

Maine Parent Guide to Autism Spectrum Disorders

Booklet 2: Accessing educational services,
social services and interventions



Maine Parent Guide to Autism Spectrum Disorders

Booklet 2: Accessing educational services, social services and interventions

Maine Autism Institute for Education and Research
5766 Shibles Hall, Room 303, Orono, ME 04469-5766
Phone: 207.581.2352
Fax: 207.581.9510
maineautisminstitute@maine.edu
umaine.edu/autisminstitute

©2015 Maine Autism Institute for Education and Research (MAIER)

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, Jan. 20, 2015.

The University of Maine does not discriminate on the grounds of race, color, religion, sex, sexual orientation, including transgender status and gender expression, national origin, citizenship status, age, disability, genetic information or veteran status in employment, education, and all other programs and activities. The following person has been designated to handle inquiries regarding nondiscrimination policies: Director, Office of Equal Opportunity, 101 North Stevens Hall, 207.581.1226.

The Maine Autism Institute's Maine Family Partnership parents have been instrumental in the creation of this *Maine Parent Guide to Autism Spectrum Disorders*. Their hope was to provide an easy-to-follow roadmap for Maine parents who suspect their child may have an autism spectrum disorder, before and after receiving the diagnosis.

This three-booklet series includes information about autism spectrum disorders, steps toward obtaining a diagnosis, and how to access educational and social services. It includes resources for gathering more information and identifying services in Maine. You will hear the voices of MAIER Maine Family Partnership parents as they reflect on their own journeys. We hope you will find this a helpful guide for your family.

We are indebted to these parents whose time and efforts have made this series possible. All photos are courtesy of Maine Family Partnership families:

Susan Abbiati	Karen Grotton Pelletier	Felicia Kasprzak
Kathleen Leopold	April Poulsen	Laurie Robichaud
Niki Sheafe	Roy Ulrickson III	

MAIER Staff and Contributors

Deborah Rooks-Ellis, Institute Director and Editor

Donna Doherty, Project Coordinator and Editor

Matthew and Nancy Brown, Autism Safety Education and Training (ASET)

Jennifer Beckett

Courtney Pacholski

Jamie Treworgy

Special thanks to Jan Breton, Director of the Maine Department of Education's Office of Special Services, for her support for this project.



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 Jan. 20, 2015.

When I see you, you seem to look right through me without seeing a thing
You're only happy when you have a song to sing
I will sing it with you for as long as I can
You are adrift in the sea but can you see the land?
If I could get inside your head and see what you see
Do you have a picture of all you can be?
It scares me not to know what the future holds
This is a story that has not yet been told.
Do you know that I love you more than life?
And that wherever this goes
I will be right there with you...
Holding your hand
And I will never let go.
Just sit for a while and let me hold you tight
And for that moment everything will be all right.
Does your life hold the promise that I always dreamed for you?
Will you find someone to have and hold on to?
Do you know how happy I am to have you here?
Can you understand all these things that I fear?
Do you know that you have changed my life?
That you are my wonderful miracle?
That your love feeds my soul...and that
Wherever this goes
I will be right there with you...holding your hand
And I don't ever want to let go.
Just sit for a while and let me hold you tight
And for that moment everything will be alright.

Matt Brown, September 2000
Written after his son received the autism diagnosis

Table of Contents

Therapies.....	7
Interventions.....	8
Choosing interventions.....	8
Are your chosen interventions effective.....	9
Program models.....	10
Applied Behavior Analysis (ABA).....	10
Early Start Denver Model.....	11
The Hanen Approach.....	11
TEACCH.....	11
SCERTS®.....	12
Evidence-based practices.....	12
Medical treatments and dietary interventions.....	15
Accessing educational services.....	16
Birth to 5 years.....	16
Child development services sites in Maine.....	17
Early intervention.....	17
Team meetings.....	18
Special education services in Maine public schools.....	18
Special education law.....	26
High school and transition planning.....	28
Navigating high school.....	28
Maine resources for transition planning.....	31
Legal issues.....	31
Final thoughts on transitioning to adulthood.....	32
Key points from Booklet 2.....	34
Selected references and resources.....	36



“Parents need to know they are not the only ones going through what they are going through. Reach out to other parents and support groups and attend as many workshops or seminars on autism as you can.”

Learning your child has an autism spectrum disorder can be difficult and sometimes overwhelming. You may experience a range of emotions, including disbelief, sadness, grief, guilt, anger and loneliness. Some parents feel a sense of relief at finally having an explanation for their child’s unusual behavior. Having a diagnosis can help guide you toward finding the right help for your child.

This volume of the *Maine Parents Guide to Autism Spectrum Disorders* will assist you in learning more about treatments and interventions for ASD, and accessing educational and social services for your child.

The final booklet of this series (Booklet 3), *The Resource Guide*, includes listings of organizations and agencies that can help you find local parent groups and online parent-to-parent support. Other parents raising children with ASD can be an excellent resource for practical information and support. We encourage parents to explore the resources listed and work with your child’s team to develop an education, intervention and safety plan that is right for your family.

Now that your child has been diagnosed with ASD, what's the next step? It can be a scary, confusing and difficult time for your family. It affects everyone involved. We hope that this handbook will help you find support and resources for what lies ahead.

Early intervention services are universally recognized to improve the outcomes for your child, maximizing his or her learning potential. However, each individual with autism is unique, and there is no one-size-fits-all treatment. In fact, no one intervention has been universally

identified as being effective for all children with ASD. The amount of information on the Internet is overwhelming and can make choosing the most appropriate program or treatment for your child overwhelming.

The following sections will discuss the more common therapies and interventions available for treating ASD before turning to the practical steps of obtaining educational and support services for your child.



Therapies

Children with ASD often need specific therapies to help with communication issues, social engagement complexities, difficulties with activities of daily life (e.g., dressing, eating, self-care), and motor and sensory challenges. The following professional therapists are frequently involved in treating children with ASD. It is important to use therapists who are certified by their national or state professional board and have experience working with children with autism. Often these therapies are covered by medical insurance or provided by early intervention or school-based programs.

Speech-Language Therapy: A speech language pathologist (also called a speech therapist or SLP) may be one of the first professionals on your child's treatment team. This is because difficulties with communication and relating are at the core of the ASD diagnosis and improvement in this area can make a tremendous difference in your child and family's life.

An SLP will evaluate your child's expressive and receptive language skills — everything from eye gaze, gestures, sounds, words and interactions with others. He or she will work with your child to develop communication skills in areas such as using language appropriately in social situations and understanding others' spoken and nonverbal communications (e.g., facial expressions, gestures). An SLP will also address any difficulties your child may have with pronouncing words correctly.

“Don't be afraid to ask questions and be honest about your concerns and hopes for your child. There is support available if you need it.”

Sometimes an SLP will include specific social skills training programs. Social skills training focuses specifically on helping your child practice and manage social situations and might involve engaging with typically developing peers. This type of training often works best if integrated into your child's typical daily activities at home, school or daycare.

If your child is nonverbal, an SLP may promote language development through visual supports, assistive devices or alternative communication systems such as the Picture Exchange Communication System (PECS) or American Sign Language (ASL). These supports may even be helpful for children who are already speaking, since it is common for children with autism to have difficulties expressing their needs. Research has shown that using an alternative system does not interfere with the development of expressive language. To learn more about these communication systems, talk with your SLP or see the resource guide.

Occupational Therapy: Children with ASD often have difficulties managing typical daily living

activities (e.g., dressing, eating, holding a pencil) or playing with other children due to difficulties with fine motor skills, processing and integrating sensory information, or planning how to physically perform tasks (motor planning). An occupational therapist (OT) focuses on these challenges, creating strategies and adaptations so your child can better participate in self-care, play and social interactions.

