## Navigating Services for Young Children with Autism Spectrum Disorder (ASD)

A Michigan Guide for Families





### March 2012

To access this and other documents on ASD, go to:

ddi.wayne.edu

### **Navigating Services for Young Children with** Autism Spectrum Disorder (ASD) A Michigan Guide for Services

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Michigan has a strong commitment to people with developmental disabilities including children with autism spectrum disorder (ASD). ASD is chronic and difficult to diagnose. However, early intervention is key to producing positive outcomes in children with ASD.

# **Statistics on ASD**



- 1 in 110 children in the U.S. has ASD (Centers for Disease Control Data & Statistics)
- ASD is the fastest growing developmental disability in the U.S. (Autism Speaks)
- Boys are 4-5 times more likely to be diagnosed than girls (National Institute of Mental Health)
- The number of individuals identified nationally with ASD is growing 10-17 percent annually (US Department of Education)
- In 2010, 15,403 students, aged birth to 26 years were identified with ASD in Michigan. In 1990 there were 1,203 students identified with ASD (Michigan Department of Education)
- ASD's occur in all racial, ethnic, and socioeconomic groups (CDC)
- About 40% of children with ASD do not talk (CDC)
- ASD is a lifelong disability
- Individuals with ASD live a normal life span
- It is not known exactly what causes ASD, but current studies suggest autism is caused by a combination of genetic and environmental factors that affect early brain development (Autism Speaks)

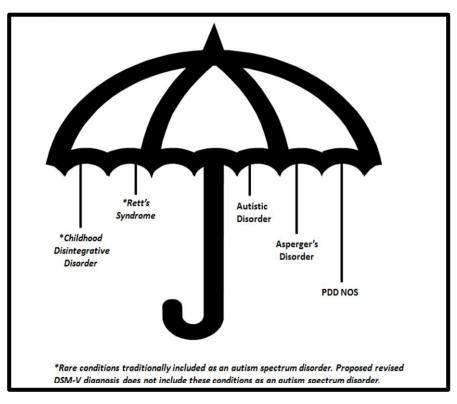
Possible Signs of ASD (American Academy of Pediatrics [AAP] Healthy Children; Centers for Disease Control Act Early)

Areas of Concern	Example
Impaired Social Communication Skills	Child Does NOT: • Respond to name (appears deaf) • Share Interests • Make eye contact • Have warm/joyful expression • Search for objects that are hidden • Point at something of interest • Interact with peers and/or family (may desire to be alone)
Impaired Communication Skills	Child Does NOT: <ul> <li>Babble or coo by 12 months</li> <li>Use gestures or any words by 12 months</li> <li>Use single words by 16 months</li> <li>Use 2-word phrases by 24 months</li> <li>Use typical speech (normal rhythm, pitch, volume)</li> </ul>
Repetitive or Restricted Behaviors	<ul> <li>Behaviors Observed</li> <li>Focused on objects or parts of objects (spinning wheels of a car, fan spinning, pushing buttons on an answering machine)</li> <li>Repetitive body movements (hand flapping, spinning, toe walking, rocking, teeth grinding, slapping self)</li> <li>Resists change in routine</li> </ul>
Other Behaviors or Concerns	<ul> <li>Over or under sensitive to lights, smells, touch, noise, tastes, pressure (sensory concerns)</li> <li>Extreme meltdowns or tantrums</li> <li>Sleeping difficulties</li> </ul>



### WHAT IS A SPECTRUM DISORDER?

ASD is a Spectrum Disorder.... .... because it affects EACH person differently. Every person has a unique set of characteristics. Each person's ability to communicate, process, socialize, and manage behaviors is different, depending on how significantly ASD has affected THEM.



\*Every 20 minutes....a child is diagnosed with autism. It's much more common than people think...learn the early warning signs of autism and if you're concerned about your child's development, talk to your doctor. Early intervention could make a big difference in your child's future." Bob Wright, Co-Founder Autism Speaks



"Autism is part of my child; it is not everything he is...my child is so much more than a diagnosis."

