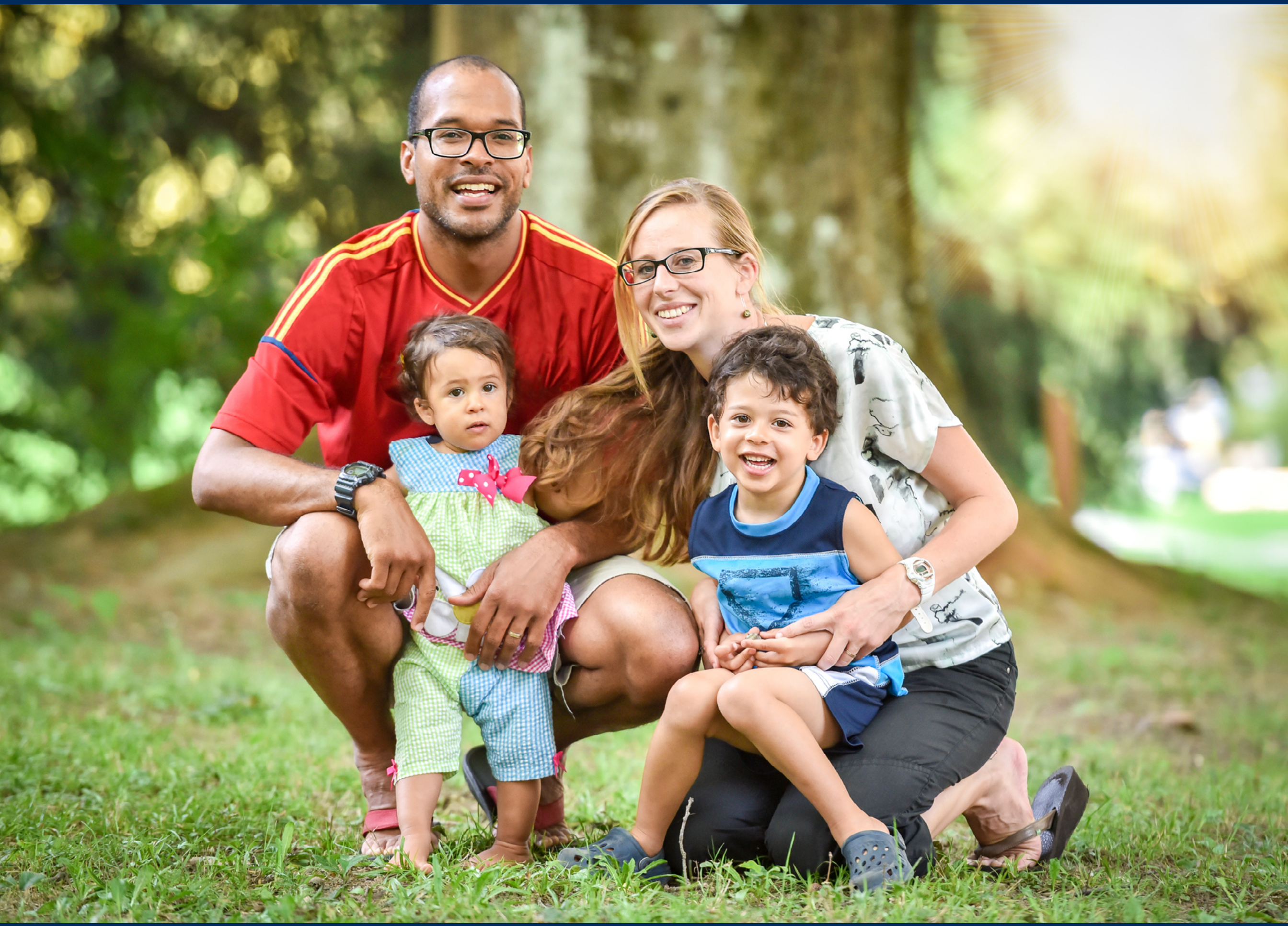
Maine Parent Guide to Autism Spectrum Disorders

Booklet 1: What to do when you suspect an Autism Spectrum Disorder



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Maine Autism Institute
for Education and Research

Developed by Maine parents for Maine families

umaine.edu/autisminstitute

Maine Parent Guide to Autism Spectrum Disorders

Booklet 1: What to do when you suspect an Autism Spectrum Disorder

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MAIER is a partnership between the College of Education and Human Development at the University of Maine and the Maine Department of Education. Our mission is to build statewide capacity to improve outcomes for individuals with autism spectrum disorder (ASD) through leadership, training, professional development, collaboration, and research. All websites listed are current as of the date of publication, June 2018.

The Maine Autism Institute's Family Partnership (FP) was instrumental in the creation of the Maine Parent Guide to Autism Spectrum Disorders in 2015. Individuals with autism, their families, and educators and professionals also played an important role in the review and revisions to our 2nd edition. Our continued hope is to provide an easy-to-follow roadmap for Maine parents and caregivers who suspect their child may be at risk for autism and to guide you to services, resources, and supports needed after diagnosis and throughout the lifespan.

Now a four-booklet series, the Maine Parent Guide to ASD includes the basics of understanding autism spectrum disorders, steps to obtaining a diagnosis, and guidelines for understanding and accessing educational and social services in Maine. Newly added content includes information, resources, and suggestions for families that include an adult with ASD and content we hope will be helpful to adults on the spectrum themselves. We have updated our resource guide with new listings to help you seek further information and access services and supports.

As you use the Maine Parent Guide, you will hear the voices of MAIER FP members as they reflect on their own journeys and offer words of advice, encouragement, and support. Many photos are courtesy of MAIER FP families and used with their permission. Throughout these volumes, we have alternated the use of "he" and "she" for ease of reading, and this does not imply gender differences in behavior or outcomes. We hope you find this a helpful guide for your family.

We are indebted to those whose time and efforts have made this series possible.

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Maine
Department of
Education

Thank you for making the Maine Autism Institute for Education and Research (MAIER) Maine Family Partnership's *Maine Parent Guide to Autism Spectrum Disorders* part of your autism journey. Whether you are personally impacted by autism, or just trying to educate yourself, we appreciate that you chose to use this guide as a resource.

The partnership has volunteered countless hours toward compiling the most useful, relevant and informative resources for Maine families, all in one place. Our hearts and minds went into this project because we too once sat where you are sitting now. We were scared, overwhelmed, anxious, sad and uncertain about what to do next. We wished there had been somewhere to turn to find the answers — to find the tools to help our children reach their highest potential.