Physical Therapy: Young children with ASD may benefit from physical therapy to help develop their muscle strength, coordination and basic motor skills used for standing, walking and playing. Older children may also benefit from

physical therapy to manage low muscle tone and improve their coordination, which may improve their ability to participate in sports and other physical activities.

Other: Other therapies have been promoted for use with children with ASD, but have less scientific support for their benefits. However, some parents report positive benefits from these additional therapies. We encourage you to gather information to investigate therapies you are considering and discuss them with your child's treatment team.

Interventions

If you have begun your search already, you already know there are many programs and interventions available for treating children with autism. Some interventions are considered comprehensive treatment models because they are designed to achieve broad learning or developmental goals. Other interventions are more focused on achieving a single skill or goal. Many of these practices have been shown to be effective through extensive research, and are called evidence-based practices (Wong, Odom, Hume, et. al., 2014).

The following sections provide an introduction to some of the more commonly used programs and interventions. We encourage you to talk with your team and service providers to gather more

information about interventions you are interested in. Seek professionals who are trained in the intervention and have the resources to implement them as intended. (See the Resource Guide for suggested sources and more information about interventions.)

Choosing interventions

Choosing the best services and interventions for your child can be overwhelming. The Ohio Center for Autism and Low Incidence (OCALI) offers the following suggestions for parents to consider when making decisions about your child's treatment in their *Ohio Parent Guide to Autism Spectrum Disorders* (2009).

“Mandy started with her first CDS playgroup around age 3, two days a week, for an hour or so. At first I stayed with her, because much of her therapies were about me learning how I could carry the activities over into our daily life to help her development. Eventually she began to stay through the playgroup without me, so she could learn to be independent. It was a hard transition for both of us.”

Questions to ask about specific interventions or programs:

- What characteristic behaviors of ASD am I trying to target?
- Does the program/therapy and anticipated outcomes address these targeted concerns?
- Does the method meet the unique strengths/challenges/goals for my child?
- Are there any harmful side effects associated with this treatment? What are the potential risks? Is there any risk of discontinuing the intervention?
- Are there any activities, foods, and so on, that will be restricted during treatment?
- What positive effects of treatment do I hope to see?
- What are the short-term and long-term effects?
- Can the treatment be integrated into my child's current program?
- How will the goals/outcomes be evaluated? How will I know if my child is making progress toward desired outcomes? What method will be used to evaluate my child's progress?
- What is the cost for treatment? Will my insurance company pay for the treatment?
- How much time does the treatment take? Can I realistically devote the time required for treatment?
- Has this treatment been validated scientifically? Have I collected information about this from a variety of sources?
- Was I able to interview other parents and professionals about the treatment? If so, list pros, cons and other areas of interest.
- Do proponents of the treatment claim that this procedure can help nearly everyone? If so, this should be seen as a red flag to slow down and be more careful in consideration of this technique, considering the wide range of abilities represented on the autism spectrum.
- What does my pediatrician and other professionals involved with my child think about the treatment's appropriateness?
- Are there alternatives that are less restrictive? Better researched?

Are your chosen interventions effective?

No one treatment is effective for all children with autism, and it is important for them to collect information to help determine if the treatment they

are using is effective for their child. The following tips should be kept in mind.

- Implement only one treatment at a time and allow plenty of time to see effects (e.g., two months or more).
- Learn as much as you can about the treatment before beginning. Note any possible side effects.
- Keep your own daily record before you start, as well as during the intervention.
- Seek feedback from other adults who know your child but do not know about the new treatment (to prevent bias).
- Ask teachers and other professionals to keep written data so you can compare with your own.
- Be sure to document any unexpected or unanticipated changes in your child.

Program models

The following are examples of the more widely found comprehensive treatment models.

Applied Behavior Analysis (ABA)

There is a long history and strong scientific support for the use and effectiveness of Applied Behavior Analysis (ABA) in children and adults with ASD. It is used both to teach new behaviors and to modify or reduce challenging behaviors.

Applied Behavior Analysis requires very careful examination of what is happening before a behavior occurs (antecedent), what the child's response to it is (the target behavior), and what happens after the behavior occurs (consequence). Close attention



is paid to both the child and what is happening around them.

Therapists develop a plan to manipulate the antecedent and consequences to shape and motivate desired behavior and/or to reduce undesired behavior. Teaching involves breaking down skills into small, measurable steps that can be built upon, repeated trials to solidify learning, and practice in different settings (e.g., home, school, etc.). Targeted skills are strengthened through the use of positive reinforcement after the child exhibits the behavior. Reinforcement for desired behaviors is individualized to maintain high levels of motivation.

ABA has been used to successfully teach individuals with autism communication, social, academic, and self-help skills, as well as work and

community living skills. Parents can also be taught to use the principles of ABA to teach desired behavior or manage undesirable behavior.

Early Start Denver Model

The Early Start Denver Model (ESDM) is a comprehensive early intervention approach for children with ASD, ages 12–48 months. Research has shown this program to be highly effective in teaching very young children across a wide range of learning styles and abilities. Parents are essential to this intervention, which usually includes 20–25 hours per week of intensive therapy. These hours are a combination of direct services, led by a trained ESDM therapist, and parent-mediated intervention embedded within the family’s routines.

The ESDM integrates principles from ABA with a relationship-focused intervention to engage young children in activities that require turn-taking and give-and-take activities (joint attention). Therapy can take place in a clinic setting or in the child’s natural environment (e.g., their home) and follows the natural interests of the child. This model of intervention places a strong emphasis on positive emotional interactions for the child. For more information on ESDM, visit the Maine Autism Institute for Education and Research website, maineautisminstitute.org.

The Hanen Approach

The Hanen Centre based in Montreal, Canada, supports the belief that parents can be their child’s language facilitators. Since parents have

the strongest bond with their children and also have multiple opportunities to interact with their children on a daily basis, parents are the obvious choice to facilitate language. Parents are trained by certified speech-language pathologists to meet the needs of their own child. The child is recognized as having the most important role in the learning process and experiences provided by adults are the learning opportunities. Learn more at hanen.org.

TEACCH

The TEACCH program was developed in the 1970s at the University of North Carolina and has grown to be one of the more commonly used family-centered, evidence-based programs to treat children with ASD. This intervention approaches the child with an understanding of the learning strengths and challenges typical of individuals with ASD, and builds a framework organizing environment, schedules, activities and visual supports to foster learning and achievement of therapy goals.

Professionals trained in the TEACCH program work closely with the family and use a variety of strategies to develop skills and promote learning and independence. These strategies include: organizing the environment to reduce distractions; providing a predictable routine with the support of a visual schedule (pictures, symbols, or words); structured activities with detailed step-by-step processes; emphasis on visual materials for learning (e.g., pictures, color coding); and clear, explicit expectations. Goals include promoting independence, flexibility, meaningful engagement

in activities, and cultivating the strengths and interests of the child. Learn more about TEACCH Autism Program at teacch.com/about-us.

SCERTS®

The Social Communication/Emotional Regulation/Transactional Support (SCERTS®) program model for children with autism focuses on building social communication and strengthening emotional regulation while providing transactional supports for the child. The program is often led by a SCERTS-trained special educator or SLP in the home or school setting in the context of daily activities. Families are supported by a multidisciplinary team (educators, OT, SLP, etc.) to address family and child goals and often includes other children who can model communication and social behavior.

The SCERTS model builds on the belief that children learn best when they can cope emotionally with everyday stressors and when they can communicate successfully with others throughout the day.

This model incorporates elements of ABA, TEACCH, and other evidence-based practices, and incorporates specific tools to teach successful social communication (picture communication systems, visual schedules, peer support, sensory supports) and support learning. The environment is modified/adapted to decrease behaviors that interfere with learning and the development of social relationships.