Sandra L. Wetendorf-Coelho, *The World* According to August—One Good Friend

Conducting an assessment and obtaining an ASD identification or diagnosis is important for families. It helps the extended family and friends to understand why the child acts or communicates in certain ways. It also allows families to obtain needed supports and services that will help their child.

**Medical Diagnosis** A Medical Diagnosis can only be provided by a qualified physician, psychiatrist, or psychologist using criteria from the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV). Terms such as Pervasive Developmental Disorder-Not Otherwise Specified (PDD NOS), Asperger's Syndrome, and Autism are all diagnoses under the ASD spectrum.

Activity	Who	Age of Child	Outcome	Next Steps
- Well Child Visit - Monitor Development	- Primary Care Provider	Birth to age 6 every well-child visit	- Identifies risks for developmental disability/ASD	- Further evaluation or refer to <i>Early</i> <i>On</i> <sup>®</sup> or other specialist for comprehensive evaluation
- Universal Screening with a questionnaire (MCHAT)	- Primary Care Provider	18 and 24 (or 30) Months	- Identifies risk for developmental disability/ASD	- If concern is identified, refer to <i>Early On</i> and/or specialist for further ASD Assessment
- Comprehensive ASD Assessment	- Multi- disciplinary Medical Team or Individual Specialist (such as neurologist, psychologist, psychologist, psychiatrist, pediatrician, geneticist, speech therapist)	Anytime	<ul> <li>Medical</li> <li>Diagnosis (ASD or another diagnosis)</li> <li>No diagnosis</li> </ul>	- Refer to <i>Early</i> <i>On</i> local school district, Michigan Special Education, or local community mental health (CMH)
Parents If you continue to have concerns contact 1-800-Early On for assistance				

**Educational Assessment** Having a medical diagnosis does not automatically translate into an educational identification of ASD if educational impact is not established. An educational evaluation is completed by a school's multi-disciplinary evaluation team and a determination is made whether your child has a developmental delay or a disability and is in need of early intervention services.

Activity	Who	Age of Child	Outcome	Next Steps
- Evaluation of eligibility for <i>Early On</i> services	- Multidisciplinary evaluation by qualified personnel	Birth to 3 Years	- Determination of eligibility or ineligibility	- Convene an IFSP meeting if child is eligible
- Evaluation for Michigan special education	- Multidisciplinary Evaluation Team	Birth to 3 Years	- Multidisciplinary evaluation team (MET) prepares report and recommendations	- Convene an Individualized Family Service Plan (IFSP) team meeting to determine eligibility or ineligibility
- Evaluation of eligibility for special education programs or services	- Multidisciplinary evaluation team	3-26 Years	- Multidisciplinary evaluation team (MET) prepares report and recommendations	- Convene an Individualized Education Program (IEP) Team meeting to determine eligibility or ineligibility

For FREE, downloadable online or print reference materials (listed below) regarding your child's development, service information, and other resources, go to *Early On* Michigan at: <u>www.earlyon.cenmi.org/products</u>



