointments), Utility Assistance, and Housing Assistance. An application must be completed, and eligibility determined in order to receive these services. In some cases, families are not aware of these programs.
- In the state of Michigan, students with disabilities are eligible to receive services from the educational system through the age of 26. Because educational services are potentially available for a greater number of years than is available in any other state, a tremendous opportunity exists to provide programming that can improve adult outcomes. School professionals in middle schools and high schools, post-high school staff, and Transition Coordinators funded through Michigan Department of Education (MDE) may support students with ASD in preparation for college/technical school participation and community and employment opportunities. Services provided by these personnel may be in addition to those provided by other public service agencies (e.g., CMHSP, Michigan Rehabilitation Services), and service coordination between MDE providers and adult service providers is challenging. ASD specific data regarding the impact of these services on adult outcomes is lacking in Michigan.

I am concerned about the **lack of social support services** for college-bound students who have Asperger's Syndrome.

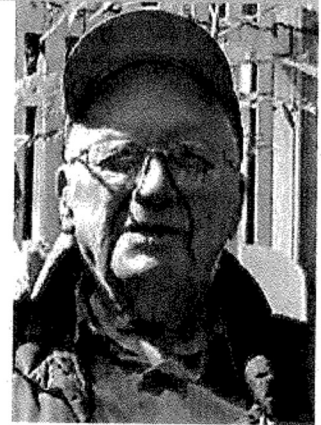
—Response from ASD State Plan Survey

- The Michigan Transition Outcomes Project (MI-TOP) is funded through the Michigan Department of Education, Office of Special Education and supports the implementation of effective transition practices to ensure all students are prepared for postsecondary education, employment, and independent living. The project includes measurable student focused planning, student development activities, and continuous family and community involvement.
- The mission of Michigan Rehabilitation Services (MRS) is to partner with individuals and employers to achieve quality employment outcomes and independence for individuals with disabilities. MRS assists with assessment of vocational interests and skills, while also providing short-term supports (e.g., training, assistance with transportation or worksite modifications). MRS often contracts with other agencies to implement supports for students with ASD to facilitate and maintain job placement. Across the state, MRS has had varied levels of success in finding meaningful and appropriate employment for individuals with ASD. Specific methods of assessment, a focus on targeted employment options, and lack of understanding of the needs of individuals with ASD sometimes hinders successful implementation.
- The Michigan Career and Technical Institute (MCTI), operating through the Department of Licensing and Regulatory Affairs (LARA) and MRS, offers a blend of support services and job training that can support individuals with ASD through advocacy efforts, empowerment, and monitoring of resources and needs in the local business community.
- First responders, such as state and local police may come into contact with individuals with ASD in a variety of ways. Individuals with disabilities, including ASD, may be more likely than the general public to become victims of crime due to their communication limitations, misunderstanding of danger cues, and the fact that they have often been taught over the years to be compliant to adult directives. Some individuals with ASD elope, or wander away from their homes, and police may be called upon to help locate these individuals when they are missing. In a few areas of the state, tracking devices are being piloted that help to locate missing individuals who have a history of elopement (e.g., Ottawa County's Project Lifesaver program). Non-profit and government agencies across the state are working to educate law enforcement personnel about the unique needs of people with ASD.
- The forms of public transit that are available (e.g., busing, shuttles, taxis) varies depending on the county and city in which the individual resides. Some counties offer door to door transportation services that can be arranged privately, but this option is not available in every area.

What Are the Gaps?

- In the Michigan ASD State Plan survey, more than 45 percent of parents who had children with ASD between the ages of 13 and 25 reported that they needed greater access to transition to adulthood services. This was the highest endorsed area of need for the 13-18 year old age group and the 19-25 year old age group. Specific areas of transition-related priorities for families included: access to higher education and technical schools, access to employment services and supports, and access to community opportunities for their young adult child with ASD.
- Different services are available for adults who have Medicaid and for those who do not. Each of the public services systems has eligibility requirements that must be met, presenting challenges to individuals with ASD and their family to access services. To meet the needs of the growing adult population with ASD in Michigan, a greater level of coordination among public service systems and agencies is needed within the state.
- While it is ideal that transition planning occurs early in a child's education to prepare them for life after high school, it is still the case that many individuals with ASD reach their 26th birthday and have no viable options for meaningful daytime activities. The school system has initial responsibility for this long-term planning, with many other parties being involved. One gap in adult services is the lack of consistency in supports provided across counties. Job supports and participation in community work settings also varies widely across the state, with some areas highly involved in competitive and supported employment while others focus on more segregated settings. Some of these differences in outcome may reflect the uniqueness of individuals with ASD and their particular patterns of strengths and needs, but others may reflect a lack of training on the part of service providers, or discrepancies in philosophies and resources that exist in various regions.
- Individuals with ASD need access to a variety of employment opportunities, including supported employment, competitive employment and customized employment. These options require that adult

service providers are well-trained in the characteristics of ASD and have the skills and resources available to engage in job development and training activities. These activities must effectively match individuals with ASD to jobs that are appropriate to their competencies and interests. Job coaches/support staff that work in public service agencies and the educational systems all need to have the knowledge and skills in these areas in order to facilitate employment opportunities and educate employers about the advantages of hiring someone with ASD. They need to understand how to emphasize the individual's abilities while seeking creative employment solutions that capitalize on student strengths. Support for the individual with ASD in the employment setting should be quickly transitioned to natural supports to ensure true integration, but in some cases, due to the unique needs of individuals with ASD, it may be necessary to have the availability of extended coaching and supports to ensure job success.



- Currently, only a limited number of transitioning students with ASD are attending colleges or universities (either full- or part-time) or enrolling in trade/technical schools. The process of transitioning to post-secondary educational opportunities must begin during secondary education with more concerted efforts to prepare students for these options. This process also requires more consistent and better support from disability support offices at universities, colleges, and technical schools. It is common for universities to report that they are struggling to meet the needs of the growing population of students with Asperger Syndrome. Professionals in post-secondary settings may require more information about accommodations that meet the social, behavioral, and academic needs of students with ASD.
- National trends suggest that a high percentage of adults with ASD continue to live with family members during their adult years. If family members are no longer able to provide this support, housing options include specialized licensed group homes (with paid support staff), or living in one's own home or apartment with or without roommates (with varying level of paid supports, if needed). It is anticipated that there will be increasing demand for housing over the next decade for adults with ASD. This issue will necessitate a partnering of public and private funding and creative solutions and incentives for housing development. The availability of affordable, safe and individualized housing options in Michigan varies depending upon geographic location and in some areas, there are long waiting lists for Section 8 housing vouchers or placement in group homes. Additionally, it can be difficult to find appropriate, well-trained staff to reliably provide support.
- Many individuals with ASD are reliant on others for transportation. The availability of convenient, affordable public transportation varies across the state. Although public transportation is the most common form of transportation used by those with disabilities, it is most often found only in the larger cities. Rural areas are more significantly challenged when attempting to provide transportation options that can facilitate independence, employment, and community involvement. Often, people who rely on public transportation find the bus schedules do not align with their work schedules (e.g., may not run on weekends or in the evenings). Lack of transportation options significantly limits access to adult activities that promote quality of life.
- The ASD State Plan Family survey indicated that a high percentage of parent respondents felt that community opportunities were lacking for their adult child with ASD. Social skills groups are available in some areas to assist the individual to join community activities, however these services are limited at the current time, and the generalization of the skills taught in group sessions to the community environments where they need to be used is not always carefully monitored. Some community participation initiatives are in place to match an individual's interest with community clubs, classes, and Parks and Recreation programs in "supported inclusion." For individuals with Medicaid, community living support (CLS) staff may assist with access to leisure and recreational activities as part of a plan of service. Even with staffing supports, the individual's ability to stay connected to opportunities for social interaction in the community depends largely on the support staff's knowledge and ability to transfer to using natural supports. Too often, social opportunities and connections are achieved solely with other individuals with disabilities rather than in truly integrated environments.
- Families with children with ASD must often consider several legal issues as their child approaches adulthood. These may include estate and financial planning, alternatives to guardianship (i.e., power of attorney), or guardianship (partial or plenary, as needed). Public funding sources generally do not

become involved in these areas with the possible exception of providing assistance to the individual or family who is applying for guardianship, or as an alternative to guardianship. Families may not always have the financial resources or information to address these issues, and in many cases, they need to begin these steps at an earlier age.

- Because professionals in the legal system do not always have adequate information about ASD, they may question, confront, or respond to individuals with ASD in ways that are counterproductive. Legal professionals and police officers require information about ASD so that they understand the diagnosis and do not misperceive the behaviors of individuals with ASD.
- Psychiatrists and other professionals do not always have a broad understanding of the characteristics of ASD and how to treat adults with co-occurring mental illness and ASD.

