

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 306, Orono, ME 04469-5766
Phone: 207.581.2352
Fax: 207.581.2428
maineautisminstitute@maine.edu
umaine.edu/autisminstitute

©2018 Maine Autism Institute for Education and Research (MAIER) — second edition

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 University of Maine is an EEO/AA employer, and does not discriminate on the grounds of race, color, religion, sex, sexual orientation, transgender status, gender expression, national origin, citizenship status, age, disability, genetic information or veteran's status in employment, education, and all other programs and activities. The following person has been designated to handle inquiries regarding nondiscrimination policies: Sarah E. Harebo, Director of Equal Opportunity, 101 North Stevens Hall, University of Maine, Orono, ME 04469-5754, 207.581.1226, TTY 711 (Maine Relay System).

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 second 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:

Susan Abbiati

Jessica Archer

Nikki Becker

Karen Grotton-Pelletier

Kathleen Leopold

Laurie Robichaud

Cheryl Stalilonis

Tony Abbiati

Connor Archer

Cathy Dionne

Felicia Kasprzak

April Poulsen

Niki Sheafe

Roy Ulrickson III

MAIER Staff and Other Contributors

Deborah Rooks-Ellis, MAIER Director and Editor

Donna Doherty, MFP Director, Project Coordinator and Editor

Autism Society of Maine

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

Jennifer Beckett

Jamie Michaud, CDS

Amy Miller, CDS

Anica Miller Rushing

Courtney Pacholski

Jennifer Seale, Ph.D., CCC-SLP

Valerie Smith, Ph.D.

Libby Stone-Sterling

Jamie Treworgy

Carrie Woodcock, Maine Parent Federation

Special thanks to Jan Breton, Director of the Maine Department of Education's Office of Special Services, for her ongoing 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 June 2018.

Table of Contents

What's next?	2
Therapies.....	3
Interventions	
Choosing interventions	5
Are your chosen interventions effective?.....	6
Evidence-based practices.....	6
Program models	7
Applied Behavior Analysis (ABA)	7
Early Start Denver Model.....	8
The Hanen Approach	9
TEACCH.....	9
SCERTS®.....	10
Medical treatments and dietary interventions	11
Accessing educational services.....	14
Birth to 5 years	14
Child development services sites in Maine.....	14
Early intervention services (Part C).....	15
Early childhood special education (Part B)	16
Team meetings	18
Special education services in Maine public schools	18
Special education law.....	26
Key points from Booklet 2	28
Selected references and resources	30

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



“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.”

– Maine Parent

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 in this series, *Resource Guide for Maine Families*, includes additional listings of organizations and agencies that offer information and support to parents and caregivers, as well as help you find local support groups. Other parents raising children with ASD are often excellent resources for practical information and support. We encourage you to explore these resources, connect with other families, and work with your child's team to develop an education, intervention, and safety plan that is right for your family.

What's next?

Now that your child has been diagnosed with ASD, what's the next step? It can be a scary, confusing and difficult time that affects the whole family. 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 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 identified as being effective for all children with ASD. The amount of information on the Internet can be overwhelming and can make choosing the most appropriate program or treatment for your child seem impossible.

The following sections will help you learn more about the most common therapies and interventions available for treating autism that are supported by scientific research. We will then turn to a discussion of the steps for obtaining educational and social 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 (SLP), or speech therapist, may be one of the first allied health care professionals on your child's treatment team. This is because communication difficulties are at the core of an ASD diagnosis.

First, the SLP will evaluate your child's speech, expressive and receptive (comprehension) language, and social interaction (pragmatic) skills. When evaluating your child's language skills the SLP takes all forms of interaction into account, including: eye gaze, pointing, gestures, sounds, words, writing, and any other means through which individuals interact with others. In addition, SLPs are often the first professionals to evaluate and often treat difficulties your child may be experiencing with eating or swallowing, including

“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.”

– Maine Parent

food selectivity as it relates to temperature and/or texture.

Primarily, SLPs assist individuals with ASD in improving and developing speech, language, and social interaction skills. This often includes strategies for successfully interpreting others' spoken and nonverbal communication signals (e.g., facial expressions, gestures). Intervention and improvements in any of these areas can make tremendous differences in your child's and your family's life. Treatment outcomes are often greatest if treatment is integrated into your child's routine environments (home, school, day care) and daily activities.

If your child does not have reliable and effective speech communication, an SLP should perform or recommend a formal augmentative and alternative communication (AAC) evaluation. AAC tools and techniques have been reliably shown to support comprehension, self-regulation, and language development. For more detailed information related to AAC see *Volume 4: Resource Guide*.

Finally, some SLPs have certification for social skills training (e.g., Picture Exchange Communication System, Social Thinking, Social Stories), in which children are given formal opportunities to practice communicating in various social situations.