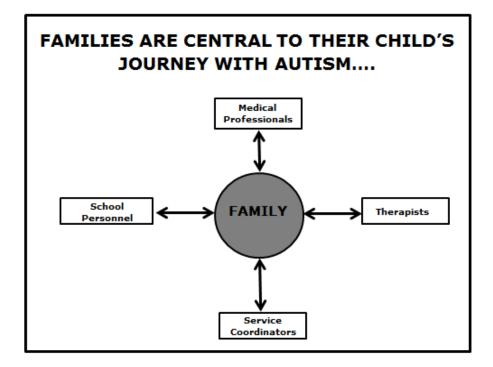
### **Helping Professionals**

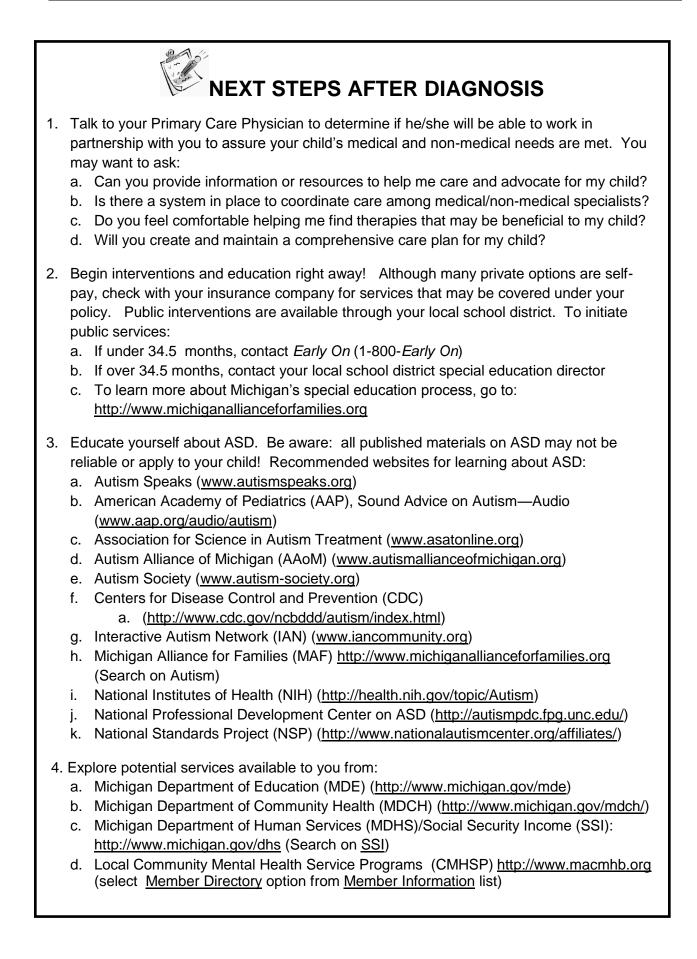
Who May be Involved?	Roles and How They May Help
Health Care Professionals	<ul> <li>Child Neurologist: physician who diagnoses and treats disorders of the brain and nervous system.</li> <li>Child Psychiatrist: physician who diagnoses and treats in mental health concerns.</li> <li>Clinical Psychologist: clinician who assesses, diagnosis, and treats mental health and developmental disorders.</li> <li>Developmental Pediatrician: physician who treats children with developmental delays, behavior concerns, and is skilled in diagnosing ASD.</li> <li>Family Physician: specializes in primary care of all ages. A family physician can screen for ASD and some have training to make a diagnosis; all can refer parents to other specialists or school district; also should coordinate care and continue to monitor the child's progress over time.</li> <li>Geneticist: a physician that diagnoses, counsels, and treats individuals with birth defects, metabolism problems, conditions that cause disabilities including ASD, and familial or hereditary problems.</li> <li>Pediatrician: a physician who specializes in infants, children, and adolescents; can screen for and diagnose ASD; refers parents to other specialists or their local school district.</li> </ul>
School Personnel	<ul> <li>Special Education Director (Intermediate School District) professional who overseas special education for an intermediate school district. There are 57 intermediate school districts in Michigan and each local school district belongs to an Intermediate School District (ISD) or Regional Education Service Agency (RESA) that provides a variety of evaluation services as well as programs and services.</li> <li>Special Education Director (Local) professional who oversees special education for a school district and is knowledgeable about referring a child for special education Teacher: teacher with specialized training in working with children with developmental disabilities and a member of the IEP team.</li> <li>General Education Teacher: teacher in a general education classroom.</li> <li>School Psychologist: professional who can administer assessments, provide interventions, and interpret educational data. Required member of Multi-Disciplinary Education Team (MET) for ASD evaluation.</li> <li>School Social Worker: required professional member on the Multi-Disciplinary Education Team (MET), and conducts case coordination and provides direct and indirect services to students with ASD and their families.</li> <li>ASD Consultant: certified teacher with expertise in ASD who provides support to students with ASD, special education, and general education teachers.</li> </ul>
	Perseverance is not a long race. It is many short races one after another.'' - W. Elliot