The goal is to build a child's confidence and competence in ways that promote spontaneous

and functional communication, increase their enjoyment in engaging with others, and make them available for other learning opportunities.

For more information on the SCERTS program model, visit scerts.com.

Evidence-based practices

Although there are many interventions available today to treat children with autism, only some have been shown to be effective for children with ASD through scientific research. These interventions are called evidence-based practices (EBP).

The National Professional Development Center (NPDC) on Autism Spectrum Disorders is a collaborative effort by three university research centers that have been working to identify and publish information about evidence-based practices for children with ASD. At the time of this publication, the NPDC has identified 27 evidence-based practices, and they continue to investigate practices that show promise. However, the NPDC cautions that not every EBP is appropriate for every child with ASD, and they advise parents to work with their service providers to choose practices that carefully match your child's unique needs.

The following table provides an overview of evidence-based practices most commonly used by professionals and service providers here in Maine. Descriptions are drawn from the NPDC EBP Fact Sheets available on their website. For more information about these and other EBPs, visit the NPDC website (autismpdc.fpg.unc.edu) or call toll free at 888.718.7303.

Most commonly used evidence-based practices used in Maine*

Evidence-based practice	Description
Antecedent-Based Interventions (ABI)	Antecedent-based interventions (ABI) include a variety of modifications that are made to the environment/context in an attempt to change or shape a student's behavior. ABI are typically implemented after conducting a functional behavior assessment which can assist in identifying both the function of an interfering behavior, along with environmental conditions that may have become linked to a behavior over time. Once factors in the environment that may be reinforcing interfering behavior have been identified, ABI are implemented to modify the environment or activity so that the factor no longer elicits the interfering behavior.
Functional Behavior Assessment (FBA)	Functional behavior assessment (FBA) is a systematic way of determining the underlying communicative function or purpose of a behavior so that an effective intervention plan can be developed. FBA consists of describing the interfering or problem behavior, identifying antecedent and consequent events that control the behavior, developing a hypothesis of the function of the behavior, and testing the hypothesis.
Modeling (MD)	Modeling (MD) involves the demonstration of a desired target behavior that results in imitation of the behavior by the learner and that leads to the acquisition of the imitated behavior. MD is often combined with other strategies such as prompting and reinforcement.
Prompting (PP)	Prompting procedures (PP) include any help given to learners that assist them in using a specific skill. Verbal, gestural or physical assistance is given to learners to assist them in acquiring or engaging in a targeted behavior or skill. Prompts are generally given by an adult or peer before or as a learner attempts to use a skill.
Reinforcement (R+)	Reinforcement (R+) is used to teach new skills and to increase behavior. Reinforcement establishes the relationship between the learner's behavior/use of skills and the consequence of that behavior/skill. This relationship is only reinforcing if the consequence increases the likelihood that the learner performs that behavior/skill. Reinforcement can be positive or negative. Positive reinforcement is the delivery of a reinforcer (i.e., something that the learner desires which may be tangible, edible, activity-based, interest-based, and so on) after the learner does the target skill or behavior.

Most commonly used evidence-based practices used in Maine*

Evidence-based practice	Description
Social narrative (SN)	Social narratives (SN) are interventions that describe social situations in some detail by highlighting relevant cues and offering examples of appropriate responding. They are aimed at helping learners adjust to changes in routine and adapt their behaviors based on the social and physical cues of a situation, or to teach specific social skills or behaviors.
Task Analysis (TA)	Task analysis (TA) involves breaking a complex or chained behavioral skill into smaller components in order to teach a skill. The learner can be taught to perform individual steps of the chain until the entire skill is mastered (also called “chaining”).
Technology-aided instruction (TAII)	Technology-aided instruction and intervention (TAII) are those in which technology is the central feature of an intervention that supports the goal or outcome for the student. Technology is defined as “any electronic item/equipment/application/or virtual network that is used intentionally to increase/maintain, and/or improve daily living, work/productivity, and recreation/leisure capabilities of adolescents with autism spectrum disorders” (Odom, Thompson, et al., 2013).
Visual supports (VS)	Visual supports (VS) are concrete cues that provide information about an activity, routine, or expectation and/or support skill demonstration. Visual supports can provide assistance across activity and setting, and can take on a number of forms and functions. These include but are not limited to: photographs, icons, drawings, written words, objects, environmental arrangement, schedules, graphic organizers, organizational systems, and scripts.

*Excerpted from the *National Professional Development Center (NPDC) on Autism Spectrum Disorders* website (autismpdc.fpg.unc.edu) retrieved Dec. 1, 2014.

“Anthony and I started right away trying to find ways to get our son to “let us in” for a little while. We were doing all the things that all of the “experts” recommended and we were seeing some progress, but something wasn’t right. I always had this feeling that I was raising a stranger in my house. I was done waiting for Timothy to let me into his world; it was time to start bringing him into mine.

I can’t tell you how this happened, what techniques I used, what changed. It was all subtle. It wasn’t methodology, it was attitude. I stopped treating Timothy like he was a patient and started treating him like a little boy. We did a lot of the same things, but I simply refused to interact with the autism. I would literally say out loud, ‘Let go of my son, he is mine and you cannot have him anymore.’”

Medical treatments and dietary interventions

Medication is sometimes necessary to help some individuals with ASD cope with anxiety, hyperactivity, sleep problems, aggression, or other behavioral or medical issues. Parents should seek the advice of their medical providers for help with these concerns. We encourage you to ask questions about the safety and use of specific medications for children with autism. For example, parents should ask about possible side effects, how the medication and its effects will be monitored, and what may be the long-term consequences of its use.

In addition, you may be aware of special diets, nutritional plans, and vitamin or mineral supplements that are being promoted in the media for treating behavioral or health-related issues experienced by children with ASD. In many cases, there is little or no scientific research to verify the benefits or identify potential risks of



these alternative therapies. If you are interested in learning about these options, talk with your medical providers or early intervention/special educators for more information.

Accessing educational services



In the United States, all children have the right to free and appropriate education under the Individuals with Disabilities Education Act (IDEA). This federal law ensures children with disabilities, from birth through 20 years old, are identified and evaluated for services. Children who qualify for services must receive appropriate educational and social services “in the least restrictive environment.” More information about IDEA and Special Education rights will be discussed later in this booklet.

Birth to 5 years

In Maine, Child Development Services (CDS) is responsible for providing both early intervention

(EI) for infants and toddlers birth through 2 years old (IDEA Part C services), and Free and Appropriate Education (FAPE) for children ages 3–5 years old (IDEA Part B services). This begins with a process called “Child Find,” in which children are located, identified and evaluated for services. You may have already been in contact with CDS during your child’s screening and evaluations, but if not, you will need to contact them to begin the process.

CDS is a statewide system of nine regional offices and one state office that work under the supervision of the Maine Department of Education. In addition to Child Find, they provide evaluations, service coordination, and support to families, and arrange for early intervention, special education and related services for children who qualify.

If you have not already been in contact with your local CDS, you can make a referral yourself, or ask your health care provider to make the referral. Referrals can be made to the CDS central referral coordinator online (maine.gov/doe/cds/families/referrals/index.html) or by calling 877.770.8883. CDS must respond to the referral by contacting you within three business days of receiving the referral.

The following information is needed to make a referral:

- Child’s name

- Date of birth
- Physical address
- Who the child lives with
- Diagnosed condition and/or areas of concern
- Parent or guardian name, mailing address and phone number
- Child's primary health care provider
- Names of agencies already working with the child

Child development services sites

Services from birth to 5 years of age are provided through the regional Child Development Service (CDS) office within your geographic area. The following is a list of the nine CDS sites and their contact information. If you are unsure which region you are in, call the state office at 877.770.8883 or check their website listings of Maine CDS sites by town (maine.gov/doe/cds/families/index.html).