In these booklets, we have sought to answer many of the questions you may have, and guide you to the resources you need to make informed choices. Whether you are just beginning your journey, or have already travelled far, we hope that this compilation will make it easier for you to face the uncertainties ahead. Rest assured that no matter the struggles, you are on your way to building a bright future for your loved one and your family.

Best wishes,
MAIER Family Partnership

Disclaimer: The Maine Autism Institute for Education and Research is a partnership of the College of Education and Human Development at the University of Maine and the Maine Department of Education. The content of these handbooks does not necessarily reflect the position or policy of MDOE or MAIER, nor should the content of this handbook be considered an endorsement for the use of any particular intervention. All listed websites are current as of June 2018.

"When our beautiful child was born, he could not have been more perfect; 10 adorable toes, 10 dainty fingers, rosy pink cheeks and a shrill cry. My husband and I were overjoyed. However, as the late nights of those first early months wore on, we found ourselves seeing the same terrifying Public Service Announcement (PSA) over and over again. That PSA was about the growing rates of autism. That quickly became our new fear. What if our 'perfect' little boy … was not?

The fear grew as time passed and Timmy exhibited some odd behaviors and was late on meeting his key milestones for speech. When he was 18 months old, a nurse practitioner filling in for our pediatrician told us to socialize him more and to come back at age 2.

We took Timmy to the library for toddler time, brought him to a play group, and made regular visits to the playground, bounce house, and anywhere else he could interact with children. By the time we went to that next appointment I knew that something was different about our son. But the 'A' word was not it. It could not be it.

I took several online 'quizzes,' read countless articles. None of it described Timmy. But I could not keep myself from pouring over more and more information about autism. The day before the appointment, I was up late, as usual, reading everything I could find on the Internet (not something I recommend if you want to stay sane). I was ready to go to bed when I clicked one last article. It was all about my son. It described him to a T — and it was written by another mother whose son had autism.

I don't remember how long I sat there, but I do remember how I felt; relieved. A sense of calm just seemed to wash over me as I realized I had known this all along. And more importantly, I realized that Timmy had autism from the moment he was born. This wasn't something that came out of nowhere and stole my son. I knew that in the morning I would walk out of the pediatrician's office with a son who had a label — a disability. But I also knew that he was the same exact boy that was lying peacefully in bed at that moment. The same boy who I loved with every ounce of my being, from the moment I heard his little heart beating. And, most importantly, I knew that he was perfect — autism and all.

I don't know what his life will be like. I worry he will be picked on, that he will be embarrassed, that he will have trouble in school. But I am pretty sure that all parents have these fears. I am confident Timmy will know he is cherished, and that his mom and dad will do everything possible to make sure he reaches his highest potential, no matter what."

What is Autism Spectrum Disorder?

Autism Spectrum Disorder (ASD) is a developmental disability stemming from problems in a child's neurological system. It is sometimes called a neurodevelopmental disorder, and it impacts how a child communicates, behaves and socializes with others. This is a simplistic definition for a wide-ranging and complex set of issues, and the impact varies greatly from one child to another.

In 2018, the U.S. Centers for Disease Control and Prevention reported that 1 in 59 children in the U.S. are affected by ASD. Autism occurs across all racial, ethnic, and socio-economic groups, and boys are four times more likely to be identified with ASD than are girls.

Currently, researchers believe there is no single cause for the disorder and both genetic and environmental factors play a role. For most families, the cause of a child's autism cannot be clearly identified. The American Academy of Pediatrics reported in 2014 that the cause of a child's autism can be linked to a known syndrome or medical condition in less than 10 percent of children.

The Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5) is used by psychologists, psychiatrists, or other specially trained medical professionals to diagnose a child with ASD. The DSM-5 criteria for ASD include difficulties with communicating and interacting with others, repetitive or restrictive interests and activities, and behavioral issues.

Symptoms of ASD may or may not be noticeable in infancy, but become more apparent in early childhood. A small number of children seem

> *"I felt like my child was alone even when I was right there next to him ... even when I was holding him in my arms. He was somewhere I couldn't go with him, and that was not OK with me.*
>
> *You see, when a child gets an autism diagnosis, there is a lot of jargon about living in the world of autism, and treatment being focused on teaching your child to let you into 'his world.' You learn to see your child through this veil of autism. I would look at him and wonder what was going on in there. Like he was in a cage called autism, and the door was locked from the inside."*

Social communication and social interaction

- Failure to respond to his name
- Makes limited eye contact
- May prefer playing alone
- Unable to communicate appropriately for their age; your child may be nonverbal, speech may be delayed, or she may use echolalia (repeating words or phrases others say to them)
- Unable to tell others what he wants or needs
- Difficulty understanding others' verbal communication or nonverbal social cues such as facial expressions and body language
- Difficulty understanding her own or others' emotions
- Does not interact with others by showing or sharing objects
- Does not respond to others' social interactions or invitations
- Difficulty making friends with his peers

Behavioral

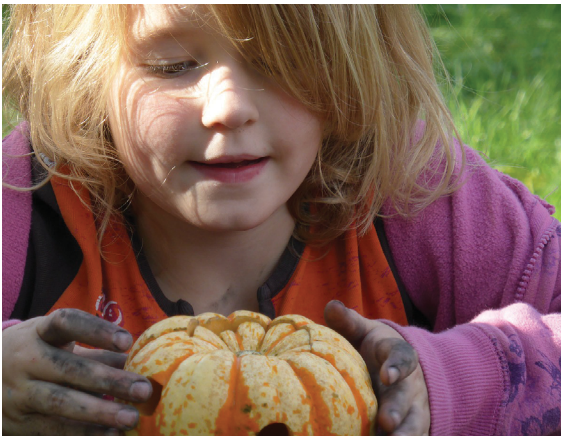
- May not like being touched, cuddled or hugged
- Unusual sensitivity to noises, textures, smells, or touch
- May hit, scream, bite, or have tantrums, often with no obvious reason
- May display repetitive or self-stimulating behaviors that do not seem to serve a purpose such as flapping hands, toe walking, rocking back and forth
- Difficulty focusing in busy or loud areas
- May use objects or toys in an unusual way (e.g., spinning the wheels on a truck to watch the motion, lining up objects)
- Fixating on objects, colors, textures or sounds
- Does not easily tolerate changes in routine

Children with ASD sometimes act out in ways that may be judged by others as misbehavior, when this may be their way of communicating stress and overstimulation. Currently, there is no cure for ASD, but early treatment and intervention can often lead to better outcomes for your child.

to develop typically in the first 18 months or so, and then seem to "lose" previously achieved developmental milestones. In some cases, children or adults are not diagnosed until later in life, but often a look back reveals ongoing social and behavioral challenges. Today, medical professionals are more aware of the importance of identifying children with ASD early in life, and screenings for ASD should be a part of every child's regular health check-ups.