### "Perseverance is not a long race. It is many short races one after another." - W. Elliot

### **Helping Professionals-Continued**

School	Occupational Therapist (OT): therapist specializing in evaluating
Personnel	and treating play and social skills, daily living skills such as getting dressed and eating, fine motor skills, hand writing, etc.
	<ul> <li>Physical Therapist (PT): therapist specializing in treating motor skills, coordination, and strength training.</li> <li>Speech Language Pathologist (SLP): therapist specializing in understanding and use of verbal and nonverbal language, pronunciation and speech sounds, understanding and use of words, reading comprehension, social skills, and writing. Required member of Multi-Disciplinary education Team (MET) for ASD eligibility.</li> </ul>
Therapists	• Behavior Analyst/Specialist: psychologist, educator, or therapist with specialized training in evaluating and treating behaviors and skill acquisition. An individual who is credentialed as a Board Certified Behavior Analyst (BCBA) can assess and treat ASD and other developmental delays based on principles of applied behavior analysis (ABA).
Service Coordinators	<ul> <li>Case Manager: A specialist, early interventionist, or others with a background in case management or coordination from a government agency such as a local community mental health service program (CMHSP), or Department of Human Services who links and coordinates services and supports for a child and family or provides financial assistance.</li> <li>Early On Service Coordinator: supports the family and is the main contact when services and supports are needed, and can answer questions and locate services to help child learn and develop.</li> </ul>





# LIVING WITH ASD



Coping with ASD in your family may seem overwhelming at times. Each person handles it differently. Some considerations include:

- 1. You may have periodic (normal) feelings of shock, anger, sadness, denial, isolation, or guilt.
- 2. Pay attention to signs that you may need additional emotional supports, such as excessive fatigue, loss of appetite, thoughts of hurting yourself or others.
- 3. Take care of yourself and your family by having friends and extended family help out both practically and emotionally, get involved with support organizations (e.g. community, faith, advocacy), and find other sources of support that will understand your challenges.
- 4. Take time for yourself and your partner.
- 5. Understand this affects siblings and make time for them individually.
- 6. Investigate governmental and private resources to assist with financial needs.
- 7. Continue educating yourself.
- 8. Establish routines in the home.
- 9. Make sure your home is safe for your child and use medical alert or identification items, especially if your child runs away (elopes) or wanders.
- 10. Appreciate the uniqueness of your child and focus on his or her strengths.

### Making Informed Decisions: Evidence-Based Practices (EBP)

Many treatment options are available to increase positive outcomes in children with ASD. It is easy to be overwhelmed. Evidence-based practices (EBP) are treatments that have been studied and found to be effective.



Below are resources that provide additional information about EBP's, and specific practices that are considered evidence-based.

National Professional Development Center (NPDC): multi-university center promoting the use of EBP's for individuals with ASD	<u>http://autismpdc.fpg.unc.edu</u> (Select <u>Evidence-Based Practices</u> in left sidebar)
National Standards Project (NSP): reviewed over 770 studies and provides information about effective treatments	<u>http://www.nationalautismcenter.org</u> (Select <u>National Standards</u> <u>Project</u> in top menu bar)
Association for Science in Autism Treatment (ASAT): provides information on EBP's, treatment options, as well as dangerous, and ineffective treatments	<u>http://www.asatonline.org</u> (Select <u>Making Sense of</u> <u>Autism Treatments: Weighing</u> <u>the Evidence</u> in the left side bar)

The following may be helpful when considering providers and treatment options:



## **QUESTIONS TO ASK PROVIDERS**

- What is the treatment and what will it do for my child?
- Is there scientific research supporting this treatment?
- How long will the treatment last?
- Is it realistic for me to use this treatment?
- How much will it cost?
- How long does the treatment take?
- When can we expect to see results?
- How do you measure progress or know my child is making gains?
- What if my child is not making gains?
- How involved is the family in the treatment?
- Are there other families who have used the treatment and may I speak with them?