CDS State Intermediate Education Unit

111 Sewell Street, 146 State House Station
 Augusta, ME 04333
 Phone: 207.624.6660; Fax: 207.624.6784

CDS Aroostook

985 Skyway Drive, Presque Isle, ME 04769
 Phone: 207.764.4490; Fax: 207.769.2275

CDS First Step

5 Gendron Drive, Suite 1, Lewiston, ME 04240
 Phone: 207.795.4022; Fax: 207.795.4082

CDS Opportunities

16 Madison Avenue, Oxford, ME 04270
 Phone: 207.743.970; Fax: 207.743.7063

CDS PEDS

163 Silver Street, Waterville, ME 04901
 Phone: 207.877.2498; Fax: 207.877.7459

CDS Reach

50 Depot Road, Falmouth, ME 04105
 Phone: 207.781.8881; Fax: 207.781.8855

CDS Downeast

247 Main Street, Machias, ME 04654
 Phone: 207.255.4892; Fax: 207.255.6457

CDS Midcoast

91 Camden Street, Suite 108
 Rockland, ME 04841
 Phone: 207.594.5933; Fax: 207.594.1925

CDS Two Rivers

250 State Street, Brewer, ME 04412
 Phone: 207.947.8493; Fax: 207.990.4819

CDS York

39 Limerick Road, Arundel, ME 04046
 Phone: 207.985.7861; Fax: 207.985.6703

Early intervention

If your child has not been evaluated by CDS already, they will contact you to be evaluated for services once the referral is made. A team of therapists (SLP, OT, PT, developmental specialists) will be gathered to assess your child and determine if he or she is eligible for services. If you have already used CDS for screening and evaluation services, and your child was determined to be eligible, the next step will be developing a plan to meet your child's needs.

“Parents have a right to be satisfied with this plan and can call meetings at any time to change or modify the IFSP or IEP in the best interest of their child.”

If your child is under age three, you will work with the CDS therapists and a service coordinator to develop an Individualized Family Service Plan (IFSP) based on your family’s goals and priorities and your child’s developmental needs. The IFSP will identify your child and family strengths, resources, priorities and concerns, and will include your child’s current levels of functioning in specific developmental areas. Measurable annual goals or outcomes will be clearly stated for each developmental area.

Services your child will receive are listed, including from whom, how often, and for how long. This may include speech, occupational or physical therapies. Most often, services for very young children will take place in your own home or where ever your child would normally be during the day.

Parents of children 3–5 years old will also work with their service coordinator to develop a plan for services. This plan is called an Individualized Educational Program (IEP) and includes similar components. An IEP includes a description of your child’s strengths and current abilities, their educational needs, measurable annual goals, and objectives that list the steps to achieve those goals.

The IEP includes a statement of how and how often you will be informed of your child’s progress

toward his or her goals. Finally, the related services and therapies your child will receive are listed, noting who will be providing the services, how frequently, and for how long. It should also identify any additional supports your child may need for learning.

Team meetings

An IEP meeting that includes parents, service coordinator and therapists will take place to finalize the plan. Parents play an important role at this meeting, yet it can also be overwhelming. The following suggestions may be helpful:

- Take along a friend or advocate can be helpful to offer support, take notes or help clarify information.
- Be willing to ask questions to clarify things you don’t understand.
- Be firm about your priorities for your child.

Ultimately, the IEP should reflect a mutually agreed upon commitment from both parents and team members. Parents must sign the consent for services and agree to the content of the IEP before services can begin.

If your child qualifies for early intervention services, they will be provided at no cost regardless of your family’s ability to pay. However, your insurance (including Medicaid), if your child has it, may be billed for services.

Special education services in Maine public schools

Parents of children with ASD often comment that navigating the public school process after a

diagnosis can be challenging and confusing. This section of the handbook will provide families with a step-by-step guide to understanding special education services for children with ASD as they take part in a public school setting.

This section includes information drawn from the *Office of Special Education and Rehabilitative Services, U.S. Department of Education Handout (2000)*. This comprehensive document, *Guide to the Individualized Education Program*, can be downloaded for free by visiting the USDOE

website (www2.ed.gov/parents/needs/speced/iepguide/index.html).

Step 1: Evaluation and eligibility for services

Your child's ASD diagnosis and eligibility for services will fall under one of two categories:

- A. Diagnosis and eligibility determined during toddler/preschool years (2–5 years old)
- B. Diagnosis and eligibility determined during school-aged years (5–21 years old)

Toddler/preschool years:

If your child was evaluated and diagnosed with ASD during his or her toddler/preschool-aged years, then your child was found to be eligible for services and may have received early intervention services through state-funded or private programs based on his or her individual needs. The process of transitioning from early intervention to public school is slightly different from the process that

takes place when children are found eligible during their school years. First, your child has already been found eligible for services. These services have been provided prior to entering public school. For this reason, your child is simply transitioned into public school with his or her existing services in place, but rather replicated in the public school setting. More information about this process is provided in Step 6.

School-aged years:

If your child is evaluated and receives a diagnosis once he or she is school aged, it is usually after a teacher or professional has made a referral based on student behavior, or academic performance and concerns. It should be noted however, that the referral process begins only after the classroom teacher has demonstrated that he or she has tried at least one evidence-based practice

or intervention with insufficient effects on the behavior or academics of concern. Parents can also make requests for a referral and testing, as well as outside agencies such as DHHS and physicians. Requests may be verbal or in writing. Parental consent is needed before a child may be evaluated, and the evaluation needs to be completed within a reasonable time after the school receives parental consent.

Step 2: Evaluation process

Your child will be evaluated by professionals from your child's school in a variety of areas depending on their suspected disability. The evaluation process can take some time to complete, as it is very thorough and involves many professionals and skilled assessors to determine eligibility for your child.

If you prefer to have an outside agency complete the evaluation, you have the right to have an Independent Educational Evaluation (IEE). You can ask the school to pay for the outside evaluation. Once your child is evaluated, a meeting will be held to discuss the results of the evaluation, which will result in one of the following outcomes:

- Your child will meet the eligibility requirements of having a disability under the

“Meetings for IFSPs or IEPs can be overwhelming for a parent. There are usually many people at these meetings, some that you may not even know. Case managers, therapists (speech, occupational and physical), teachers, and education techs may be at this meeting. As a parent, you have the right to bring someone with you to help you understand your rights as a parent, help you understand the discussion, and offer support. These meetings can often be difficult for non-professionals.”

“I have to say, for the most part, my kids have been blessed with wonderful teachers. People who have been more than willing to make simple accommodations so my children were able to be successful. I, in turn, have always made myself accessible to them-offering anything in the way of support, information and guidance. I think it is important to have open communication with your children's teachers. I look at it as teamwork.”

Individuals with Disabilities Act (IDEA), and it is recommended that he or she receive special education services to access the curriculum.

The school will begin the next steps to develop an Individualized Education Plan (IEP) or

- Your child will meet the eligibility requirements of having a disability, but will not require special education services to access the curriculum, and rather requires accommodations and adaptations in the classroom to make gains in the classroom setting. The school will begin the next steps to develop a Section 504 plan or
- Your child will not meet the eligibility requirements of having a disability or eligibility to receive special education services, accommodations or adaptations.

Parents have the right to challenge any decision by calling a hearing. For more information

see the Maine Parent Federation fact sheets (startingpointsforme.org/content/fact-sheets) for easy downloading. These fact sheets also include information about the differences between the IEP process and the 504 processes. If you are unable to access these guides online, you may also call the Maine Parent Federation at 207.588.1933.