You do not have to wait until your child has enrolled in school to receive services from an SLP. In fact, early intervention services have proven to be widely beneficial for young children with ASD. That said, Speech- Language services and supports for individuals with ASD can (and often do) continue through the school years. Many individuals benefit from Speech-Language support and services even after high school. The American Speech and Hearing Association's ProFind tool can help you locate your nearest licensed SLP: asha.org/profind.

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

“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.”

– Maine Parent

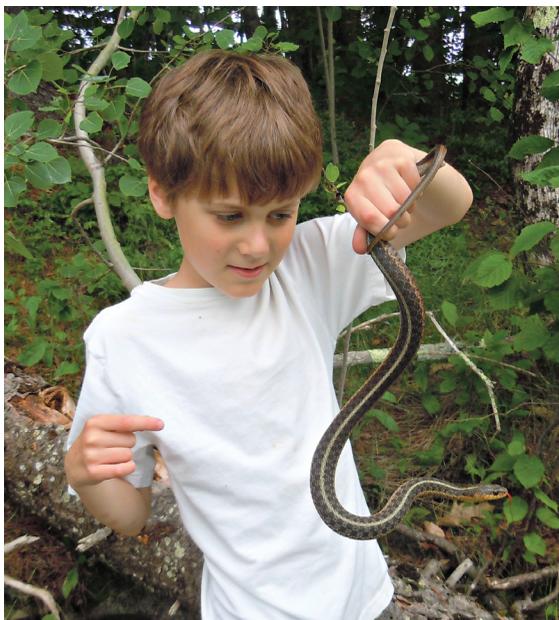
playing. Older children may also benefit from physical therapy to manage low muscle tone and improve their coordination, which may improve their ability to participate in physical activities (e.g., sports).

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, you know there are many programs and interventions available for treating children with ASD. 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. Practices shown to be effective through extensive research 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 in which you are interested. Seek professionals who are trained in the intervention and have the resources to implement them as intended.

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 questions for parents to consider when making decisions about your child's treatment in their *Ohio Parent Guide to Autism Spectrum Disorders* (2009).

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 to 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 is the cost for treatment? Will my insurance company pay for the treatment?
- How many hours daily/weekly will this 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? What pros and cons did I learn from these interviews?
- 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 do my pediatrician and other professionals involved with my child think about the appropriateness of this treatment for my child?
- 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 to collect information to help determine if the treatment is effective for

your 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.
- To prevent possible bias, seek feedback from other adults who know your child but do not know about the new treatment.
- 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.

Evidence-based practices

Although there are many interventions available today to treat children with autism, only some have scientific evidence demonstrating their effectiveness for children with ASD. 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 service providers to choose practices that carefully match your child's unique needs.

The table on pages 12–13 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.

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) for 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), the child's response to the event (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 (the context of the behavior).

Therapists develop a plan to manipulate the antecedent and consequences in order to shape and motivate desired behavior, and/or to reduce undesired behavior. ABA involves breaking down skills into small, measurable steps that can be built upon, repeated trials to solidify learning, and

“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.’”

– Maine Parent

practice in different settings (e.g., home, school, etc.). Targeted skills are strengthened through the use of positive reinforcement when the child exhibits the desired behavior. Reinforcement for desired behaviors is individualized to maintain high levels of motivation.

ABA has been used to successfully teach communication, social, academic, and self-help skills to individuals with ASD, 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 Maine

Early Start Maine is an initiative of the Maine Autism Institute for Education and Research (MAIER) in partnership with Maine Child Development Services (CDS). The ESM team is comprised of nationally certified ESDM therapists who provide ESDM training, consultation, and ongoing support to early intervention providers working with toddlers diagnosed with autism across the state of Maine.

Toddlers diagnosed with autism are assessed by the ESM team using the ESDM Curriculum Checklist, and teaching objectives are developed to address the child's needs and family priorities. The ESM team provides ongoing support and consultation to a family's primary service provider and monitors the child's progress on the ESDM objectives.

Parental involvement is a crucial part of the Early Start Maine program. Primary service providers explain and model teaching strategies to parents and caregivers to use at home, and



then coach them in using ESDM strategies during everyday activities such as meals, bath time and play.

For more information about ESM, contact CDS (877.770.8883; maine.gov/doe/cds/contacts.html) or MAIER (207.581.2352; maineautisminstitute@maine.edu). The ESM program receives significant support and funding from the Maine Department of Education, Office of Special Services and Maine CDS.

Early Start Denver Model

The Early Start Denver Model (ESDM) is a comprehensive early intervention approach for children ages 12–48 months with ASD. Research suggests 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 support and encouragement we received was the most helpful part of the Early Start Denver Model. Everyone was so involved in our child’s well-being and progress.*”

– Early Start Maine Parent

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 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 about the Hanen Approach 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. It builds a framework that organizes the 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

Parent Coaching Modules: The Maine Autism Institute for Education and Research (MAIER) offers *Parent Coaching Modules*, an online resource for parents and caregivers, based on the principles of the Early Start Denver Model. Modules are designed to encourage positive emotions and happy interactions with your child in a manner that promotes learning. Each module includes an introduction to a specific ESDM goal and steps for meeting that goal, including readings, videos, and activity cards for support. Families can use the Parent Coaching Modules either with your early intervention provider, or on your own. To access the modules, visit MAIER’s Parent Coaching Modules webpages: umaine.edu/autisminstitute/parent-coaching-modules.