# WHEN REVIEWING TREATMENT OPTIONS

- Use common sense when considering any treatment options—be especially careful if there are promises of "cures".
- Be careful if payment for treatment is expected before it begins.
- Consider the source and be careful of hard sells.
- Verify information on more than one reputable website.
- Talk to your Primary Care Physician (PCP) about treatment options.
- Look for research studies (e.g. clinical trials) that might be recruiting participants, to cover the cost of evaluations and/or interventions.



#### Service Options—Education

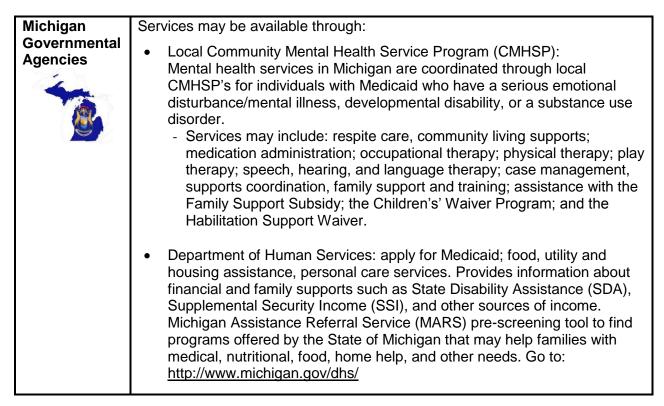
It is likely your local school district will play a key role in coordinating services for your child. The Michigan Department of Education administers special education services for Michigan. It also assures compliance with the federal Individuals with Disabilities Act (IDEA 2004) and state rules for special education. For further information about special education law and school services, go to MDE Special Education at <u>http://www.michigan.gov/mde</u> (select <u>Offices</u> in left menu; select <u>Special Education</u> in table) or call 517-373-0923.

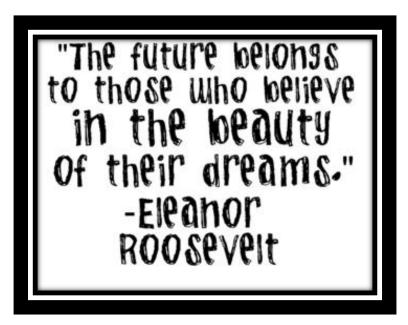
Services for				
Children	Early On 🦯			
Under 3	Early On is Michigan's system of early intervention for children 0-3			
Years	years with developmental delays and/or disabilities and their families.			
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	Early On may connect families with services provided through local Community Mental Health Service Program or Department of Human Services.			
	<ul> <li>Early On may connect families with services provided through the local school district, Intermediate School District (ISD), or Regional Educational Service Agency (RESA).</li> </ul>			
Services for	A child eligible for <i>Early</i> On may also be eligible for Michigan Special			
Children 0-6	Education Services.			
Years				
	<ul> <li>If a child is eligible for early childhood special education programs or services, the Local Educational Authority (LEA)/Intermediate School District (ISD) will coordinate the programs and services, and develop either an Individualized Family Service Plan (IFSP) (children birth up to age 3) or an Individualized Education Program (IEP) (children 3-6).</li> </ul>			



### Service Options—Family

There are a number of options available to families through governmental agencies.





#### Service Options—Other



Whether or not a child qualifies for the above services, many families seek additional supports for their child. The services may include speech therapy, occupational therapy, physical therapy, behavior management (Applied Behavior Analysis/ABA), family counseling, and academic tutoring. The services may be delivered through a hospital, agency, center, or individual.

Private Provider Programs	<ul> <li>A number of private individuals, agencies, and organizations provide treatment options for ASD. Some of the services may include:</li> <li>Applied Behavior Analysis</li> <li>Speech and Language Therapy</li> <li>Occupational Therapy</li> <li>Physical Therapy</li> <li>Psychiatric or psychological Intervention</li> <li>Academic tutoring</li> <li>Family counseling</li> <li>Contact your local advocacy organization, parent groups, or</li> </ul>
Health Systems Programs	<ul> <li>Primary Care Physician (PCP) to obtain information on credible and quality programs in your area.</li> <li>Major health systems throughout Michigan may provide ASD treatments, and often coordinate services with a multi-disciplinary team to best match the needs of the child and family. Some of the professionals that may be involved are: <ul> <li>Developmental pediatrician</li> <li>Psychiatrist or psychologist</li> <li>Behavior analyst</li> <li>Speech and language pathologist</li> <li>Occupational therapist</li> <li>Physical therapist</li> </ul> </li> </ul>
University-Based Programs	<ul> <li>Some Michigan universities offer treatment programs and services for ASD. Other universities are conducting ASD research studies. Research universities may offer opportunities for families. This can serve as a form of intervention to the child. Contact the university and colleges in your area to see if they offer: <ul> <li>Any services for children with ASD or their families</li> <li>Research studies in which you or your family may qualify or be eligible</li> </ul> </li> </ul>