After eligibility for services has been determined, the school will put together a team of individuals for your child. This team will work together with you and your family to develop an educational plan that will meet the needs of your child in the school setting.

Step 3: Putting together the team

The school will put together a team of professionals to work with you and your family. Team members could include regular education teachers, special education teachers, speech therapists, occupational therapists, physical therapists, behavior analysts/consultants, special education directors/coordinators, and any other professionals that may have direct

contact with your child in the school setting.

Parents and caregivers are encouraged to include outside team members that may have a beneficial impact on the decision making process for your child's educational goals. Examples may include physicians, advocates, in-home service providers, and other family members that may provide you with support.

The team will look at the most recent assessments of your child and the recommendations made by qualified physicians and professionals and consider the individual needs of your child. Based on that information, the team will develop a plan that outlines the specific strengths and needs of your child, adaptations and accommodations that your child requires to be successful in school, and the goals and objectives that the teachers and support staff will work on over the school year. This plan is called an Individualized Education Plan or IEP.

Step 4: Scheduling an IEP meeting

The school schedules and conducts the IEP meeting

“IEP meetings are probably one of the most important and valuable meetings that you will ever have for your child during their school years. This is where their services are decided upon. They can be very stressful. As a parent, you want the best for your child. You want your child to succeed, to get everything that they could ever possibly need. You are emotionally involved. On the other side of the table are the educators. They are not as emotionally invested. They have to look at how your child's disability affects their education and make decisions.... [However,] you are your child's best advocate. The IEP team should be willing to explore any options that you put on the table.”

for your child. School staff must do the following in preparation for the meeting:

- Contact all team members including parents
- Notify parents early so that they have an opportunity to attend
- Schedule the meeting at a mutually convenient time and place for the school and parents
- Explain to parents the purpose, time, and location of the meeting, who will be attending, and inform them that they may invite people to the meeting who have knowledge or special expertise about the child (U.S. Department of Education, 2000)

Step 5: Preparing for an IEP meeting

You can prepare for your child's IEP meeting in the following ways:

- **Respond to the meeting invitation to let the team know that you are planning on attending.** If you plan to bring someone with you that was not invited, let the team know so that they can have enough copies of important documents and materials. If you cannot attend, then ask to reschedule the meeting at a time more convenient for you. Make sure they know that attending the meeting is important to you.
- **Bring all important documents with you to the meeting.** If you have reports, progress notes, letters from doctors, or any other materials that you may have questions about, bring them to the meeting. You may find it helpful to gather your child's records

into one binder or folder, if you have not done this already, so the information is easy to transport. You can also ask for copies of documents from the school prior to the meeting, and if an IEP draft is available, you can ask to have a copy of that as well so that you can review it before the meeting.

- **Build a positive relationship** with at least one person on the team (i.e. teacher, speech therapist, behavior specialist). This will help to make you feel more comfortable at the meeting and feel like you have a go-to person if you have questions.
- **Write down your thoughts, concerns or questions** before the meeting so that you will not forget something as the meeting takes place. Review prior reports/assessments/evaluations and write down notes to ask questions about during the meeting.
- **If you have private evaluations that you would like the team to review, you should provide them to the team ahead of time** so that people can review before coming to the meeting. This will help to not take away valuable minutes during the meeting.
- **Ask for a copy of your rights before the meeting** so you can read them prior.
- **Bring a trusted friend, advocate or family member** with you if you feel like you might need additional support.

These helpful tips can be read in more detail at the following websites:

“At the end of your meeting, ask for a summary. Make sure that you fully understand exactly what is happening with your child’s education and why. Take notes; document everything. In a week or so you will get a copy of what was decided at the IEP meeting. Read it twice. I have had times when the document I received was slightly different from what was said at the meeting. One or two words, as minor as it may seem, can change how a service is offered. If you find a change, contact the Special Ed office immediately.”

- greatschools.org/gk/articles/tips-for-a-successful-iep-meeting
- understandingspecialeducation.com/IEP-tips.html

Step 6: Individualized Education Plan – The IEP meeting

To help determine what special education and related services your child needs, the IEP team will begin by looking at your child’s evaluation results, such as classroom tests, individual tests given to establish the student’s eligibility, and observations by teachers, parents, paraprofessionals, related service providers, administrators and others.

This information will help the team describe your child’s present educational performance level — in other words, how your child is currently doing in school. This will help the team develop annual goals to address those areas where your child has an identified educational need (U.S. Department of Education, 2000).

The U.S. Department of Education *Guide to the Individualized Education Program* (2000) identifies the following areas typically covered in an IEP:

- Child’s current performance, strengths and needs
- Child’s educational placement
- Measureable and observable goals and objectives that cover areas of need (i.e., academic, behavior, self-care, motor development, social and emotional development, communication)
- Participation with peers
- Participation level in state and district testing
- Specific timelines and dates for services to be provided
- Additional adaptations and accommodations needed to make progress towards goals and objectives
- Specific information pertaining to transportation and transition needs if applicable
- Information on progress monitoring and data collection

An IEP is a legal document. Once agreed upon, the school is required to provide the services that are outlined in an IEP. The key phrase here is once agreed upon. During an IEP meeting, the services will be discussed with all team members.

You, as a parent, have the right to agree to the terms of an IEP, or to disagree and appeal an IEP at which time the team will need to hold another meeting to discuss your concerns with the IEP. If changes cannot be agreed upon at that time, a mediation process will begin and attorneys may be contacted to represent the school and family.

The Maine Parent Federation offers assistance to families for educational issues through their Family Support Navigators program. Support workers can provide assistance to guide you through the IEP process, help you organize documents and information in preparation for meetings, or attend meetings with you if needed. For more information, see their website startingpointsforme.org/content/family-support-navigators, call 800.870.7746 or email parentconnect@mpf.org.

You may also agree with parts of an IEP while disagreeing with other parts. If there are parts of the IEP that you disagree with, the team can start working on the parts that were agreed upon while working on the details of the parts that were not.

Each meeting is documented with a written notice. The written notice includes the information discussed and agreed upon, including services to be provided. Parent concerns are also documented in this notice. As parents, you have seven days to dispute or comment on the information provided in the written notice.

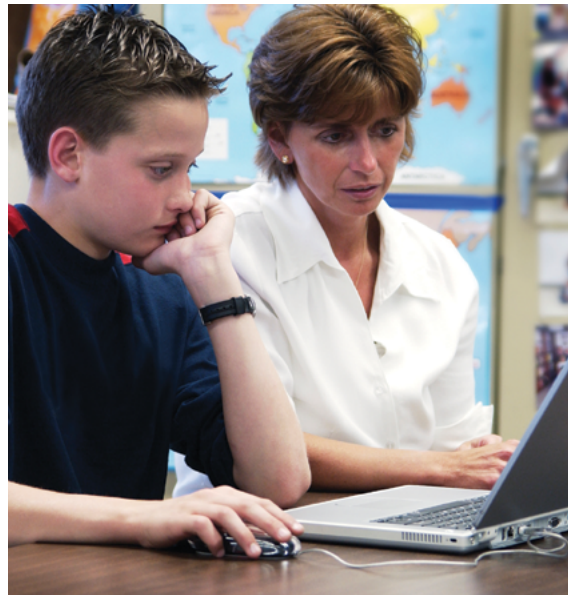
If your child was transitioning from an early intervention program/services, then he would have an IFSP (Individualized Family Service Plan). An IFSP may transfer into an IEP once your child starts public school, or the team may decide to

create a new IEP based on your child's needs. This is determined at a transition meeting before your child enters public school.

During the transition meeting, you and your current service providers will have a meeting with the new school providers. Each provider (i.e., speech therapist, occupational therapist, etc.), will provide a description of where your child is in her current services, and make recommendations for services to be carried over into the school setting. The new providers will ask questions and talk about what the school setting looks like and how they will accommodate the needs of your child.