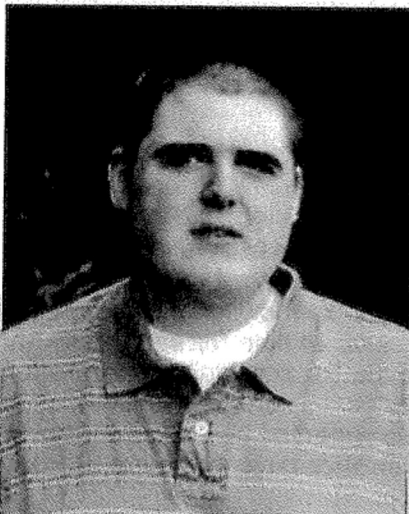
My son is at the age where he will no longer receive services; sadly he is in **no way prepared** to enter a world where he will be mainstreamed.

—Response from ASD State Plan Survey

Recommendations

1. Ensure that eligibility criteria are applied consistently throughout the state by the various public service agencies and explore ways to better coordinate eligibility criteria across agencies.
2. Create a state resource and information center to increase access to information, materials, referrals, and systems to help adults with ASD and their families navigate the transition to adulthood and adult supports through their lifetime.
3. Provide a single point of entry for public adult services. This could involve exploring having one case manager to help the individual and/or their family to navigate the service delivery system and identify appropriate supports needed.
4. Improve service coordination in the public adult service system. Clarify the roles and responsibilities of each public agency such that services can be provided more consistently, efficiently, and in a synchronized manner both within agencies and across agencies.
5. Create professional development training options focused on ASD for adult service providers, secondary and post-secondary educational professionals serving transitioning students, caregivers, program administrators, medical professionals, nursing homes, first responders, and employers.
6. Families and individuals with ASD should be actively involved in the process of identifying and establishing appropriate and acceptable living situations. Regulations that restrict funding to specified options should be reviewed and addressed. More options for housing should be explored and expanded such as the "Getting your own address" program.
7. Work with Offices of Disability Support Services, MI-AHEAD and Resource Centers for Persons with Disabilities within community colleges and universities to ensure a successful transition to higher learning and to secure necessary accommodations, supports, and resources for individuals with ASD. In collaboration with colleges, universities, and technical schools, identify creative ways that individuals with ASD who have a range of needs may be involved in post-secondary education, work, and social opportunities on campuses.
8. Improve public transportation options through working with MDOT, public transportation systems, and other private agencies (e.g., taxi companies) to create ideas and develop initiatives/incentives to expand options for individuals with ASD.

9. Improve the transition process from secondary education to post-high programming, and to adult service agencies. Implement a model that brings together representatives from educational and adult service agencies who have dedicated planning time to focus collaboratively on transition outcomes.
10. Collaborate with MRS, CMHSP, advocacy agencies, and private corporations to educate employers about working with individuals with ASD.
11. Develop a system to start communicating with families and individuals with ASD prior to the age of 18 about options available in the adult years. Education should focus on legal issues, as well as options for independence, higher education, employment, and leisure/recreational opportunities, and applying for public services.
12. Explore and expand pilot models to achieve better employment outcomes across the state (e.g., Project Search, Customized Employment).
13. Explore and expand community participation models across the state to promote a sense of belonging for the person with ASD. Such inclusive models will serve to increase the network of natural supports and improve quality of life throughout the community.
14. Refine and broaden data collection efforts to identify individuals with ASD and evaluate outcomes for adults with ASD in Michigan. Relevant areas of data collection might include: employment, post-secondary educational opportunities, housing, social/leisure/recreational opportunities, medical/physical health, and other quality of life outcomes.



Focus Area: Physical, Mental, and Behavioral Health Care

Overall Goal

Across the lifespan, all individuals with ASD in Michigan will have access to high quality, coordinated medical care and behavioral and mental health services provided by knowledgeable, compassionate providers.

Summary of Area

Autism Spectrum Disorder (ASD) is a neurobiological disorder, caused by a host of genetic, metabolic, physiological, and environmental mechanisms, which are not yet fully understood. The complexity of the disorder has a pervasive impact on the quality of life of both the individual with ASD and their family. Due to the ongoing health, educational, and family needs of most individuals with ASD, it is essential that the medical community becomes more strongly involved in the diagnosis and care of people on the spectrum. Individuals with ASD and their families must have access to an array of health care services that effectively meet their functional and clinical needs across the lifespan. However, the health care system is struggling to meet the needs of individuals with ASD. The issues that require intervention are ever changing across the lifespan and require the involvement of primary care providers, mental health providers, and numerous specialists from a variety of fields. Well-trained service providers that implement effective practices are in short supply.

Even though the medical field has developed a greater understanding of developmental disabilities over the past twenty years, the management of developmental disabilities like ASD has often been passed to sub-specialists such as developmental pediatricians. Many primary care physicians report lower confidence in providing primary care to children with ASD than those with other neurodevelopmental conditions such as cerebral palsy and attention deficit disorder (Golnik, Ireland, & Borowsky, 2009). In one study of primary care physicians, few saw themselves as a direct provider of comprehensive ASD care and most found that coordination of care was difficult, especially when it involved reimbursement. Physicians also lacked awareness of community resources (Carbone, et al. 2010).

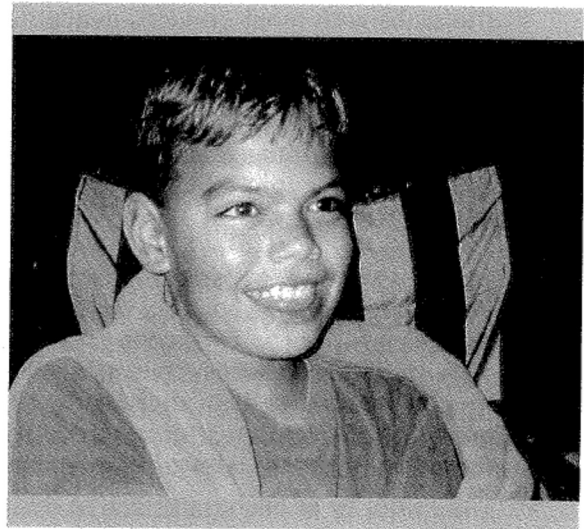
Several studies, have documented the frustration and dissatisfaction that parents of children with ASD often experience, both with initial diagnosis and ongoing management of their child's care. When surveyed, parents of children with ASD were frequently dissatisfied with the primary care physician's ability to answer questions and understand how the child's condition affects the family compared to children with cognitive impairment or a physical disability (Liptak et al 2006). In another study of families living with ASD, only 20 percent of the participants reported that their health care provider helped them learn about ASD. Parents indicated that early negative experiences with their primary care physician influenced future interactions regarding their child's care and added to stress as they attempted to navigate through the health care system (Rhoades et al., 2007).

In most states, behavioral and mental health services for individuals with ASD are most frequently delivered by private agencies and providers or the local community mental health (CMH) system. In early childhood, services might include Early Intensive Behavior Intervention (EIBI), play-based therapies, and respite services. In adulthood, individuals on the spectrum may obtain services from the local CMH as they attempt to negotiate the variety of supported living arrangements available to them, as well as support services for accomplishing activities of daily living, transportation, supported employment, and recreational activities. A majority of children with ASD may not be eligible for services through the local CMH due to income level but often will become eligible as they enter adulthood. Therefore families are often dependent on private family funds or insurance for services. Parents report significant frustration when insurance companies refuse coverage for treatments supported by the research literature. For those individuals and families that have financial resources or insurance coverage for ASD, locating providers that utilize evidence-based interventions can be a challenge.

Key Findings in Michigan

What Is Currently in Place?

- An effort has been made in Michigan to establish medical homes. Children's Special Health Care Services has a grant to build an integrated system of care for children with special health care needs. The major activity of the grant has been to support 13 pediatric practices to improve their medical homes for children and youth with special health care needs. The Michigan Primary Care Transformation Project (MIPCT) has identified 68 pediatric practices in the state who obtained official medical home certification in 2010 by meeting National Council on Quality Assurance (NCQA) or Physician Group Practice Incentive (PGIP) criteria. However, few practices that serve children, including those that qualify as medical homes, are fully prepared to provide comprehensive medical services, including diagnosis and treatment plans, for children and youth with ASD.
- Efforts have been made through the Michigan Chapter of the American Academy of Pediatrics (MIAAP) to increase awareness of ASD among primary care physicians and establish universal screening for ASD.
- For individuals with Medicaid, the Michigan Department of Community Health (MDCH) contracts with 18 Prepaid Inpatient Health Plans (PIHPs), which are comprised of single or multiple Community Mental Health Services Programs (CMHSPs) for services to children and adults with developmental disabilities. Each PIHP is required to have an array of specialty services and supports for both children and adults including community living supports, medication administration, occupational therapy, physical therapy, play therapy, speech, hearing and language, case management, supports coordination, respite care, and family support and training. In adulthood, individuals on the spectrum may obtain services from the PIHP/CMHSP as they attempt to negotiate the variety of supported living arrangements available to them, as well as support services for accomplishing activities of daily living, transportation, supported employment, and recreational activities. A CMHSP must prioritize who receives public mental health services, and when it cannot address all local needs, establish a waiting list process that ensures systematic access into services. Without Medicaid and a priority need, a person with ASD is unlikely to get services from CMHSP.
- The Children's Waiver Program (CWP), administered by the Michigan Department of Community Health (MDCH) and implemented by CMHSP, provides intensive home and community based services to children with severe developmental disabilities who meet an institutional level of care. Approximately half of the 464 children served by the CWP are children with ASD.
- The Family Support Subsidy (FSS) Program was established in statute in 1984 and is currently funded entirely from federal funds. The local CMHSP determines eligibility and provides access to this subsidy program. The FSS provides a monthly payment of \$222.11 to families with net incomes of less than \$60,000 who have a child or children with severe developmental disabilities living with them. Families use the FSS for the special needs of the child and their family. Families may be eligible for this program if they have a child under age 18 who has been recommended by a local or intermediate school district's multidisciplinary evaluation team with an eligibility category of cognitive impairment (CI), severe multiple impairment (SXI), or ASD. Children with ASD must be receiving special education services in a program designed for students with ASD or in a program designed for students with severe cognitive impairment or severe multiple impairments. Of the current recipients, almost 60 percent have incomes of less than \$20,000. Children with ASD are the fastest growing FSS population with 67 percent of current recipients having an ASD label per the Michigan Department of Community Health Family Support Subsidy data base summary as of December 1, 2011.