It is important to remember—whether you are receiving treatment in school-based programs, public service agencies, universities, health systems, or privately the providers involved should be working together with YOU to coordinate care for your child!

### Resources

Resource Name	Solution Contact Information	Telephone Contact Information
Association for Science in Autism Treatment (ASAT)	www.asatonline.org.	
American Academy of Pediatrics (AAP)	www.aap.org (Search on Autism, Select <u>AAP Children's</u> <u>Health Topics: Autism</u> )	847-434-8000
American Academy of Pediatrics (AAP), Healthy Children.Org	www.healthychildren.org (Search on Autism)	
Autism Alliance of Michigan	www.autismallianceofmichigan.org	313-964-2620
Autism NOW	www.autismnow.org	855-828-8476
Autism Society	www.autism-society.org	800-328-8476
Autism Speaks (Family Response Team)	www.autismspeaks.org	888-288-4762
Centers for Disease Control (CDC) (Autism Spectrum Disorders)	www.Centers for Disease Control.gov (Search on Autism)	800-232-4636
Early On	www.1800Early On.org	800-327-5966
Interactive Autism Network	www.iancommunity.org/cs/home	
Michigan Alliance for Families	www.michiganallianceforfamilies.org	800-552-4821
Michigan Department of Community Health (MDCH)	www.michigan.gov/mdch	517-373-3740
Michigan Department of Education (MDE) Early Childhood Special Education	www.michigan.gov/mde (Select Programs, then <u>Early Childhood</u> <u>Special Education</u> )	517-373-0485
Michigan Department of Education (MDE), <i>Local</i> School District Map	<u>www.michigan.gov</u> (Search on <u>Michigan School District Map</u> )	
Michigan Department of Education (MDE), <i>Office of Great Start</i>	www.michigan.gov/mde (Select <u>Offices</u> in left sidebar, select <u>Great</u> <u>Start</u> from table)	517-373-8483
Michigan Department of Human Services (MDHS)	www.michigan.gov/dhs	
Michigan Head Start	www.michheadstart.org	517-374-6472
National Institutes of Mental Health (NIMH)	www.nimh.nih.gov (Search on Autism)	866-615-6464
National Dissemination Center for Children with Disabilities (NICHCY)	www.nichcy.org	800-695-0285
National Autism Center (NAC): National Standards Project (NSP)	www.nationalautismcenter.org (Select <u>National Standards Project</u> in menu bar)	877-313-3833
National Professional Development Center (NPDC)	www.autismpdc.fpg.unc.edu	
STatewide Autism Resources and Training (START)	www.gvsu.edu/autismcenter	616-331-6486

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National Institutes of Mental Health (NIMH). Retrieved online: <u>http://www.nimh.nih.gov/health/publications/autism/nimhautismspectrum.pdf</u>

National Professional Development Center (NPDC). Evidence-Based Practices (EBP's). Retrieved online: <u>http://autismpdc.fpg.unc.edu/content/evidence-based-practices</u>

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Navigating Autism Services: A Community Guide for Missouri. Department of Mental Health, Division of Developmental Disabilities. Retrieved online: <u>http://dmh.mo.gov/docs/dd/navigationguide.pdf</u>

Ohio's Parent Guide to Autism Spectrum Disorders. Ohio Center for Autism and Low Incidence (OCALI). Retrieved online: <u>http://www.ocali.org/view.php?nav\_id=48</u>