Step 7: Implementing an IEP

After an IEP is agreed upon, you will be given a



“School has been a roller coaster of sorts, but at this point my son has an amazing team and is doing extremely well. What I have learned along this journey is that educating him really is a team effort with the parent being the team leader. Things work really well when the team listens to the parent and everyone on the team looks at the child as an individual and creates a plan that works for him. Communication between home and school has been the key to his success.”

copy of the IEP, as well as all the providers and teachers. Teachers and service providers have access to the IEP and understand their specific goals and objectives, as well as how to carry out their accommodations, supports and modifications. It is the school’s responsibility to make sure that the IEP is being carried out as designed. The team now begins to provide the services outlined in the IEP.

Step 8: Progress monitoring/reports

The team is obligated to report on your child’s progress toward meeting the goals and objectives of the IEP as often as progress is reported for non-disabled students in the regular education setting. For example, if students in the regular education setting receive report cards three times a year, then your child with ASD will also receive progress reports three times a year. These reports discuss your child’s progress based on his or her IEP goals and objectives.

Step 9: IEP review

The IEP team reviews your child’s IEP annually or more often if either you or school members would like to meet sooner to discuss progress. At the IEP

review, the IEP may be revised if necessary. All team members are invited to the IEP review meeting, and as parents, you have the same rights as the initial meeting in regards to the implementation process.

If you do not agree with the IEP and placement, you may discuss your concerns with the IEP team and try to come to an agreement of services. You may request additional testing, an independent evaluation, mediation (if available) or a due process hearing. Parents may also file a complaint with the state education agency (U.S. Department of Education, 2000). The Maine Parent Federation, listed in the resources at the end of this handbook, offers assistance to parents when faced with these circumstances.

Step 10: Re-evaluation

At least every three years your child must be re-evaluated for eligibility of services. This evaluation is often called a triennial. The purpose is to find out if your child continues to be a child with a disability, as defined by IDEA, and to determine your child’s educational needs. Your child can be re-evaluated sooner if the team finds it necessary (U.S. Department of Education, 2000).

“The more knowledgeable and prepared that you are, the better the outcome. It may take a while. You might have to get some outside help. You may even have to concede on an issue or two. However, you should walk away with the knowledge that your child is going to get what he or she needs to be successful. Do not settle for less.”

Special education law

Special education law is a complex topic, and beyond the scope of this handbook. However, parents of children with ASD need to be aware of your child’s rights under the Individuals with Disabilities Act (IDEA) and the best approaches for working with schools and other professionals. Several Maine parent organizations and national resources listed throughout this handbook, and in the Resource Guide, are excellent sources for more information about issues related to your child’s rights under special education law. We recommend you see these for more information and guidance.

What does FAPE mean for your child?

- Every child must receive an education from the public school system without additional costs to the parents or guardians from kindergarten through age 21. (This may also apply to pre-K, if your school district offers it.) Schools cannot deny services due to lack of funding or trained personnel.

- Any child with a qualifying disability is entitled to receive an IEP (individualized educational program) or 504 plan designed to fit their unique academic needs.

Accommodations and modifications can be made to help your child access the general education curriculum. Examples of this may include:

- Assistance from a paraprofessional (e.g., educational technician)
- Alternative textbooks, audio books or electronic books
- Shortened or condensed assignments and tests
- Alternative assignments and tests
- Individualized behavior plan
- Individualized classroom placement
- Use of computer or tablet
- Use of visual/picture schedule and aids
- Additional time provided for work completion and/or transitions
- Alternative grading system or use of a pass-fail system
- Scheduled additional breaks
- Specialized instruction if necessary
- Provide specialized or alternative transportation
- Assistance for extracurricular activities

What FAPE does **NOT** do:

- Provide your child with the best education available. The school system must only provide what the law dictates. Many go over and above what is required, but some do not.

- Provide tuition for a private or religious school. Only schools that accept federal funding are required to follow IDEA.
- Provide assistance for you to homeschool your child. However, if you do homeschool your child you may have access to school facilities, and receive some services, such as occupational or speech therapy, at the school.
- Students must be allowed to access school transportation (i.e., busing) and receive an education as close to their homes as possible.
- Students can be removed from the classroom to receive specialized instruction. The reasons for these services must be included in the IEP.
- When children are placed in a more restrictive setting, all efforts must be made to include the child with disabilities in as many activities with their peers. These activities might include recess, physical education class, music class, lunch time and other extra-curricular activities.

What does LRE mean for your child?

- Schools must educate students with disabilities in the same classroom as their non-disabled peers to the maximum extent appropriate.
- Accommodations and modifications (such as those listed above) must be utilized to ensure the child is placed in the least restrictive environment for academic and non-academic activities.
- There are times when alternative placements are appropriate due to behavioral, social, emotional or academic challenges of the student. However, the school district must follow guidelines that justify a more restrictive placement.
- Schools must include justifications for placement in the IEP.
- Parents have a right, as part of the IEP team, to be included in placement decisions.

What LRE does NOT mean:

- Parents ultimately decide where the child is placed. Though parents must be included in IEP development, the team must take into account what is appropriate for the child. If the parents disagree with the placement, there are procedures in place to mediate any conflicts with the school district.
- Every child is given the opportunity to start out in the general education classroom. However, if the environment does not allow for success, then a more restrictive environment may be deemed appropriate.

“The seven most important letters that a parent of a child with autism must know and understand are FAPE and LRE. According to the Individuals with Disabilities Act (IDEA), every child has the right to receive a Free Appropriate Public Education (FAPE) in the Least Restrictive Environment (LRE) available.”

High school and transition planning

As your child with autism enters high school, it becomes increasingly important to plan for life after graduation. This means early discussions, exploration and planning with your child and his or her education team. Transition planning that begins early can provide your adolescent with the guidance and support he will need to make the transition to adult life in his community. This includes planning for further education, work, recreation, transportation, health care, self-determination, legal issues and community living.

In Maine, schools are required to begin transition planning for all children with an IEP by the time

they turn 14-years-old. The student, parents and IEP team must work together to create a plan to investigate options and opportunities based on your adolescent's needs, interests and plans for the future. It is important to keep in mind that once your child graduates or ages out of public education (at age 21), all entitled services end. Access to adult services will be based on your young adult's meeting qualifications for specific services and the availability of funding and resources.

Navigating high school

This section provides some helpful guidelines parents should keep in mind as their child progresses through high school and includes suggestions for working with your child's IEP team on transition planning. This information was compiled from *The Parent's Guide to College for Students on the Autism Spectrum* (Brown, 2012) and *Pathways to Transition* (Woodfords Family Services).

Grades 9 and 10

- Federal law requires transition planning begin at age 14, focusing on the student's course of study as it relates to his or her long-term plans
- Individualized transition planning should focus on developing a vision for employment and post-secondary education
- Your child should attend and participate



in IEP meetings to articulate his or her disability, strengths and needs

- Help your adolescent create and use a time management system for class assignments and out-of-class activities
- Classroom accommodations should be negotiated directly with teachers rather than relying on a resource room
- Work toward increasing independence at home, and encourage your adolescent to be responsible and accountable for managing his or her free time and academic demands
- If your child is not eligible for special education services, investigate eligibility for 504 accommodations
- Discuss possible career options
- Discuss different routes to employment such as higher education, technical training, or supported employment

If your adolescent is considering continuing education:

- Discuss with your adolescent a plan for further education beyond high school

If your adolescent is planning to enter the workforce:

- Explore community vocational opportunities and become familiar with vocational services even if further education is planned
- Discuss the importance of work experiences and job-related skills such as resumé preparation and interviewing

There are resources for your son or daughter to get work-related training and experience while they are in high school through Maine's Career Centers. Any

youth aged 14–21 is eligible to receive services and no formal assessments are required. These centers offer training and employment opportunities, including summer jobs, to help teens gain skills that will ultimately make them more employable. Students with ASD who receive training while they are in high school are more likely to be employed later in life (C. Dionne, Autism Society of Maine, personal communication).