Children with ASD often look "normal," but their behavior and development is not typical. The table above lists characteristics commonly seen in children with ASD. Your child may experience some or many of these characteristics. The severity of behavior and impact on day-to-day functioning varies widely from child to child.

Screening and diagnosis



Chances are, if you are looking at this handbook, you have just cause for concern about your child. The following sections will guide you through the process of having your child evaluated for ASD. It also provides some helpful advice and insights from MAIER Family Partnership parents who were once where you are today.

It is important to keep in mind that ASD can be a medical diagnosis (discussed in the following section) or it can be established for educational purposes. The educational definition identifies children who are eligible for educational services under the Individuals with Disabilities Education Act (IDEA). Having a medical diagnosis of ASD does not automatically qualify a child for educational services. See Booklet 2 of this series for more information about educational evaluations and services.

Step 1: Know the signs

Your child may exhibit one or more of the behaviors listed in the previous section. Signs and symptoms vary from child to child and may differ in frequency and intensity.

The more common signs of an autism spectrum disorder include:

- Avoids eye contact or physical touch
- Difficulty communicating, speech delays, or echolalia (repeats words or phrases)
- Self-stimulating behaviors (repetitive behaviors that do not seem to serve a purpose such as flapping hands, rocking or spinning)
- Becomes upset by minor changes
- Unusual sensitivity to sensory stimulation (e.g., noises, textures, touch)

> *"Don't wait to act on your concerns. If you suspect something is wrong, seek help right away. Don't wait to see if your child will outgrow problem behaviors or catch up on missed milestones — don't even wait for an official diagnosis. Early intervention is the most effective way to assist in your child's development."*

- Lack of engagement with others when playing
- Unusual use of toys (e.g., lining them up, spinning etc.)
- Does not respond to his name

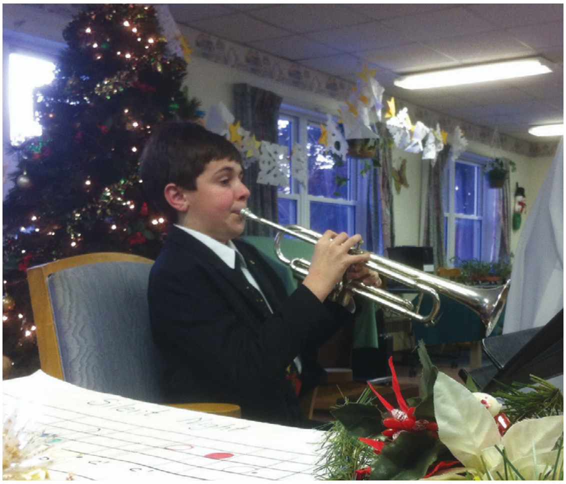
For more information about the warning signs of autism, or to help you assess your child's development, we recommend the following websites:

- **Centers for Disease Control and Prevention** (cdc.gov/ncbddd/autism)
- **First Signs** (firstsigns.org)

Document the behaviors you see in your child. No one knows your child better than you do, so it is important that you are able to provide your child's pediatrician with as much information as possible. When documenting this information, be sure to include the following:

- Identify each behavior you are concerned about
- Note how often the behavior occurs and how long it lasts
- If possible, identify triggers (events or situations that lead to the behavior)
- Note when or if your child has met key milestones such as smiling, rolling over, walking or talking

Consider completing the **Modified Screening Checklist for Autism in Toddlers (M-CHAT).** This is a developmental screening tool developed for parents and professionals to be used with children 16 to 30 months of age. M-CHAT helps to identify children who should receive a more comprehensive developmental



> *"He was delayed in his physical development, walking at 17 months. He had limited eye contact and was just emerging with the start of word sounds. He was starting to play with toys strangely, like just spinning the tires of his trucks to watch the movement.*
>
> *He was very interested and almost obsessive with letters, and often became fixated on uncommon objects like fans. He also would suddenly get very upset, crying, screaming or hitting, sometimes even biting, for no reason. It seemed to me that with time he might develop normally, as typically developing children have issues with some of these things, but for the experts, there were too many to discount. They diagnosed him with Autism Spectrum Disorder."*

> *"This is time that you cannot afford to waste if your child has autism. You can put yourself on the cancellation list, call frequently to check for an earlier appointment, and be persistent."*

and autism evaluation. You can complete the M-CHAT online (m-chat.org).

You will be asked to answer questions about your child such as:

- Does your child ever use his/her index finger to point, to indicate interest in something?
- Does your child smile in response to your face or your smile?
- Does your child respond to his/her name when you call?
- Does your child take an interest in other children?

Step 2: Make an appointment with your child's pediatrician

Make an appointment with your child's pediatrician as soon as possible. Be sure to let the office know the reason you are requesting an appointment. Bring documentation of the behaviors you are concerned about and be prepared to answer questions. There are no medical tests that can diagnose ASD, so getting a thorough history from parents is a very important start. Your pediatrician will likely administer the M-CHAT or other autism screening tools, so completing this ahead of time will give you time to consider each question carefully.

It is the natural inclination of parents to excuse or minimize their child's behavior whether they

mean to or not, but it is very important to be completely honest when filling out the M-CHAT or responding to questions about your child's development or behavior. It may be helpful to ask another caregiver or someone close to your child to complete one as well, or even accompany you to the doctors, as they may see things you do not.

If, during the screening process, your child's pediatrician sees any possible indicators of ASD she will recommend your child be seen by a developmental pediatrician or other specialist with expertise in ASD for a full evaluation. Do not be afraid to advocate for your child. If your pediatrician does not share your concerns you still have the right to request an evaluation. If the doctor refuses, try to compromise. Ask that your child be seen again in a certain time period and continue to document your concerns.