- Medicaid is a federally-funded, state-run form of health insurance that provides access to medical providers for individuals and families with limited incomes and resources. This program pays for health care costs, including doctor's visits and eye-care.
- MICHild is a health insurance program for uninsured children in Michigan. HMOs and other health care plans throughout Michigan provide MICHild services. Qualifying families pay a \$10 monthly premium without copays or deductibles.
- In the ASD State Plan Family Survey, 62 percent of the respondents marked autism insurance coverage as one of their top priorities for the state. In April 2012, autism insurance coverage legislation was passed with benefits planned to begin in October 2012 if a child has an approved diagnosis of autism spectrum disorder by a qualified professional.
- Adults with ASD who have severe impairments and meet the criteria for developmental disability, as defined in the Michigan Mental Health Code and have Medicaid, are provided an array of services and supports by the CMHSP if they are Medicaid beneficiaries and services are "medically necessary." An adult with ASD who is not a Medicaid beneficiary must meet the criteria for developmental disability as defined in the Michigan Mental Health Code and be a priority population. Depending upon the severity of their ASD and whether it is co-occurring with intellectual disabilities, individuals may receive care in licensed group homes, their families' home, or their own homes for up to 24 hours a day, seven days a week, if medically necessary. They may also receive daytime supports (such as skill-building or supported employment), medication administration, and mental health therapy.
- Behavioral and mental health services are provided by private non-profit and for profit agencies around the state with most services available in the metropolitan areas. However, the availability of high quality, evidence-based interventions is limited across all age groups and geographic locations.
- A tele-health system to disseminate information and services more broadly throughout the state is under development and will be piloted by Eastern Michigan University's Autism Collaborative Center through a one-time allocation of funding from the Michigan legislature.

It would be helpful to have insurance companies **provide coverage** for outside services like occupational and speech therapy.

—Response from ASD State Plan Survey

What Are the Gaps?

- In Michigan and across the country, there is a shortage of specialty care providers. According to a 2010 Physician Survey, about six percent of active health care providers listed psychiatry as their primary specialty with only 2 percent in child and adolescent psychiatry. If 2 percent of the 2,614 Michigan physicians are child psychiatrists, then the state has approximately 52 child psychiatrists to meet the mental health needs of more than 15,000 children and adolescents with ASD. In 2009, Michigan had only eight Developmental Behavioral Pediatricians for its 2,309,198 children (Michigan Department of Community Health Survey of Physicians, 2010).
- The majority of Michigan's active mental health providers are found in metropolitan areas (86.6 percent), while micropolitan (8.8 percent) and rural (4.6 percent) areas have fewer providers (Michigan Department of Community Health, 2008).
- Some children with ASD without Medicaid are not eligible for services from local CMHSP and therefore receive limited or no public support. They are dependent on private family funds or insurance for services, and some insurance does not cover specific services for children with ASD. Individuals and families that have resources find it challenging to locate providers that deliver evidence-based interventions.
- Psychiatrists and other mental health providers do not always have a broad understanding of the characteristics of ASD and how to treat individuals with co-occurring ASD and mental illness.
- The state has an insufficient number of programs and providers with experience addressing significant behavior challenges/crisis intervention. Highly specialized skills are necessary to develop

and implement a comprehensive plan that is capable of directly addressing crisis level behaviors through the use of functional assessment and analysis, particularly for extremely challenging behavior problems in some individuals with ASD.

Recommendations

1. Increase training for health care providers through expansion of ASD specific information in the curriculum of medical education programs (e.g., medical schools, nursing schools, primary care residency programs, dental schools). In particular, providers need to understand signs and symptoms of ASD, changing needs across the lifespan, co-occurring medical and mental health conditions, and crisis intervention.
2. Promote general disability education for health care providers focusing on communication techniques and sensitizing practitioners to potential aversive sensory stimuli in their care settings. This would include dentistry, nursing, radiology, speech therapy, occupational therapy, medical technology, hospital transport, community living support, among others.
3. Coordinate care between primary care providers, mental health providers and educational professionals through the use of an electronic communication tool such as the e-portfolio.
4. Improve access to subspecialists in rural areas of the state through the use of innovative tele-health programs.
5. Proposed autism insurance legislation should be reviewed with knowledge of the research literature on evidence-based services for individuals with ASD (e.g., speech therapy, applied behavior analysis) and the long-term costs associated with limited early intervention programming.
6. The Michigan Department of Community Health should provide information to providers about evidence-based and promising practices.
7. Explore the possibility of a 1915(c) Home and Community-Based Waiver for children with ASD (birth to 18) to provide intensive services in their home and communities as a potential approach for serving non-Medicaid children with ASD.
8. Increase availability of respite services to families in all areas of the state through awareness of available resources and innovative programs that recruit and train respite providers.
9. Address the shortage of both in home and hospital-based crisis intervention services for children and adults with ASD in all areas of the state. This should include increasing the number of trained professionals capable of implementing evidence-based interventions for managing significant challenging behaviors.
10. Increase the retention and recruitment of providers qualified to render the priority services identified in the Michigan ASD State Survey of Families. These may include peer supports, family therapy, speech therapy/communication training, and applied behavior analysis.

We need medical and dental providers who are **trained** in ASD.

—Response from ASD State Plan Survey

Overall Goal

Educators and service providers have access to high quality, comprehensive professional development focused on evidence-based practices to address the critical needs of individuals with ASD across the lifespan.

Summary of Area

Each section in the Michigan Autism Spectrum Disorders State Plan discusses professional development needs across specific areas such as early intervention, families, education, health care, and adult services. This section of the document highlights the importance of professional development as a broad, essential goal for the state in order to move forward in our ability to meet the needs of individuals with ASD. This section also highlights professional development needs that are not addressed in other areas of the plan.

Knowledge and Training of Providers

In order for children and adults with ASD to achieve positive outcomes, providers who work in schools, health care, and community service programs need to be well-versed in EBP. From screening to evaluation and schooling to employment, providers must understand how to best identify, support, teach, and train individuals with ASD if they are to have a good quality of life. With the support of well-trained early interventionists, children with ASD will develop better communication and learn more adaptive behaviors that reduce the likelihood of significant challenging behaviors to set them on a positive life course.

With support from highly qualified school personnel, students with ASD are more likely to be fully included in regular classrooms with access to the general curriculum. When adolescents and young adults with ASD are taught and coached by knowledgeable and skilled providers, they are more likely to go on to post-secondary education or technical training, to be gainfully employed, and actively engaged in community life. To achieve these positive outcomes, states must commit to provide quality professional development, training, and mentoring opportunities for the professionals and paraprofessionals who support individuals with ASD.

We need more **training** for para-educators to better help students with ASD.

—Response from ASD State Plan Survey

Around the country, many states are experiencing a shortage of providers to support the many needs of individuals with ASD. In its 2003 report, McLesky, Tyler, and Flippin found that 98 percent of the nation's school districts reported shortages of special education personnel. A report by the U.S. Department of Health and Human Services predicts that by 2020 the nation will need 37 percent more direct support professionals to meet the long-term support needs for people with developmental disabilities (<http://aspe.hhs.gov/daltcp/reports/2006/DSPsupply.htm>). Some shortages are specific to the needs of individuals with ASD, such as the need for more behavior analysts who are trained in specific interventions that are highly effective for teaching individuals with ASD and addressing significant behavior challenges. In addition to a shortage of personnel, many of the providers who are available lack the necessary knowledge and skills to deliver high quality, evidence-based services to individuals with ASD and their families.