Maine's Career Centers are located throughout the state by four regions. Call the Career Center hotline (888.457.8883), contact them by email (jobbank.careercenter@maine.gov), or visit their website (mainecareercenter.com) for more information and to learn where your local Career Center is located.

The National Secondary Transition Technical

“ Having a child that is nearing the end of high school, I began thinking about what comes next and realized that I was aware of very few resources. When I was asked to be part of this project I saw this as an opportunity to research this topic with the hope of creating a more concise resource for myself and other parents. My goal was to shed light on the options that parents of students with ASD are presented with as their child prepares to transition out of high school. This has been an incredible journey and I can't wait to see what lies ahead for my son.”

Assistance Center website (nsttac.org/content/students-families) includes many resources and links for transition planning, including interactive websites to guide you and your teen in decision-making. The Family Transition Planning Folder is a good place to start and provides an outline of the important questions to explore in your planning.

Grades 11 and 12

- Finalize the transition IEP. Your teen should increase participation and initiation of all things related to their educational services
- Participate in summer jobs or volunteer activities
- Practice interviewing skills
- By age 16, needed transition services must be included in the student's IEP

If considering continuing education:

- Work with a guidance counselor to develop a list of possible colleges and post-secondary schools
- Research schools online
- Visit potential schools
- Apply to selected post-secondary schools

There are books written specifically to guide adolescents with autism and their families when planning for college. For example, one Maine Family Partnership parent suggests *The Parent's Guide to College for Students on the Autism Spectrum* by Jane Thierfeld Brown & Colleagues (2012) as a helpful guide. We encourage you to seek additional resources, including those listed in the Resource Guide, to assist you through this process.



If your teen is planning to enter the workforce:

- Contact local and state agencies involved in employment services (see the Resource Guide). A good place to begin is the State of Maine Department of Labor Bureau of Rehabilitation Services. You can visit their website (maine.gov/rehab) or call 207.623.6799
- Explore the Employmentforme.org website, developed by the Maine DHHS Department of Labor and the Muskie School of Public Health to provide information about employment resources and initiatives in Maine. Check out the section especially for youths in transition.
- Contact the Social Security Administration to learn about and plan for financial aspects of employment such as work incentives. Visit their website (socialsecurity.gov/disabilityresearch/wi/generalinfo.htm) or call 800.772.1213

Things to keep in mind for the end of high school:

- At age 18, your teen has the legal right to make all decisions in relation to his or her special education progress unless you have petitioned the court for guardianship or your teen has chosen to share or delegate decision-making to you.
- Entitlement to special education services ends when your adolescent graduates, withdraws from high school, or reaches age 21.
- School districts are required to provide students who graduate with a regular diploma or who age out with a Summary of Performance (SOP). This document includes a summary of their academic achievement and performance of daily functions (e.g., communicating, time management), and includes recommendations for assisting them in reaching their post-secondary goals.

Maine resources for transition planning

There are several organizations and agencies in Maine dedicated to helping adolescents and young adults with disabilities and their families prepare for the transition to adulthood. The Autism Society of Maine (asmonline.org) and the Maine Parent Federation (startingpointsforme.org) both have excellent resources for transition, including workshops, online videos, and a lending library with books and DVDs you or your teen can borrow.

Access Maine.org (accessmaine.org) is a website dedicated to providing a variety of information and resources for Maine citizens with disabilities.

In addition to a section devoted to transition planning, there are many other sections with helpful information, resources and links on a variety of important topics, including housing, transportation, employment, advocacy and other topics related to independent living.

The Pine Tree Society (pinetreesociety.org), a statewide organization located in southern Maine, initiated an Autism Transition Program in 2014. This program was developed specifically for young men and women ages 16–21 with a diagnosis of ASD. Workshops help adolescents build the skills they need for adult life. For more information, visit their website or call: 207.397.2141.

This is not a complete listing. Talk with your education and health care providers for information about resources in your area. For more information on these resources, see the resources and references listed at the end of this handbook and in the Resource Guide.

Legal issues

Although it may be hard to imagine your adolescent as a legally independent adult, there are important legal issues to consider as your child approaches late adolescence. One important thing to keep in mind is that by law, once your child turns 18, he or she will have reached the age of majority in Maine. This means your child is no longer considered a minor, and will have the right to make legal choices as an adult. This includes consent for educational evaluations and the IEP while in school, as well as the right to vote, marry, get a credit card and obtain medical treatment.

As a parent, you may want to consider whether your adolescent is able to make these adult decisions safely and appropriately. For some individuals with autism, considering guardianship or another form of legal oversight for decision-making may need to be considered. It is important to begin considering these issues well before your son or daughter turns 18, so you can be prepared for these changes.

To learn more about guardianship options available in Maine, see the Maine DHHS Office of Aging and Disability “Guide to Understanding Adult Guardianship and Guardianship Alternatives in Maine.” This guide is available online and is free to download (maine.gov/dhhs/oads/guardianship/guide.shtml). You can also contact Developmental Disability Services for more information on guardianship and its alternatives for your family by email OACPDS.DHHS@maine.gov or call 207.287.6595.

Each family will need to find the right amount and types of support their family member with ASD will need to achieve the highest degree of independence possible. We encourage you to contact the organizations we have suggested, read

books and online resources, and talk with your professionals and other parents for support and guidance in this important task.

Final thoughts on transitioning to adulthood

The Pacer Center, a parent training and information center for families of children and youth with disabilities offers the following suggestions for teens and young adults facing the transition to adulthood.

These tips are excerpted from the Pacer Handout “Ten Tips that May Help Your Child’s Transition



“I am a young adult with ASD. I started off working for my local fire department when I was 14. I absolutely loved being there, but I never thought I would become a firefighter because of my ASD. I am now a part-time firefighter for my home town, and I absolutely love what I do. I am now in school to become an EMT and become a full-time firefighter. Just because you have ASD, don’t let it stop you from becoming the person you want to be. I myself have better days than others, but that happens to all of us. Don’t let it stop you from achieving your dreams. We all have dreams, go for it!”

to Adulthood,” which can be downloaded in full for free on their website (pacer.org/parent/php/PHP-c107.pdf).

1. **Develop self-determination and self-advocacy skills.** All young people need a strong sense of their strengths, abilities, interests, and values.
2. **Expand social and community support networks.** Social and community networks are more than fun, they are important tools that help tie people into the community and provide a wider network of support.
3. **Build a work resume.** Many young people struggle to find work experiences that help



them compete in the job market. Summer jobs, helping neighbors and volunteering are great solutions.

4. **Learn soft employment skills.** These include things such as being able to accept direction, returning from breaks on time, deal with conflict, have the confidence to make decisions, and engage in appropriate communication.
5. **Practice money management skills.** Financial education is an important part of transition. Children need the self-determination skills developed through saving, spending, gift giving and budgeting.
6. **Connect with adult service providers.** The IEP team will no longer be available to coordinate disability-related services young adults with ASD may need, such as accommodations, transportation, physical or speech therapy, and job development services.
7. **Explore housing options.** While some young adults may stay in the family home at least for the short term, others may live in residential housing with services, cooperative housing, dormitory at an educational institution, an apartment with or without roommates, or they may own a home.
8. **Plan for health care needs.** Like most people, young adults with disabilities need to begin managing their health care, prescription drug use, and insurance issues.
9. **Visit post-secondary training and education programs.** Visiting a college or

“Transitions can be challenging for both you and your child. Think positive.”

training program can help young adults with ASD visualize the future.