There are facilities around Maine where your child can receive a comprehensive evaluation by a mulitidisciplinary team. They include:

- Eastern Maine Medical Center Pediatric Specialty Clinics (Bangor)
- Edmund N. Ervin Pediatric Center, MaineGeneral Health (Waterville)
- Southern Maine Health Care Developmental-Behavioral Pediatrics (Westbrook)
- The Barbara Bush Children's Hospital at Maine Medical Center Developmental-Behavioral Pediatrics (Portland)

This is not a complete listing. Ask your pediatrician to refer you to a diagnostic center in your area.

Step 3: While you wait

It can take up to six months for an evaluation appointment. In the meantime, there are many things you can do to help your child before he receives an actual diagnosis.

Contact your local Child Development Services. Maine's Child Development Services (CDS) is the educational system that provides both Early Intervention (EI) for children birth through 2 years and Free Appropriate Public Education (FAPE) for children age 3 through 5 years.

Under the supervision of the Maine Department of Education, CDS operates nine regional sites around the state that provide case management

> *"Parenting a child with autism is not about what is right for parents, but what is right for your child to have a successful life."*

> *"So I dove into my research, made calls and got Nathan lined up for appointments. I spoke with Child Development Services (CDS) to find out what could be done for early intervention services. Before his appointment with them, I had already set him up to be seen two times a week by a speech therapist in her office. He started with a CDS developmental and occupational therapist coming to our home for therapy soon after. Because Nathan showed mild symptoms of autism, I knew that I couldn't 'cure' him, but with the best support I could give him, he could have a great chance at normalcy."*

and direct instruction for families with young children. They also arrange for early intervention, special education and related services to the families they serve. See Booklet 2 for a listing of the CDS sites in Maine or visit the CDS website (maine.gov/doe/learning/cds).

CDS offers valuable support to children and families. This includes screening and assessment, integrating intervention into daily routines, coaching for families, home visits and direct instruction. These services are typically provided at no cost to families, although CDS may request to access insurance with parent permission.

If your child is already in school, talk with her teacher. Ultimately, the school district is responsible for identifying all children with disabilities. If your child's disability affects her ability to learn in the general classroom setting, or impacts their social development, then a plan is developed for needed accommodations. For more information on accessing educational services see Booklet 2 of this series.

Begin related services. Speech therapy, occupational therapy (OT), and/or physical therapy (PT) may be helpful for your child and can begin even before a diagnosis is made, but you will need a referral from your child's pediatrician. It is also important to check with your insurance company (including MaineCare) to see what they will cover as this varies from one insurance carrier to another.

> *"I find being a parent of a child with autism challenging when I often don't know why he acts as he does or how to help how he is feeling … It is hard to be stared at and judged when he is having a hard time, screaming and crying; for him, and as his mother, for myself … For me as mother and woman, I feel often quite alone as a special needs parent."*

If your child is 18 years or younger and diagnosed with ASD, you can apply for MaineCare benefits through the Katie Beckett Option. Katie Beckett is for children with serious health conditions who may not otherwise qualify for MaineCare. Katie Beckett may cover related services not covered by your existing insurance using a sliding fee scale based on your family's financial circumstances. To qualify, you must submit an application and meet specific financial and medical criteria.

You can find more information and an application online (maine.gov/dhhs/ocfs/cbhs/eligibility/katiebeckett.html) or by calling the Office of Child and Family Services, 207.624.7900. The ASM suggests writing "Katie Beckett" at the top of your application if you do not meet MaineCare income requirements, but are applying for Katie Beckett specifically. Both the Autism Society of Maine and the Maine Parent Federation offer support to families in applying for MaineCare and MaineCare through Katie Beckett. See

> *"We focus on how we can set our boys up for success. When we see something our son with ASD is having a harder time with, we work with our support team to try to think of ways we can give him the foundation he needs to master the issue in the future."*

Volume 4: Resource Guide for their listings under "Family Support."

Educate yourself. Know your rights and the rights of your child. Booklet 2 of this series includes information on accessing services and supports available to children who qualify for services, a discussion of potential interventions, and your rights under the Individuals with Disabilities Education Act (IDEA). Booklet 4 of this series includes listings of many websites, books, and other resources that can guide you.

It is important to understand that autism is a spectrum disorder. No two children on the spectrum are quite the same and different treatments work for different children. Some parents and professionals feel very strongly about specific treatment models, and there are many different schools of thought. If your child is attending school, they will follow the educational model, but you may decide to pursue other therapeutic models as well.

While you sort through the wide range of material out there, be mindful that the best way to support your child is to build and work with a team of professionals you trust and who support your views and wishes. As you and your team discuss various treatment options, keep in mind that the interventions you choose should work with your child's unique strengths to help him in the best possible way. Interventions identified as evidence-based practices (EBP) have reliable scientific evidence that supports use with children with ASD (see Booklet 2). Be cautious of programs that promise a cure. Work with your team to determine

> *"You are an expert regarding your child. No one knows your child better than you. You (not the pediatrician, special education teacher, psychologist, etc.) are the only one who has lived with your child day and night since he or she was born. Therefore, it only makes sense you would be an active member of the decision-making team. Be wary of any service provider or agency who doesn't welcome your insights or collaboration."*

what is necessary and best for your child.

In addition to this booklet series, the Autism Society of Maine (asmonline.org) and Autism Speaks (autismspeaks.org) are good places to continue your research.

The National Professional Development Center on Autism Spectrum Disorders (autismpdc.fpg.unc.edu) offers Autism Internet Modules and EBP briefs on interventions currently identified as evidence-based practices for treating individuals with ASD. The briefs are free to download and accessible for both parents and professionals.

Research local service providers and visit their facilities. Due to the limited number of facilities in the state, there are often long wait lists for acceptance. If you find a place (or places) you like, put your child on the wait list right away. Doing so does not commit your child to attend or receive services, but will ensure a spot if you do ultimately choose that facility.

Continue to document your child's behaviors, especially in response to treatments. It will be important to have this information when attending the diagnostic evaluation. Videotaping your child is helpful for documenting behaviors as well.

Step 4: Create a system to manage records

Once the appointments start, you will find paperwork piles up quickly. You will want to create a system for managing your child's records for easy access. Most records will not be available electronically, so you will need a place to store hard copies.

If you already have a filing cabinet at home, designate a drawer for your child. You will also need a transportable binder or folder you can bring to appointments with you. A large three-ring binder or expandable file folder will work, but other possibilities include organizers designed just for this purpose and are available online (e.g., Baby Briefcase or TrueCore FlipTop).