The most frequent modes of training professionals and direct service providers involve presentations such as workshops and conferences. Although beneficial to obtain basic information, this type of training is frequently insufficient to change the behavior and practice of a provider. Work by Joyce and Showers (1995) shows that training alone rarely leads to application of skill with only 5-10 percent of training participants changing their behavior. However with coaching and follow up, 80-90 percent of participants involved in training implement what was taught. This data is well-supported by other studies as well as real world experience that shows little behavior change from simply attending a professional development session.

In order for professionals and direct care providers to significantly change behavior and implement new strategies and processes, professional development must be re-formulated to include elements of ongoing teaching, technical assistance and coaching, community learning groups, and accountability measures. Exposure to relevant readings and workshops may be helpful, but these tools must be accompanied by ongoing support from, and problem solving with, others who have expertise and experience specific to ASD. Effective training must include hands-on training and feedback and follow-up monitoring and accountability. Additionally, professional development must become more accessible (e.g. through distance learning) to a wide range of providers who may struggle to participate in traditional professional development programs due to geographical or scheduling constraints.

Due to the broad and often complex needs of individuals with ASD, there is a wide range of interventions that are potentially effective and it is difficult for providers to become proficient in many different interventions. Providers serving individuals with ASD must work as a team to achieve the most effective outcome. In *Educating Children with Autism*, the National Research Council (2001) stated "Effective programming for children with autism and their families requires that the direct service provider (e.g., special education teacher, regular education teacher, early childhood teacher, speech and language pathologist, private providers) be a part of a support system team, not an isolated individual that is struggling with complex neurological, sociological, educational, and behavioral problems" (p. 184). Therefore, providers must learn skills to function as a team to implement the most effective programs, which requires skills in communication, teaming, problem solving, and conflict resolution.

Knowledge and Training of the Community

Finally, it is not only professional, direct care providers and families who need training but also community members who will come across individuals with ASD throughout their daily lives. With the rising incidence of ASD, it is certain that encounters will occur between individuals with ASD and law enforcement officers, emergency responders, foster care workers, child and family service workers and many others. Unfortunately, many of these interactions are confusing and overwhelming to people lacking information about ASD. For example, individuals with ASD are four to seven times more likely to have an encounter with law enforcement than the general population (Debbaudt & Rothman, 2001). When police officers lack information about ASD, the consequences can be devastating because many people with ASD are unable to communicate sufficiently or become upset in new situations with unfamiliar adults. Nationally, many public safety departments are participating in training to become more aware of ASD and other disorders. However, these efforts must expand their reach to include all first responders. The specialized training developed for first responders can serve as a model of training for other community members who need information about people with ASD.

Key Findings in Michigan

What Is Currently in Place?

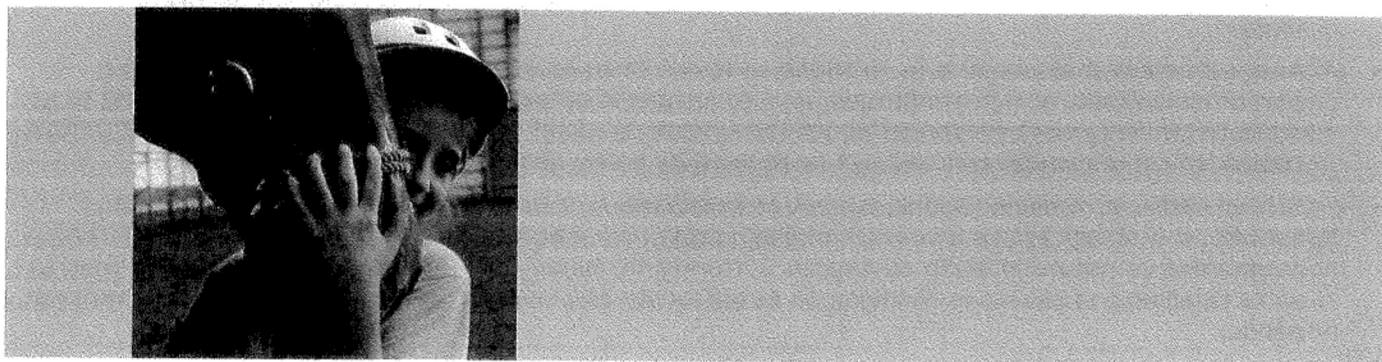
- Michigan now has several universities offering an ASD teaching endorsement and the state currently has 832 teachers with an autism endorsement.
- A state funded project, START, provides intensive professional development opportunities along with training in teaming and coaching to educators in order to promote implementation of evidence-based practices. Similar types of intensive training for non-school professionals and direct care providers are limited.
- Although many first responders in Michigan have not been exposed to information about ASD, parent organizations, non-profit groups, and government agencies across the state are working to educate law enforcement personnel about the unique needs of people with ASD. For example, Dennis Debbaudt's first responder training has been used by many groups.
- School systems, provider agencies, parent associations, non-profit organizations, state funded initiatives, and others are sponsoring training opportunities around the state in topics ranging from augmentative communication to advocacy. Currently, Michigan does not have a centralized system to allow families and providers in Michigan to easily locate and register for trainings that best meet their needs.

What Are the Gaps?

- Across the state, the availability of high quality professional development may be inconsistent due to financial disparities and geographical limitations.
- In the Michigan ASD State Survey of School Professionals and the Michigan ASD State Survey of Families, families and school professionals identified education and training for school personnel as one of the top priorities for the state.
- Paraprofessionals in schools and direct service providers in work and living settings need to receive ongoing training to reduce the turnover rates and inconsistent service provision.
- Many health care providers do not have the training or expertise to work with individuals with ASD, particularly adolescents and adults. Families have limited health care options for general health care and treatment of co-occurring conditions. The complexity of ASD layered on other behavioral, mental health, or physical health concerns makes treatment challenging. Primary care providers, psychiatrists, and psychologists may have only limited knowledge of ASD and may therefore be less effective in the treatments and practices they recommend for these individuals.
- Families report a shortage of respite providers, especially in rural areas and some urban areas. Although the state unemployment rate remains high, the training needed to prepare potential respite providers is not readily available.
- Many adult service providers through Community Mental Health Service Programs and Michigan Rehabilitation Services are gradually being exposed to the rising number of individuals with ASD. In 1990, only 1,203 individuals with ASD were served under the ASD special education eligibility label in Michigan and therefore adult service providers interacted with only a small number of people with ASD. As the numbers of school age students with ASD have gradually risen in the state, the number of adults with ASD too has risen. Many adult service agencies and providers are not fully prepared for the massive wave of young adults with ASD who will be entering the adult system over the next several years.

Recommendations

1. Expand evidence-based, high quality pre-service and in-service professional development, technical assistance, and mentoring opportunities to ensure that Michigan has providers able to support individuals with ASD to be fully included in all aspects of their community. Identify innovative ways to develop, deliver, market, and fund pre-service and in-service professional development opportunities that promote evidence-based and promising treatments. The development of best practice guidelines and standards for practice would help guide the development of pre-service and in-service training curricula related to effective interventions and practice.
2. Ensure that institutions of higher education and state sponsored trainings utilize the literature and resources on evidence-based practice as the foundation for pre-service and in-service professional training.



3. Work with universities to train more students in shortage areas, such as applied behavior analysis, to increase the number of these providers in schools, mental health settings, and adult service agencies.
4. Work with universities to more effectively train pre-service general education teachers about autism, as well as about the classroom management skills and academic supports that will facilitate the participation of students with ASD in general education settings.
5. Develop more training for paraprofessionals working in schools and direct support providers working in community based services with individuals with ASD. Find creative ways to offer this certification such as through distance learning and online opportunities.
6. Identify models and mechanisms for training respite providers and create a better system for families to access trained respite providers.
7. Identify models and funding for community members who need training such as first responders, public transportation personnel, and providers in agencies that provide indirect services such as foster care workers.
8. Additional professional development recommendations for health care providers, school personnel, and adult service providers are provided in the respective focus area sections of this document.

START training was very helpful. However, more **coaching** for implementation is needed.

—Response from ASD State Plan Survey

Funds from multiple sources, including public, private, federal, and state must be brought together to support the recommendations laid out in this document. The Autism Council should explore logical ways to implement the plan with existing organizations and resources as well as examine the need for additional funding and potential sources of such funds.

Sufficient funds must be directed toward the treatment and services for young children with ASD who need intensive early intervention services to maximize each child's learning potential, which will prevent costly lifelong supports. Jacobson, Mulick, and Green (1998) estimated that a three-year investment in Early Intensive Behavioral Intervention would produce considerable savings by lowering support costs over a lifetime and improving the quality of life of individuals and their family. Public funds alone cannot manage the cost of providing intensive early treatment. Funding should include: public spending for treatment and support, including Medicaid, special education funds, and other state funded programs; the child's family both directly and indirectly; and funding through health insurance and private agencies. This approach will help achieve a more balanced approach to funding the treatment of ASD.