10. **Prepare for change.** Helping your child plan for the future can lead to success, as long as you stay flexible. Plans will change no matter how carefully they are developed, and life includes challenges and stumbling points. Allowing your son or daughter to be flexible

with future plans help him or her develop the self-determination and self-advocacy skills important for adult life.

In Maine, families can contact the State of Maine/Department of Health and Human Services for information on disability services, housing, health (including MaineCare), Social Security, guardianship, employment and vocational rehabilitation in the state of Maine. Visit maine.gov/dhhs or call 207.287.3707. See the Resource Guide for additional resources for your child's transition to adulthood.

Key points from Booklet 2

- Remember that you are not alone; reach out to other parents and support groups offered by Maine organizations and agencies.
- Know your child's rights under IDEA and do not be afraid to advocate for your child.
- Take someone you trust with you to school meetings if possible; a second set of ears and the presence of someone who can support your concerns can be valuable.
- Making decisions as to what are the best therapies and interventions for your child is a process; don't be afraid to ask questions, seek information and support from other families and professionals, and listen to your heart.
- There are many interventions, practices and therapies available to treat children and adults with ASD, but only some are supported with scientific evidence. Talk with your service providers and professionals and be wary of any treatment promising a cure.
- Transitions can be challenging. Be patient with yourself and your child.
- Start transition planning early; seek out resources and support that is available to help.
- Consider guardianship issues early; better to have the necessary legal concerns addressed before your child reaches the age of majority (18-years-old).

“ I have been a special educator for 18 years, and in that time I have worked with hundreds of parents, specialists and students to develop educational programs that meet the specific needs of each student. Eight years ago I met Ethan. Ethan was a small, energetic little boy with a great smile, bright blue eyes, and autism. As we got to know Ethan as a student we learned that Ethan was in foster care and had been since he was three months old. Ethan was my student for less than a year before he moved. From time to time I would check up on his situation to see if he had been adopted. A year later, Ethan was still in foster care. I had difficulty grasping the idea of this seven year old boy, despite his challenges, never having a permanent home or family. It just never seemed fair.

I talked to my family about the possibility of adopting Ethan. There were a lot of unknowns. Would we be able to meet all of Ethan’s needs? I thought that we would be well prepared to bring Ethan into our home, given my background. Time and a myriad of experiences, however, had a definite effect on my optimism at the time. I still believed that we could be the family that Ethan needed, but quickly learned that is was going to be much more difficult than we had originally expected. I quickly realized that being a child’s teacher is not the same as being a child’s parent. Translating how to best teach someone was not the same as being the best parent. My educational training and experience have definitely helped along the way, but I would be remiss to say it has made it any easier.

When I think back on that time now, I am surprised by my naivety. We have had some incredibly frightening moments. We have monthly psychiatric appointments, specialist appointments, medication management, IEP meetings, behavior plans, section 28 services, and visits to the emergency room after Ethan punched a window or swallowed an aluminum can tab on Thanksgiving. When I think of all the challenges we have faced I am surprised that my family has weathered it all. I am so thankful for the amazing support we have had from our extended family and friends and those we have met along the way.

Our son Ethan has been a permanent part of our family for seven years now and is a freshman in high school. Life with Ethan has been a challenge and there will likely be more. But when I watch him talking with peers at track practice or hear him say that he loves his family, I know we made the right decision. No matter what your situation is, there is always support available, so don’t ever lose hope.”

Selected references and resources

Therapies and interventions

National Professional Development Center (NPDC) on Autism Spectrum Disorders website (autismcdc.fpg.unc.edu/), retrieved Dec. 1, 2014.

Ohio Center for Autism and Low Incidence (OCALI) (2009). *Ohio's Parent Guide to Autism Spectrum Disorders*. Columbus, Ohio; OCALI.

Rogers, S. J. and Dawson, G. (2010). *Early start Denver Model for young children with autism: Promoting language, learning and engagement*. New York: Guilford Press.

Rosenblatt, A. I., Carbone, P. S., and Yu, W. (Eds.). (2013). *Autism spectrum disorders: What every parent needs to know*. Elk Grove Village, IL: American Academy of Pediatrics.

Wong, C. Odom, S. L., Hume, K., Cox, A.W., Fettig, A., Kucharczyk, S., Brock, M.E., Plavnick, J.B., Fleury, V. P., and Schultz, T.R. (2014). *Evidence-based practices for children, youth, and young adults with Autism Spectrum Disorders*. Chapel Hill: the University of North Carolina, Frank Porter Graham Child Development Institute, Autism Evidence-based Practice Review Group.

Special education services

Maine Department of Education. Special Education: maine.gov/doe/specialed/index.html

Maine Department of Education. Child Development Services: maine.gov/doe/cds/

Maine Parent Federation, 2010–2014. startingpointsforme.org/content/productdescription

Special education law

Pacer Center Publications:

- *Special Education Rights:* pacer.org/publications/specedrights.asp
- *School Accommodation and Modification Ideas for Students who receive Special Education Services.* pacer.org/parent/php/php-c49.pdf
- *School Accommodations and Modifications.* pacer.org/publications/pdfs/ALL15.pdf
- *Least Restrictive Environment (LRE): An English Translation of Key Legal Requirements.* pacer.org/parent/php/php-c7.pdf

State of Maine Department of Education: maine.gov/doe/specialed

Wrightslaw: wrightslaw.com. A website dedicated to accurate, reliable information about special education law, education law, and advocacy for children with disabilities.

Selected references and resources

Special education law (cont.)

U.S. Department of Education, Office of Special Education and Rehabilitative Services, 2000. *A Guide to the Individualized Education Program*. ED Pubs Editorial Publications Center, Jessup, MD.

IEP Tips: How to Prepare for an IEP Meeting: understandingspecialeducation.com/IEP-tips.html

High school transition and future planning

Access Maine. *Transition Planning (Ages 14–25)*. accessmaine.org/living_transition.htm

Access Maine. *A Transition Guide for Families of Youth and Young Adults with Developmental Disabilities*. accessmaine.org/Toolkits/GuideforFamilies/guide.htm

Autism Society of Maine: Resources and workshops. Call 800.273.5200, email: info@asmonline.org or visit their website: asmonline.org/default.asp

Brown, Jane Thierfeld (Ed.D.), et al. (2012). *The Parent's Guide to College for Students on the Autism Spectrum*. Shawnee Mission, KS: AAPC Publishing.

Brown, Jane Thierfeld (Ed.D.). (September 17th, 2014). Personal communication.

Loo, Stephanie. Asperger's Association of New England. (Aug. 7, 2014). Personal communication.

Lowell, Allyson and Martinez, Dina. *Pathways to Transition*. Portland, ME: Woodfords Family Services.

Maine Parent Federation. Information packet on transition, online videos. Call 800.870.7746 (Maine) or 207.588.1933, Email: parentconnect@mpf.org or visit their website: startingpointsforme.org

Ohio Center for Autism and Low Incidence (OCALI). (2009). *Ohio's parent guide to autism spectrum disorders (2nd ed.)*. Columbus, Ohio: OCALI. Available online: ocali.org/project/ohio_parent_guide_to_ASD

Ohio Center for Autism and Low Incidence (OCALI). Lifespan Transitions Center: ocali.org/center/transitions

Pine Tree Society "Autism Transition Program": pinetreesociety.org/autismtransition.asp or by calling: 207.443.3341

Maine Parent Guide to Autism Spectrum Disorders



Photo courtesy of Felicia Kasprzak

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

Booklet 2: Accessing educational services, social services and interventions

Booklet 3: 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.