You will want to have sections for:

- Evaluations
- Progress reports
- Individual Education Program or Therapeutic Education Program
- Each treatment your child is receiving (OT, PT, speech, etc.)
- Pediatrician/developmental pediatrician
- Legal papers
- Insurance papers
- Other

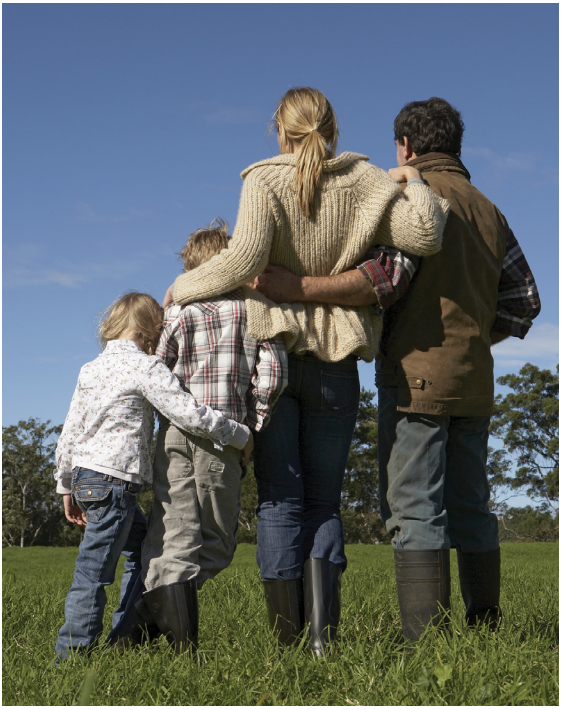
You should also keep a business card for each professional and agency, create a phone log to document your calls to professionals, and develop a system for saving the autism information or articles you collect.

The Maine Parent Federation offers additional information and support to families in getting organized, and can help you through this process. Contact the MPF by phone (800.870.7746) or email parentconnect@mpf.org.

> *"It is a good idea to call the diagnostic facility before your appointment so they can let you know what to expect and what documents you need to bring with you."*

Step 5: The evaluation

Your child's evaluation appointment will not look like a visit to the pediatrician's. The evaluation process can take two or more hours and will likely take place in an open room with several toys available. There will be a team of evaluators (often a speech pathologist, occupational therapist, and developmental pediatrician) who will observe your child. Each will ask your child to complete certain tasks or play with certain toys.



The evaluation will assess each of the developmental domains: motor, language, self-help, social and cognitive skills. You should be prepared to answer questions as well, and behavioral, social and educational records will be reviewed.

You may receive the diagnosis before you leave the appointment, or may be asked to come back for a follow-up appointment to receive the assessment results.

Step 6: What's next?

If your child receives a diagnosis, you will want to start treatment as soon as possible. Refer to Booklet 2 of this series for more information about treatment options, accessing educational and social services, and your legal rights and laws that can impact your choices.

Other things to consider:

Contact the Autism Society of Maine. The ASM provides education and resources to support individuals on the autism spectrum and their families, including their Autism Information Specialist program. This program helps families navigate the system in their local area by providing a support person to work directly with you

> *"Children with autism still love their parents. You may have to look at all the ways your child communicates to learn how your child expresses affection and try not to take it personally if your child expresses affection differently than other children. Children who don't like to be hugged are responding negatively to the physical sensation it evokes, not the person hugging them."*

> *"I take great joy in Andy's achievements, most being simple and natural things for typical children, yet are hard fought for us. He now has the ability to be proud of himself as well, which is so amazing to see … I focus on all the awesome things he can do and not what he can't. I focus on the achievements, not the struggles."*

through the process. Contact the ASM by phone (800.273.5200) or email (info@asmonline.org).

Obtain case management services. There are many agencies that offer these services. A social worker from the developmental clinic can help you find an agency, or you can research available providers here:

- **Child and Family Services/Maine DHHS:** Visit maine.gov/dhhs/ocfs/cbhs/services/case-management.html or call 207.624.7900
- **Autism Speaks:** Visit autismspeaks.org/resource-guide/state/ME or call 888.288.4762

Find a support group. It is common for families raising children with ASD to experience feelings of isolation and sadness, and your friends and family may not understand the unique challenges and experiences of family life that includes a child with autism. In many parts of Maine, there are support groups available for parents and siblings of children with autism. Visit the Autism Society of Maine website (asmonline.org) for a list of support groups in Maine, or call 800.273.5200.

Order or download the 100 Day Kit from Autism Speaks. This free, comprehensive tool helps parents of children newly diagnosed with ASD. To order, call 888.288.4762 or download it at autismspeaks.org/family-services/tool-kits/100-day-kit.

Other conditions sometimes associated with ASD

Children with ASD may have other health issues or medical conditions that also affect their behavior, learning, and overall health. These are sometimes called co-morbid or co-existing conditions. At times it can be difficult to pinpoint which symptoms are related to autism and what may be another co-existing medical or behavioral condition.

Some specific conditions are more common in children with ASD, but this does not mean all children will experience them. These could include mental health and behavioral disorders, neurological conditions and medical conditions. As a parent you should bring your concerns to the attention of your health care provider so the appropriate tests and evaluations can be done.

Medical conditions may be diagnosed at birth or may develop or become more apparent as your child gets older. Your health care provider may suggest additional testing for your child (e.g., hearing test), or refer you to other specialists (e.g., geneticist, neurologist) based on his physical exam and medical or developmental history. Knowing if your child has other conditions can often help you when making decisions about his social and educational services.

Your health care provider may recommend genetic testing. According to the American Academy of Pediatrics, genetic abnormalities are identified in 10–20 percent of children with ASD that are tested. This information may be useful if a known condition is identified and for future family planning.

Currently, genetic researchers are working to better understand the genetics of autism and its relationship with environmental factors that may also contribute to autism.

In addition to speaking with your health care provider, you may want to visit the American Academy of Pediatrics website designed for parents (healthychildren.org). From the home page select "Health Issues/Conditions" to find in-depth health-related information regarding children with autism.