In April 2012, Senate Bill No. 414 and Senate Bill No. 415 were passed to provide health insurance coverage for the diagnosis and treatment of autism spectrum disorders. Applied behavior analysis may be subject to a maximum yearly benefit of \$50,000 for children between the ages of birth to 6 years of age, \$40,000 between the ages of 7-12 years of age, and \$30,000 between the ages of 13-18 years of age. Coverage is limited to a member up to age 18. This coverage is all-inclusive of treatments for autism, including speech, occupational, and physical therapy; and psychiatric and psychological care. Therapy for ASD will be covered only after a medical diagnosis of ASD is given by a licensed psychologist or physician. Senate Bill No. 981 was passed to reimburse carriers and third party administrators (TPAs) for paid claims for the "diagnosis of autism spectrum disorders" and "treatment of autism spectrum disorders" as those terms are defined in Senate Bills 414 and 415.

Grant funding should be sought from federal sources such as the Combating Autism Act funds through the *Health Resources and Services Administration* (HRSA). In 2006, Congress passed the first piece of legislation specific to ASD. The *Combating Autism Act* (CAA) authorized \$920 million in federal funding over five years for basic research, surveillance, public awareness, and early identification initiatives. While the majority of the funds were targeted for research, the CAA earmarked \$36 million in 2008 for treatment and support services through the Health Resources and Services Administration. A state plan was one of the eligibility requirements for receipt of these funds. On September 20, 2011, the *Combating Autism Reauthorization Act* was signed into law. The reauthorization act renews the 2006 *Combating Autism Act* for another three years and authorizes \$693 million in federal support for autism research and treatment. However, before monies authorized in the law can become available funding must be appropriated.

To implement a coordinated and comprehensive state plan in Michigan, it is necessary that the Autism Council explores options to improve funding for ASD coordination and services statewide. The Council should review additional grant options, promote collaboration amongst researchers from multiple universities across the state, and develop regional networks for ASD services that result in improved resource-sharing and efficiency. Additionally, state agencies need to work in partnership to better coordinate and allocate resources.

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Applied Behavior Analysis (ABA): ABA is an evidence-based approach that seeks to teach adaptive behaviors and reduce the frequency of challenging behaviors. It includes multiple assessment strategies to understand the relationship between environment and behavior.

Asperger Syndrome (AS): An autism spectrum disorder without cognitive impairment or speech delays. Individuals with AS typically experience impairments in social interaction and pragmatic language, and usually have intense areas of interest and some ritualized or rigid patterns of behavior.

Autism: Autism is a complex, lifelong neurobiological disorder that is part of a group of disorders known as autism spectrum disorders (ASD). It is four times more common in males and occurs in all racial, ethnic, and social groups. Autism impairs a person's ability to communicate and relate to others. It is also associated with rigid routines and repetitive behaviors. Characteristics can range from mild to severe.

Autism Spectrum Disorders (ASD): Autism Spectrum Disorders are a set of disorders that include autism, Asperger syndrome (AS), and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS). All individuals with ASD demonstrate difficulties in the areas of communication and social interaction. Individuals with ASD also exhibit restricted or repetitive behaviors or interests. The expression of ASD characteristics vary among individuals.

Combating Autism Act (CAA): This federal legislation passed in 2006 authorized \$920 million in federal funding for a variety of autism initiatives.

Combating Autism Reauthorization Act of 2011: The reauthorization of the 2006 *Combating Autism Act* was signed on September 20, 2011 and renewed the act for another three years. It authorizes another \$693 million in federal support for autism research and treatment.

Community Living Supports (CLS): CLS staff works to increase or maintain personal self-sufficiency. This allows individuals more opportunities for community inclusion including the ability to remain in one's home. The supports may be provided in the person's home or in community settings.

Community Mental Health Services Programs (CMHSPs): Mental health services for individuals with developmental disabilities (including ASD), mental illness, and substance abuse are coordinated through local CMHSPs.

Competitive Employment: Competitive employment involves work in the competitive labor market with an established business or through self-employment. Competitive employment may be performed on a full-time or part-time basis in an integrated setting comparable to that of others performing similar work. Individuals are compensated at or above the minimum wage, but not less than the customary wage and level of benefits paid by the employer for the same or similar work performed by employees who are not disabled.

Culture of Gentleness: The culture of gentleness is based on the Gentle Teaching philosophy of John McGee, Ph.D. The core principles are based on a psychology of human interdependence. It asks caregivers and care providers to look at themselves and their spirit of gentleness in order to find ways to express warmth and unconditional valuing towards those who are the most disenfranchised from family and community life. It views the caregiver role as critical and requires a deep commitment to personal, organizational, and social change.

Customized Employment: The customized employment process is a flexible blend of strategies, services, and supports designed to increase employment options for job seekers with complex needs through the voluntary negotiation of the employment relationship with an employer. The job seeker is the primary source of information and drives the process. The customized employment process begins with an exploration phase that lays the foundation for employment planning. Planning results in a blueprint for the job search, during which an employment relationship is negotiated to meet the needs of both the job seeker and the employer.

Department of Community Health (DCH): In 1996, DCH was created through the merger of the Department of Public Health, Department of Mental Health, and Medical Services Administration (from the Department of Social Services). DCH oversees health policy and management in Michigan.

Department of Human Services (DHS): The Department of Human Services (DHS) is Michigan's public assistance, child and family welfare agency. DHS directs the operations of public assistance and service programs through a network of over 100 county departments of human service offices around the state.

Department of Licensing and Regulatory Affairs (LARA) (formerly Michigan Department of Energy, Labor, and Economic Growth [DELEG]): Within the state of Michigan, this department oversees issues related to energy, employment, professional licensing, construction, and commerce.

Diagnostic Evaluation for ASD: A full clinical assessment to determine if an individual meets the diagnostic criteria for ASD. The evaluation may include physical, neurological, psychological and genetic testing; clinical observations; parent interviews; developmental histories; speech and language assessments; and behavioral observations. There is no medical test for ASD.

Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revisions (DSM-IV-TR): The Diagnostic and Statistical Manual of Mental Disorders (DSM), published by the American Psychiatric Association, is the standard classification of mental disorders used by mental health professionals in the United States. The current DSM-IV-TR, published in 1994, is under revision.

Early On®: Michigan's early intervention system for developmental delays and/or disabilities for infants and toddlers aged birth to three years of age. *Early On* supports families as their children learn and grow.

Early Periodic Screening Diagnosis and Treatment (EPSDT): Early and Periodic Screening, Diagnostic and Treatment (EPSDT) provides comprehensive and preventive health care services for children under age 21 who are enrolled in Medicaid. EPSDT is important to ensure that children and adolescents receive appropriate preventive, dental, mental health, developmental, and specialty services. The goal of these prevention-oriented services is the early identification of conditions that can impede children's natural growth and development so as to avoid the health and financial costs of long-term disability.

Easter Seals Living with Autism Study: In cooperation with the Autism Society of America, Easter Seals surveyed over 2,500 parents of children with autism and typically-developing children about daily life, relationships, independence, education, housing, employment, finances, and health care.

Evidence-Based Practices (EBP): Treatment and educational strategies whose efficacy has been validated through published research in peer-reviewed professional journals.

Individuals with Disabilities Education Act (IDEA): The federal law ensuring a free and appropriate public education to all children with disabilities. IDEA governs how states and public agencies provide early intervention, special education, and related services to eligible infants, toddlers, children, and youth with disabilities.

Individualized Educational Program (IEP): In the U.S., the IDEA requires public schools to develop an IEP for every student with a disability who is found to meet the federal and state requirements for special education. The IEP must be designed to provide the child with a free appropriate public education (FAPE).

Job Coach: Job coaching refers to the training of an employee by an approved specialist, who uses structured intervention techniques to help the employee learn to perform job tasks to the employer's specifications and to learn the interpersonal skills necessary to be accepted as a worker at the job site and in related community contacts. In addition to job-site training, job coaching includes assessment, job development, counseling, advocacy, travel training, and other services needed to maintain the employment.

Least Restrictive Environment (LRE): The least restrictive environment is identified as one of the six principles that govern the education of students with disabilities. By law, schools are required to provide a free appropriate public education (FAPE) in the LRE for students who have disabilities. LRE means that a student who has a disability should have the opportunity to be educated with non-disabled peers to the greatest extent possible. They should have access to the general education curriculum, extracurricular activities, or any other program that nondisabled peers are able to access.

Medical Home: A community-based primary care setting which provides and coordinates high quality, planned, family-centered health promotion and chronic condition management.

Michigan Department of Education (MDE): The Department of Education, under the direction of the Superintendent of Public Instruction, carries out the policies of the State Board of Education. The department implements federal and state legislative mandates in education, and oversees the schools districts in the state of Michigan, providing leadership and supervision over public education.

Michigan Rehabilitation Services (MRS): Michigan Rehabilitation Service exists within the Department of Licensing and Regulatory Affairs. It is the federally mandated (and federally funded, with a state match) public rehabilitation agency in Michigan providing services for individuals with disabilities to gain and maintain employment, self-sufficiency, and independence. To qualify, individuals must have a mental or physical disability that is a significant barrier to employment, have a need to benefit from vocational rehabilitation services, and must want to work.

Michigan Transition Outcomes Project (MI-TOP): MI-TOP is funded through the Michigan Department of Education, Office of Special Education and supports the implementation of effective transition practices to ensure all students are prepared for post-secondary education, employment, and independent living. The project includes measurable student focused planning, student development activities, and continuous family and community involvement.

Multi-Disciplinary Model: An evaluation and intervention approach that involves professionals from several disciplines, such as education, psychology, medicine, occupational therapy, speech-language pathology, and working in conjunction with an individual and family.

Occupational Therapist (OT): Certified professionals who help individuals in the areas of fine and gross motor development, visual motor integration, visual perception, neuromuscular control, response to sensory stimuli, bilateral coordination, and motor planning. Some occupational therapists have training in sensory integration therapy.

National Longitudinal Transition Study 2 (NLTS2): The NLTS2 was funded by the U.S. Department of Education and documents the experiences of a national sample of students who were 13 to 16 years of age in 2000 as they moved from secondary school into adult roles. The study focused on a wide range of important topics, such as high school coursework, extracurricular activities, academic performance, post-secondary education and training, employment, independent living, and community participation. The study produced information of interest to many audiences, including state and local education agencies, the U.S. Congress, the U.S. Department of Education, parents, teachers, researchers, advocates, and policy-makers.

Paraprofessional: A trained aide who assists a professional person such as a teacher.

Part B of the Individuals with Disabilities Education Act (IDEA): Part B provides assistance for education of all children with disabilities, ages 3-21. In Michigan, eligible individuals with disabilities may receive special education and related services under IDEA Part B through age 26.

Part C of the Individuals with Disabilities Education Act (IDEA): Part C was established in 1986 by Congress to ensure that infants and toddlers (from birth to age three) at risk for or with a developmental delay and their families receive appropriate early intervention services. Michigan's *Early On* is the program for Part C.

Person-Centered Planning: An individualized planning process that takes into consideration the person's unique strengths, learning styles, and life circumstances. The person with a disability, such as ASD, and the family guide the process and make the ultimate decisions about services and supports.

Pervasive Developmental Disorder (PDD): A diagnostic category of disorders in the Diagnostic and Statistical Manual for Mental Disorders, 4th edition (DSM-IV) that includes autism, Asperger Syndrome, childhood disintegrative disorder, Rett's Syndrome, and Pervasive Developmental Disorder-not otherwise specified (PDD-NOS). PDD is frequently used synonymously with autism spectrum disorders. The upcoming DSM, 5th edition has proposed replacing PDD with autism spectrum disorders (ASD).

Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS): Individuals who have symptoms common with autism, but who do not meet all of the criteria that are required for an autism or Asperger diagnosis. Also known as atypical autism.

Primary Care Provider (PCP): A primary care provider is a pediatrician, family practice physician, nurse practitioner, or physician's assistant that provides medical care for an individual or family.

Project Lifesaver: Project Lifesaver International helps provide rapid response to save lives and reduce potential for serious injury for adults and children who wander due to Alzheimer's, autism, Down Syndrome, dementia, and other related cognitive conditions. This program provides in-depth training for law enforcement and other public safety agencies on the use of specialized electronic search and rescue equipment, technology and procedures, as well as teaching rescuers how to communicate with people who have cognitive conditions, all of which are essential to the successful rescue of missing persons who wander or otherwise become lost. They certify search and rescue personnel and provide ongoing management to participating agencies.

Project SEARCH: Project SEARCH is dedicated to providing education and training to young adults with intellectual and developmental disabilities through an innovative workforce and career development model that benefits the individual, workplace, and community. Its primary goal is to secure competitive employment.

Respite Care: Respite gives the family a break, similar to childcare, and provides the child with opportunities to develop social skills with peers and adults outside of the family. For older children or adults, respite care allows the individual with ASD to build independent living skills. Respite care service may be available for the family of an individual who qualifies for enrollment in a Community Mental Health Service Program. Short-term care may occur in the family's home or out-of-home by a trained caregiver.

Self-Determination: The four principles of self-determination are freedom, authority, support, and responsibility. Freedom refers to the fact that individuals have the same rights as all citizens. Authority prioritizes control of financial resources to the individual with the disability. Support refers to the organization of resources in individualized ways based on the needs and desires of the person with the disability. Responsibility references the efficient use of funds as an investment in a person's life, rather than to purchase services or slots.

Service Coordination: Service coordination is often described in terms of specific service delivery functions and activities aimed at assisting individuals and families to obtain appropriate and needed services from agencies in a community or geographical area.

Service Provider/Provider: Any professional, paraprofessional, or direct care worker that provides educational, health, mental health, daily living, or employment service or support.

Sheltered Workshop: Sheltered workshops provide people with intellectual and developmental disabilities employment opportunities in segregated environments that are isolated from the community. In general, these employment settings are associated with low earnings and limited interactions with non-disabled individuals.

Speech and Language Pathologists: Certified professionals who treat disorders related to speech, language, communication, articulation, and fluency.

Supported Employment: Supported employment refers to competitive work in integrated settings with supports and assistance. These supports may include job coaching, transportation, assistive technology, specialized job training, and supervision, as needed. Individuals in supported employment earn at least minimum wage.

System of Care: System of care is an approach to collaboration and coordination across systems, communities, agencies, families and youth that promotes the physical, emotional, intellectual and social wellness of children and youth across the lifespan. In partnership with youth and families, a system of care creates a coordinated network of services and supports that is characterized by multi-system sharing of resources and responsibilities.