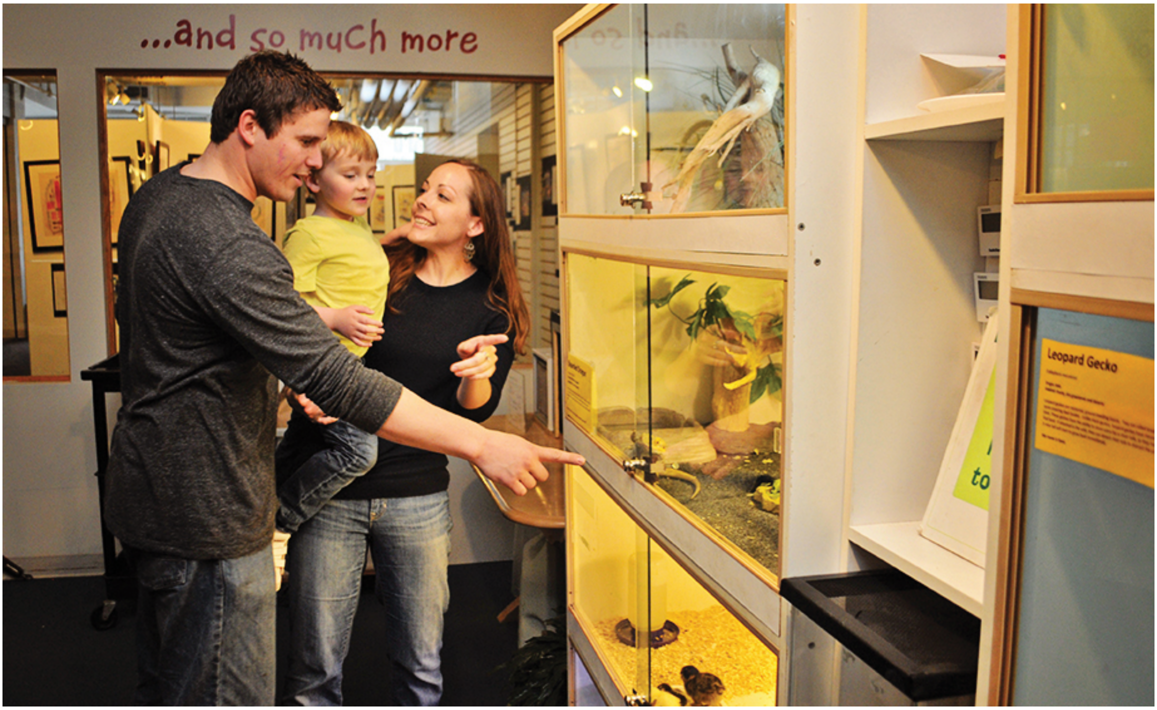
> *"Children with the same diagnosis may be radically different from one another. If you know one person on the autism spectrum, you know one person on the autism spectrum. Children are not defined by their diagnosis; it is in fact only a piece of who they are, and the expectations parents and caregivers have for their children should be likewise individualized."*

Adjusting to family life

Parents often describe the day their child was diagnosed with autism as "life-changing," and the impact of the diagnosis can ripple through the whole family. It can alter family finances, roles, responsibilities, and relationships in unexpected ways. How this affects your family life will depend on your child's strengths and challenges, your family make-up and dynamics, and the support you have now or develop over time.

One of the first changes parents face is in adjusting your expectations for your child and your family. Family life that includes a child with autism can be more unpredictable and challenging, and each family member may grieve, adjust, and move forward at different speeds. Although it may seem impossible at times, maintaining family traditions and rituals, perhaps in new ways, can help your family stay strong and build resiliency.

Research suggests that families with children with disabilities that have strong connections and support from extended family members, friends, and their community often fare better than those



who do not. Many times, family and friends want to help, but are unsure or nervous about offering. Begin by letting others know about your child's diagnosis, answering their questions, and suggesting concrete ways they can help if they offer. Accepting offers to babysit, join them for a family meal or activity, or just listen to you can provide you with some helpful respite and support. In addition, spending time with your child can help allay fears and misconceptions they may have about autism.

Siblings

It is common for parents to worry about the impact of raising a child with autism on your other children, if you have them. Depending on the age, spacing, and individual temperament of each child, his or her concerns and reactions will be different. Out of necessity, there will be less time for siblings and behavioral expectations may be different, all which may seem overwhelming and unfair to a child. This is a time to be open and honest with them, in an age appropriate way, about autism, its impact on their sibling, and on your family life. Research on siblings of children with disabilities tells us that siblings often do no better or worse than those without, and siblings may even develop a unique sense of tolerance and compassion for others.

As a parent, there are things you can do to help siblings adjust. Encourage them to express their fears and feelings, and try to acknowledge them in a non-judgmental way, even if it is difficult at times. Help your children learn how to interact with their sibling at their comfort level, but allow for self-exploration as well. In some cases, siblings develop unique ways to interact that you would not have thought of! Most importantly, plan regular one-on-one time with each child, however short that time might be. This time together can be a healthy outlet for both of you!

This section is just a beginning. For more information and resources on siblings:

- **Autism Society of Maine (ASM)** offers several books from their lending library that address sibling and family issues, and are free to borrow. Visit the ASM website Resource Library (asmonline.org/library) or call 800.273.5200.
- **Organization for Autism Research (OAR)** offers free, downloadable guides specifically for teens, young children, and parents to address living with a sibling with ASD (researchautism.org/how-we-help/families/sibling-support).
- **Sibling Support Project** (siblingsupport.org) is a National program dedicated to concerns of brothers and sisters of people with special needs. Online resources include suggested reading, online support groups, workshops, and information on Sibshops- peer support groups for school-age siblings.

Partners/spouses

Maintaining a healthy relationship with your partner or spouse may be the last thing on your mind when you are facing the uncertainty, stress, and busy lives that come with raising a child with autism. While one of you may be ready to spring into immediate action, the other may be struggling to accept the diagnosis. It may be difficult not to take out your frustrations, fears, and stress on your partner.

While each relationship is different, the added stress of raising a child on the spectrum can seem overwhelming for any couple. However, it is not insurmountable. In fact, current research on marital relationships in families that include a child with autism suggests these marriages are no more likely to end in divorce than other marriages. In some cases, spousal relationships are strengthened as they face the autism journey together.