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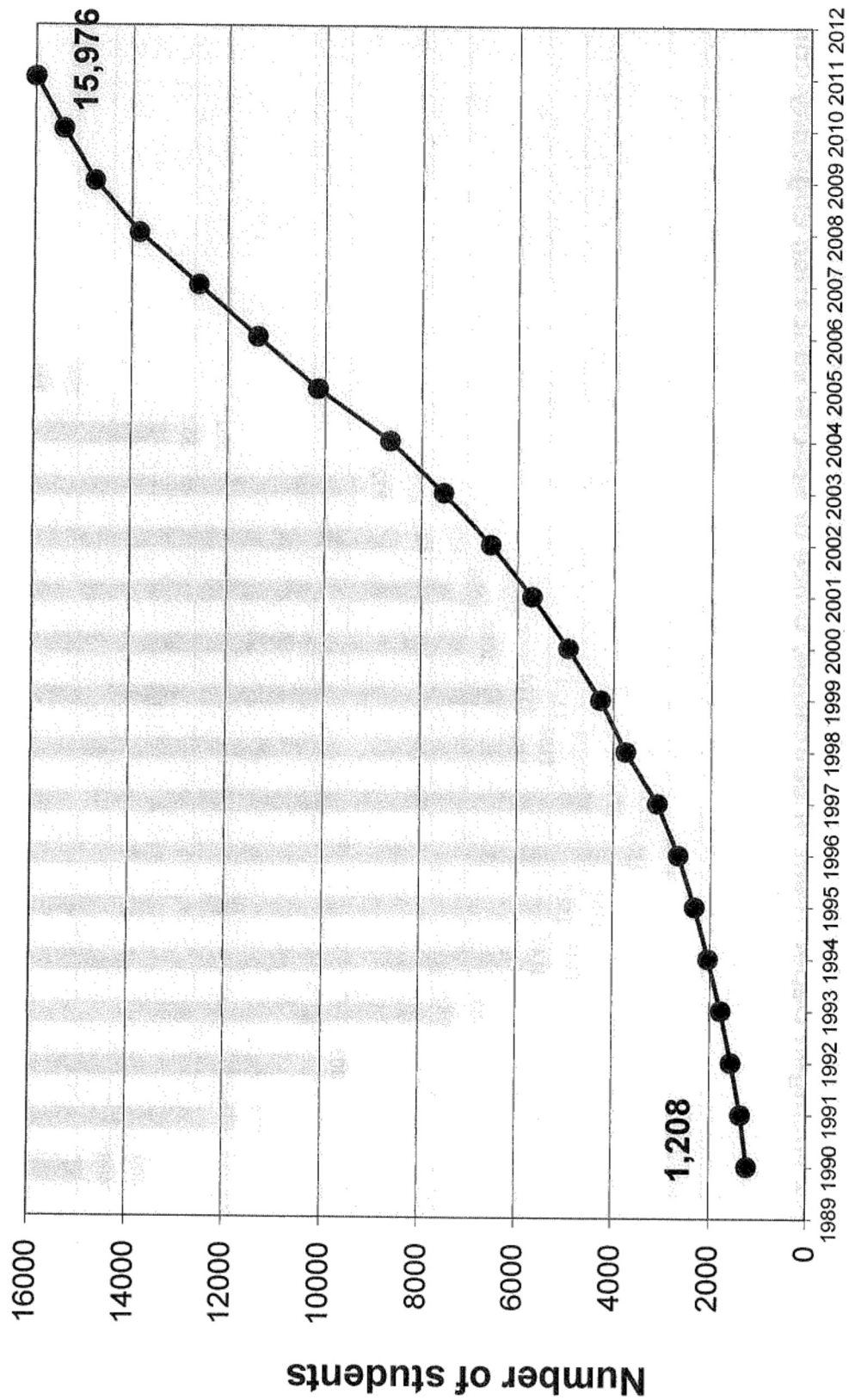
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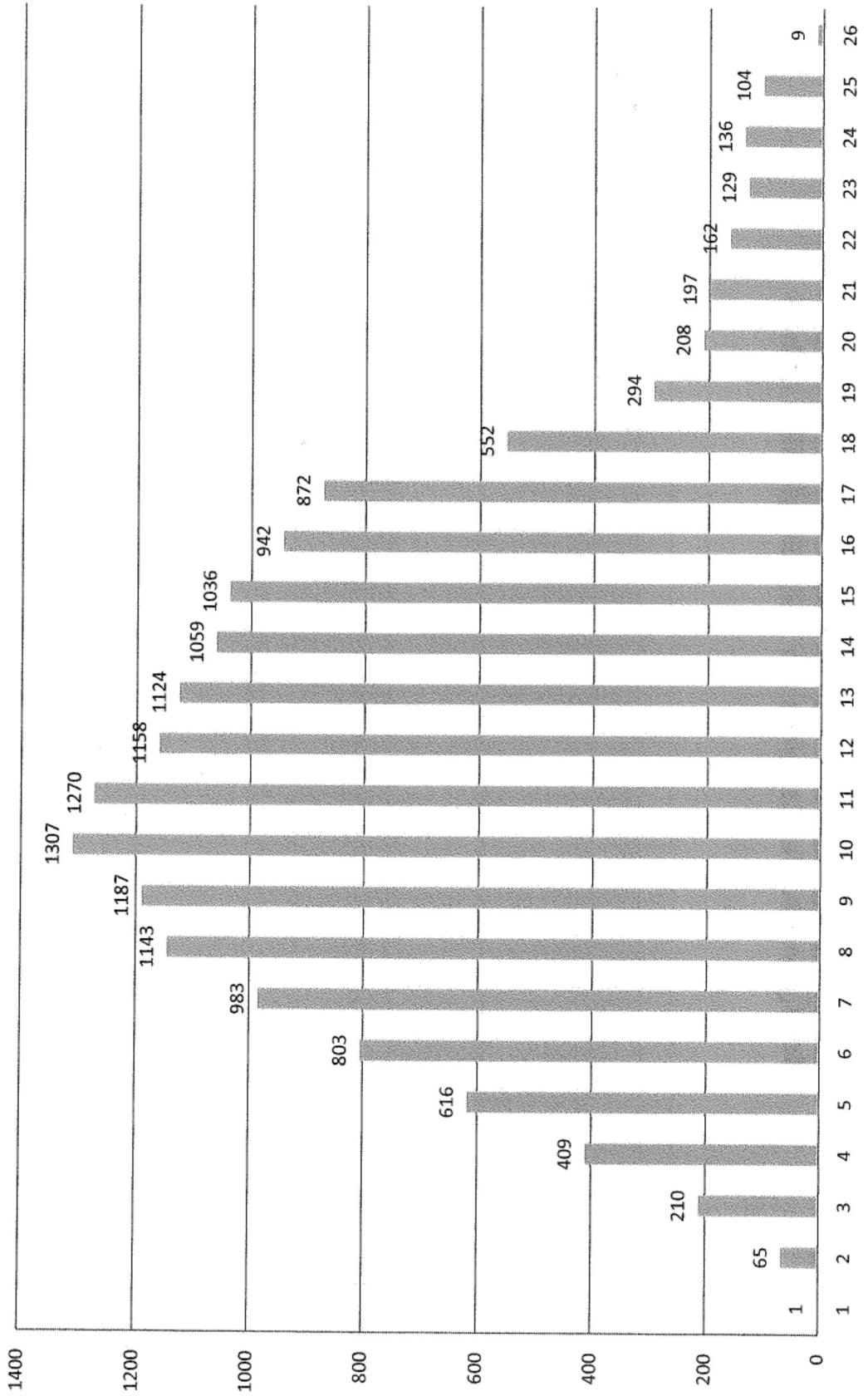
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Appendix 1

Michigan Students with an ASD Eligibility Label



Michigan Students with an ASD Eligibility Label by Age
Based on 2011 Michigan Department of Education, Office of Special Education Eligibility Count



Appendix 2

State Plan Survey Information

In order to gather information for the Michigan ASD State Plan, family members and school professionals were surveyed separately and anonymously using Survey Monkey, an online survey tool. This survey was made available on the Michigan ASD State Plan website and distributed to numerous agencies, organizations, and individuals via email distribution lists and listservs. Survey data were collected from January, 2011 to March, 2011. A total of 312 family surveys and 612 school professional surveys were completed.

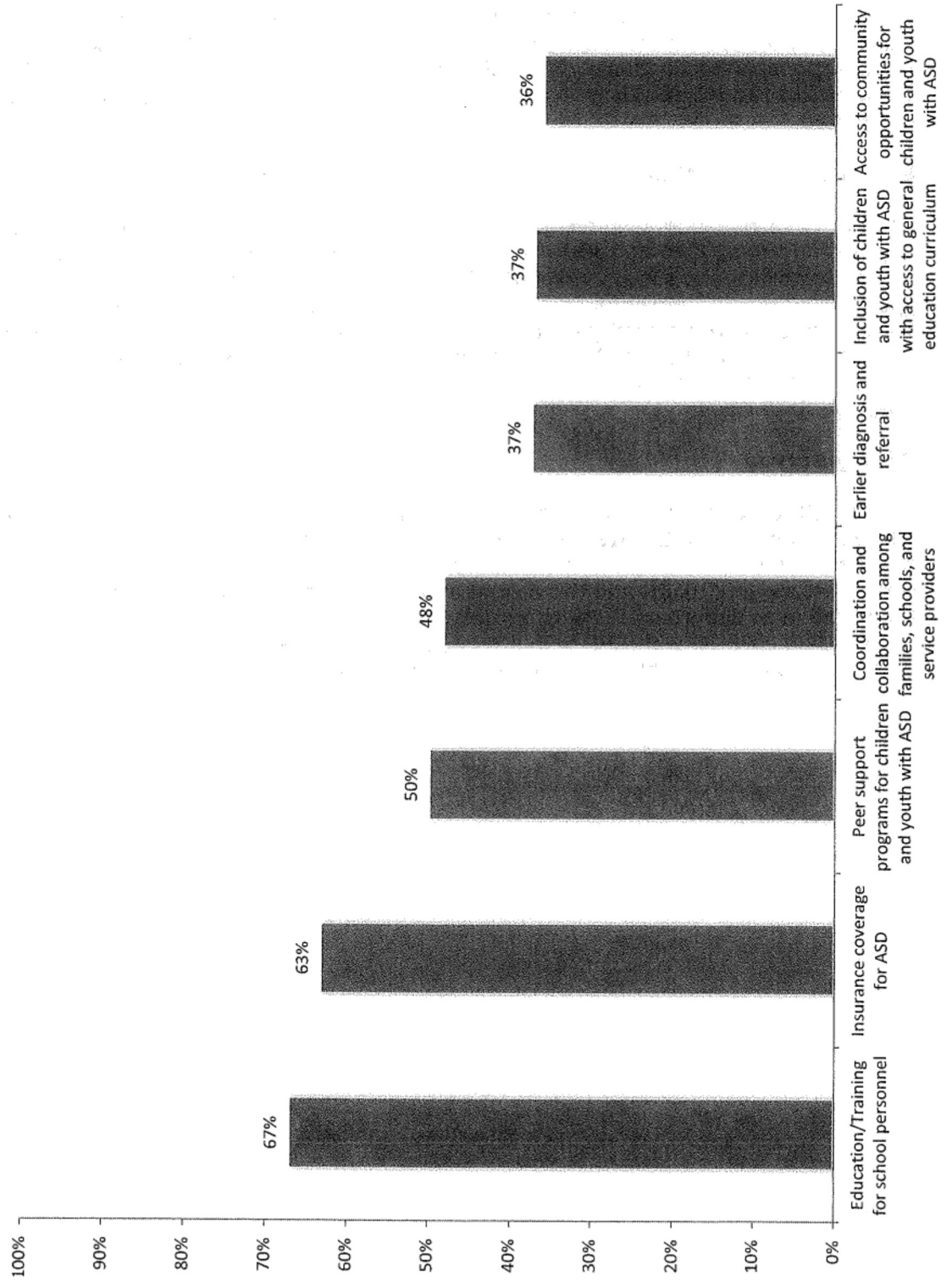
School Professional Survey

Of the 612 respondents who completed the school professional survey, 25% identified themselves as special educators, 11% as autism consultants, and another 11% as speech/language pathologists. Other respondents included social workers (10%), school psychologists (6%), general education teachers (5%), special education administrators (9%), non-special education administrators (3%), and occupational therapists (5%). The majority of respondents came from the Southeast region of the state (44%), followed by the Southwest (26%), and the central area of the state (17%). Most respondents indicated that they worked in suburban (37%) or rural settings (30%). Twenty percent indicated they worked in medium-sized cities.

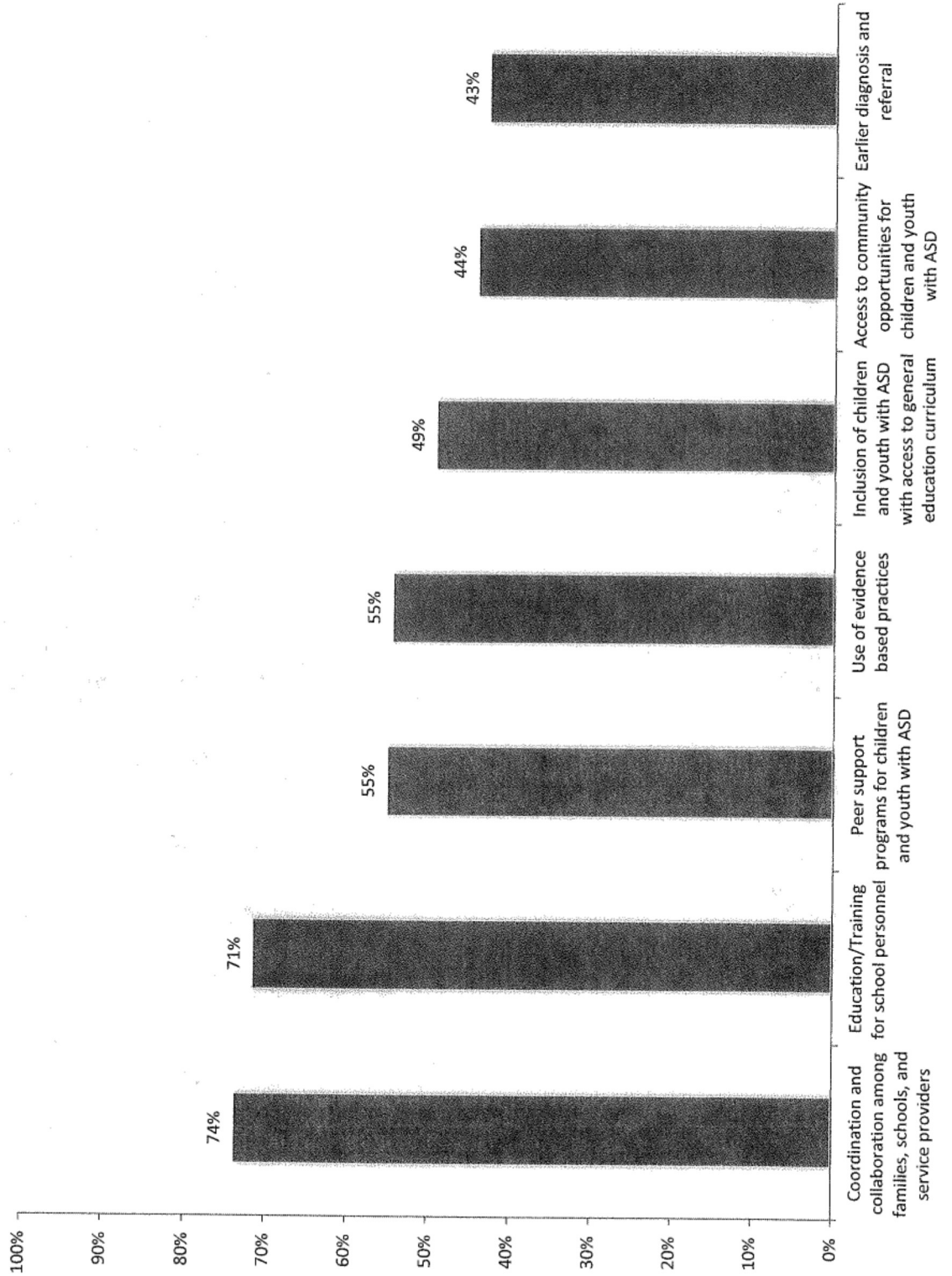
Family Survey

Of the 318 respondents who completed the family survey, 85% were mothers of individuals with ASD, 8% were fathers, and 3% were grandparents. Four percent had other familial relationships (e.g., siblings or other relatives). Family respondents were primarily from the southeast region of the state (50%), the southwest region (20%), and the central area of the state (18%). Forty-seven percent described the area they lived in as suburban, 23% as a medium-sized city, and 21% as rural. More than 70% of surveyed families had children with ASD who attended public elementary or secondary schools, while 11% had children who were educated in public center-based school programs.

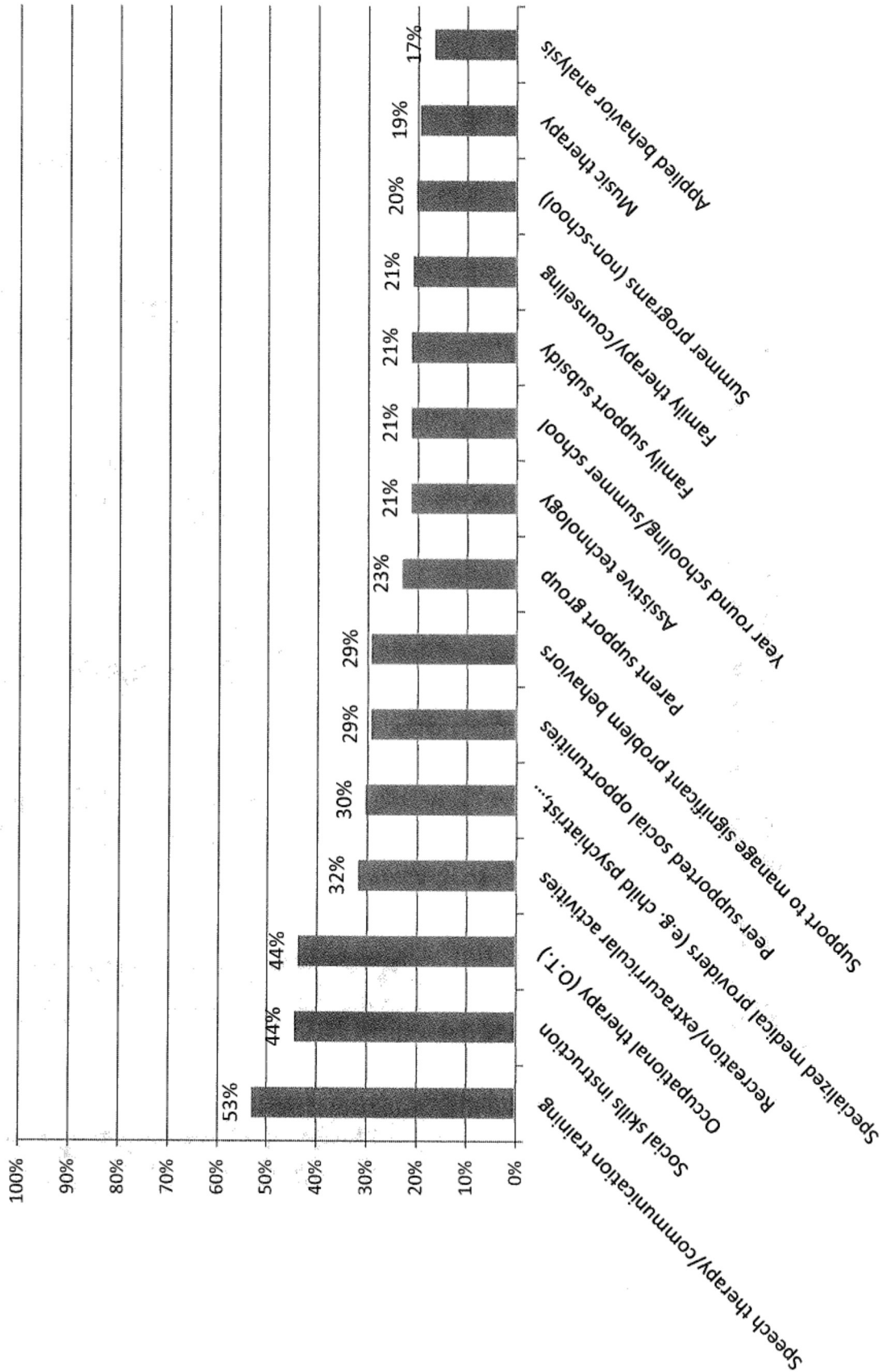
Michigan ASD State Plan Family Survey Top Seven Priorities Identified by Families



Michigan ASD State Plan School Professional Survey Top Seven Priorities Identified by School Professionals



Michigan ASD State Plan Family Survey Top 15 Services Used by Families in the Past 6 Months



Michigan ASD State Plan Family Survey Top 15 Services Needed by Families in the Past 6 Months