Experts offer these suggestions to couples for keeping their relationships strong while dealing with the day-to-day challenges of raising a child with ASD:

- Acknowledge that each of you may react differently to the diagnosis and that each of you are impacted in different ways. Be open and honest in talking together about your goals for your child.
- Recognize it may take some time to adjust to the life changes that can come with the diagnosis. This can include changes to work life and careers, and may affect one partner more than the other.
- Make time together a priority! Schedule it in your day planner, even if it is a quick 15 minute walk or watching a movie together late at night. Make it a goal NOT to talk about the kids!
- Share the daily responsibilities as best you can; this includes school, therapy, and medical appointments, and decision-making. Think of yourselves as a team!
- Ask for practical help from extended family and friends or utilize respite services, when you can, to allow for "couple time."
- If necessary, seek help from a counselor, whether faith-based or community-based. Talking with someone, either as a couple or by yourself, can be helpful for your relationship.
- Take care of yourself. It may seem impractical to consider taking that half hour for meditation, coffee break with a friend, or walk after dinner, but time alone, or with a caring friend, can do wonders for you own mental health, and your intimate relationships as well.

Family time

Finding ways to spend family time together enjoying activities you have in the past is an important way to help your family adjust and stay healthy. Flexibility and pre-planning is vital, but the benefits can outweigh the extra work. The MAIER Family Partnership has developed the *"Places and Spaces Project"* to assist families find fun places around the state to explore with your family and lists special events for families impacted by autism. Check out the *Tip Sheet for Visiting New Places*, online directory, and additional resources available on the MAIER website: umaine.edu/autisminstitute/maine-family-partnership/places-and-spaces.

Final tips for parents

Helpguide, an online resource for mental and emotional health, offers these tips for parents of children with autism. Visit their website (helpguide.org/home-pages/autism-learning-disabilities.htm) for more parenting tips, including "Helping your child with autism thrive."

Learn about autism. The more you know, the better equipped you'll be to make informed decisions for your child. Educate yourself about treatment options, ask questions and participate in all treatment decisions.

Become an expert on your child. Figure out your child's triggers, what "bad" or disruptive behaviors and what elicits a positive response. What does your child with autism find stressful? Calming? Uncomfortable? Enjoyable? If you understand what affects your child, you'll be better at troubleshooting problems and preventing situations that cause difficulties.

Accept your child, quirks and all. Rather than focusing on how your child with autism is different from other children and what he or she is missing, practice acceptance. Enjoy your kid's special quirks, celebrate small successes, and stop comparing your child to others. Feeling unconditionally loved and accepted will help your child more than anything else.

Don't give up. It's impossible to predict the course of an autism spectrum disorder. Don't jump to conclusions about what life is going to be like for your child. Like everyone else, people with autism have an entire lifetime to grow and develop their abilities.

Key points from Booklet 1

- If you have concerns about your child, don't wait. Early intervention is the best way to help your child.
- Educate yourself: knowledge is power. The more you know, the better prepared you will be to help your child. Don't be afraid to ask questions.
- Create a team to support your child. Look for professionals you trust, who listen and respect your insights and opinions.
- Remember: You are the expert regarding your child. Don't be afraid to advocate for what your child needs.
- Create a support network for yourself and other members of your family. Locate parents or caregivers with shared experiences or find a local support group.
- Learning your child has autism will likely change your expectations for your family life, but that does not mean it cannot still be joyful and fulfilling. Find new ways to maintain your family rituals, traditions, and recreational activities together.

“No doubt about it, having kids changes your life, in an instant. I remember bringing our first baby home from the hospital. We carried him in, placed his seat on the floor and just looked at him. Now what? I had absolutely no clue whatsoever as to what to do with him. You would think that he would have come with some sort of owner’s manual. There I was with this 8 lb. 6 oz. ball of need, and I was overwhelmed. How could anyone possibly entrust me with the care of a baby? How could I possibly do this? What was I thinking?

I remembered a story my sister told me about when she brought her first child home. She, too, was overwhelmed by the enormity of the situation. She had been up all night with her crying baby. She was tired and at her wit’s end, thinking, ‘When is this going to end?’ At that moment, she realized that it wasn’t. She needed to accept that this was how things were going to be — this was what her life was about now. Things would change, he would grow up; it would get easier. She needed to accept and move on. She told me once she came to this realization, things got better.

That is the single best advice I have ever been given as a mother. That first year was quite a learning experience for me. I think I had the cleanest, most fed, washed, and changed baby on the planet. I was uber-mom, and I was going to do everything right.

Imagine my dismay, when my curly-headed, chubby, boy-of-baby-goodness started to retreat into his own world. His words, his eye contact ... slowly diminished before my eyes. What had I done wrong? What was I doing wrong? Was it the tuna I had eaten during my seventh month of pregnancy? Had some errant germ broken through my barrier of sterilization? I panicked. I was so afraid that this was somehow my fault ... that perhaps my greatest fear was reality — I shouldn’t have had a child; I was obviously not good enough to be a mother. Oh, it was quite the pity party; I should have had it catered.

It took us two years to get a firm diagnosis for our son. During that time, I forgot about being the ‘perfect’ mother; I stopped stressing out about clean laundry and sterile bottles. The only thing I cared about was my son — him. Not his clothes or his bottles or even his lack of eye contact or language — him. It was during that time that my sister’s advice came back to me. I needed to accept that this was who my son was. I needed to accept that this diagnosis, though helpful in explaining some things, didn’t alter anything. I was still his mom — and he, still my son. Nothing in the world can ever change that. Not even dirty dishes. For that I am thankful. We accepted and we moved on.”

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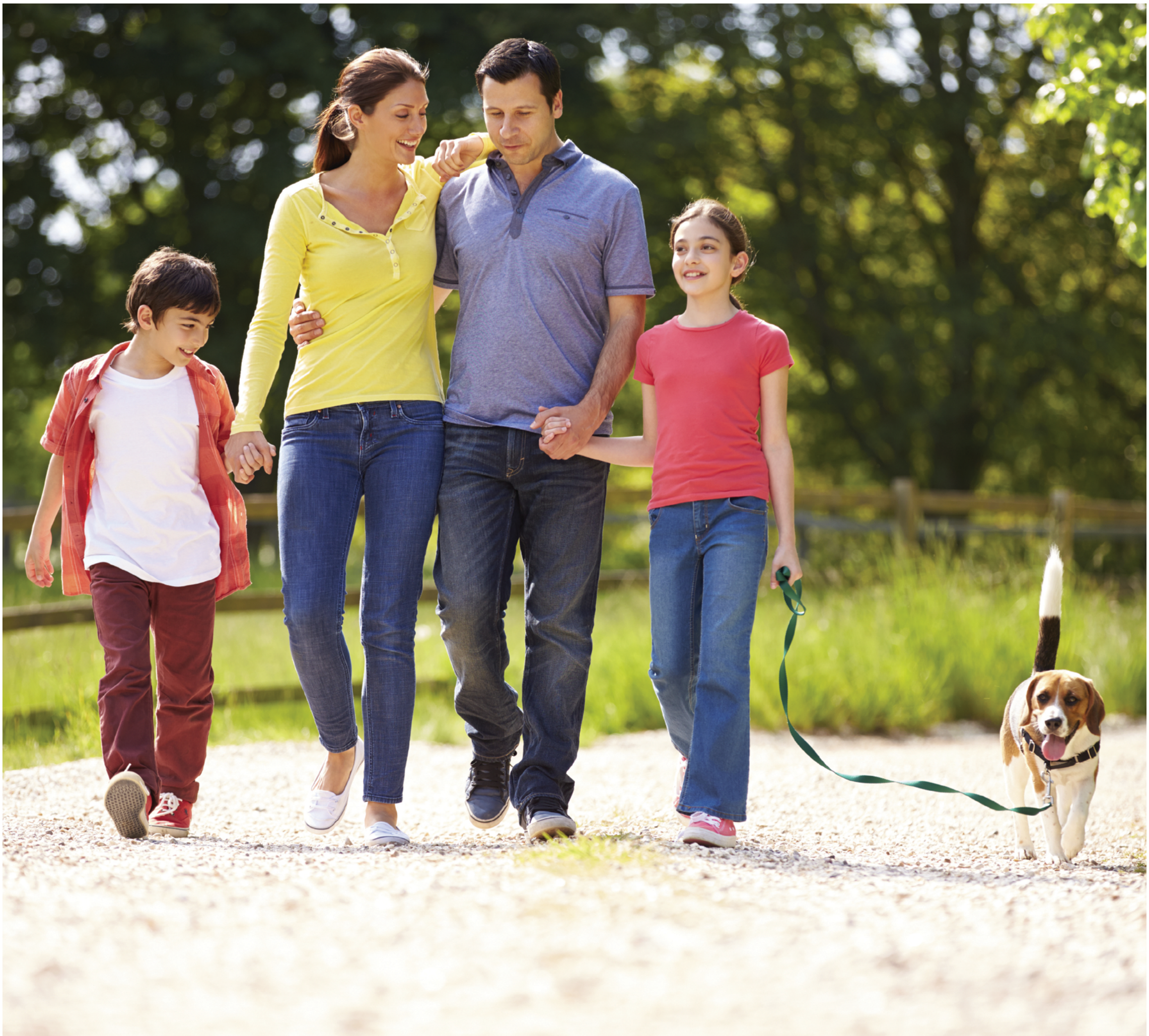
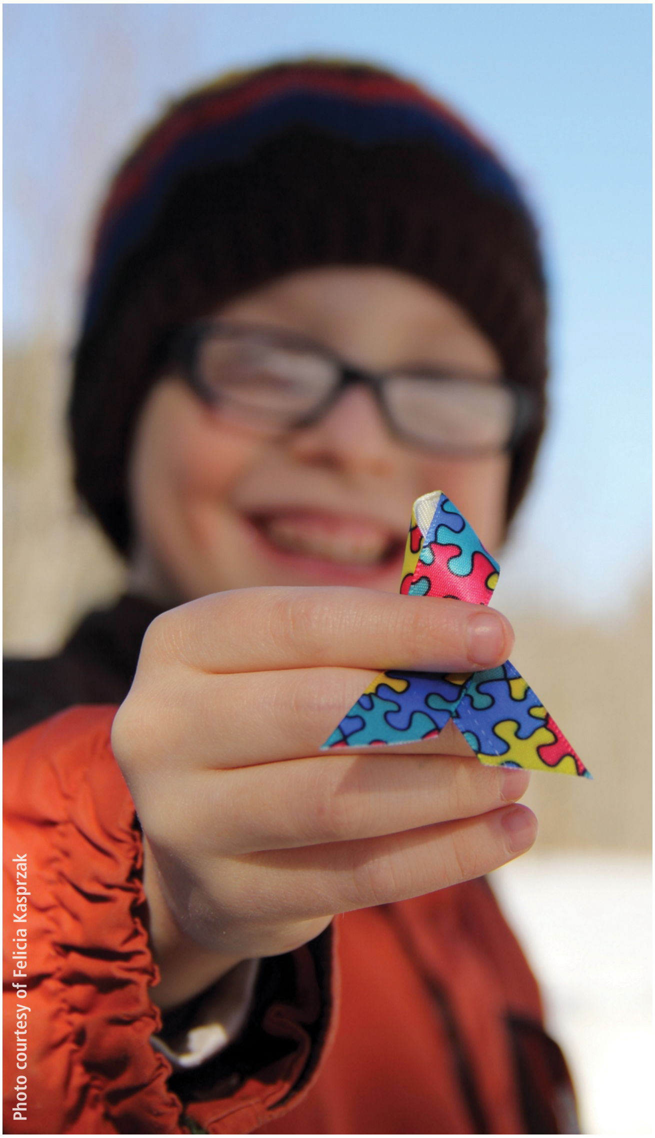


The Maine Autism Institute offers a Family Partnership (FP) program dedicated to providing outreach to families affected by autism spectrum disorders across the state of Maine. MAIER staff and families work together to identify issues of concern for Maine families and collaborate on projects such as this Maine Parent Guide and our Places and Spaces project. In addition, the MAIER FP hosts both educational and recreational family events to strengthen community ties and encourage family-to-family networking and support. Join MAIER FP to receive news, event announcements, and other information important to families by contacting MAIER by email (maineautisminstitute@maine.edu) or phone (207.581.2352).



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Maine Parent Guide to Autism Spectrum Disorders

Booklet 1:
What to do when you suspect an Autism Spectrum Disorder

Booklet 2:
Accessing educational and social services and interventions

Booklet 3:
Living with Autism: High school and adult life on the spectrum

Booklet 4:
Resource guide for Maine families

The Maine Autism Institute for Education and Research works to build statewide capacity to improve outcomes through leadership, training, professional development, technical assistance, collaborative consultation, technology, and research for individuals with autism spectrum disorders (ASD) throughout the spectrum and life cycle.

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