“ Choosing to pursue, or not to pursue,
a certain type of therapy does not make you
a bad parent.”

– Maine Parent



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 focuses on building social communication and strengthening emotional regulation while providing transactional supports for the child. The program is 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 typically developing 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. SCERTS 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 your child's confidence and competence in ways that promote spontaneous and functional communication, increase enjoyment in engaging with others, and make your child available for other learning opportunities.

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

“It is so hard to navigate the media, and sometimes friends and family, that tell you about the latest article promoting the latest this or that. There is always some new technique, supplement, treatment, medicine, or idea that claims to have potential benefits for people with autism, but for which there is very little scientific evidence. It is so hard not to want to follow those headlines and spend the money and time because you want to chase the hope offered by those claims.

When I read those articles and feel my anxiety building, I do three things:

- 1. I go to the Association for Science in Autism Treatment website asatonline.org to see if there are peer-reviewed scientific studies on this treatment or intervention.*
- 2. I ask my child's team what they have heard and what they think. Talk with your OT, PT, psychiatrist, therapist, ABA, pediatrician, and the other families whose children have ASD. I ask everyone!*
- 3. I sit down with my partner and we consider: Is this something we now think has relevance or promise? Will the possible benefits outweigh the costs? What would this look like for our family? And will trying this have possible long-term consequences?*

We then make an informed decision about the intervention. Ultimately, this process helps us remember later on that we made a decision with the best information available at the time. And that's the best we can do.”

– Maine Parent

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.

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 to assist in identifying both the function of an interfering behavior, and environmental conditions that may have become linked to the 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) describe social situations in some detail by highlighting relevant cues and offering examples of appropriate responding to prepare individuals for upcoming social situations. 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.

Accessing educational services

In the United States, all children have the right to a “Free and Appropriate Education” (FAPE) under the Individuals with Disabilities Education Act (IDEA). This federal law ensures special education and related services to eligible children with disabilities from birth through 20 years old. You will find more information about IDEA and special education law later in this volume.

Birth to 5 years

Currently, Child Development Services (CDS) is the lead agency for Early Intervention (Birth through 3 years) and Early Childhood Special

Education (3–5 years) in Maine. This begins with a process called “Child Find” in which children are identified and evaluated for services.

Nine regional CDS sites serve the geographical regions of Maine under the supervision of the Maine Department of Education. If you are unsure which regional site covers your location, call the state office at 877.770.8883 or check the list of towns covered by each site on the CDS website: maine.gov/doe/cds/sitelocations.html.

Below is the list of the regional sites and their contact information:

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 Downeast

9 Resort Way, Ellsworth, ME 04605;
Phone: 207.667.7108; Fax: 207.664.0461

CDS First Step

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

CDS Midcoast

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

“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.”

– Maine Parent

“*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.*”

– Maine Parent

CDS Opportunities

16 Madison Avenue, Oxford, ME 04270;
Phone: 207.743.9701; 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 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

CDS welcomes referrals from both families and providers. Referrals are made by calling the CDS Central Referral Coordinator at 877.770.8883, faxing a Child Find Intake Form to 207.624.6661, or completing an online referral at maine.gov/doe/cds/families/referrals/child-find.shtml.

The following information is needed to make a referral to CDS:

- Child’s name, date of birth, physical address, and gender
- Who the child lives with
- Name of child’s childcare/preschool (if applicable)
- Names of other agencies working with the child/family (if applicable)
- Name and contact info for child’s Primary Healthcare Provider
- Parent or guardian name, mailing address, and phone number
- Diagnosis (if applicable)
- Explanation of concern(s)

Early intervention services (Part C)

CDS provides services to infants and toddlers with developmental delays and/or disabilities in accordance with Part C of IDEA. If your child is under the age of three years, once the referral is made, a Service Coordinator will contact your family to discuss the referral and explain Early Intervention (EI) Services.

If you are interested in moving forward, CDS will schedule a first visit with you and your child in his natural environment (i.e., your home or childcare). The first visit consists of completing paperwork and conducting the 5 Domain Evaluation/Assessment of your child (Cognitive, Communication, Motor, Social/Emotional, and Adaptive). A Service Coordinator and one or two other professionals will conduct this visit.

In Maine, there are three ways a child can be determined eligible for Part C services:

1. Meets Maine’s criteria for *development delay* by demonstrating a significant delay in one

area of development or a moderate delay in two or more areas,

2. Has a “*diagnosed physical or mental condition which has a high probability of resulting in developmental delay*” which is defined under IDEA, or
3. Demonstrates a significant developmental delay that was not captured by the standardized evaluation tool, but warrants use of “Informed Clinical Opinion” by the evaluators.

If your child is eligible for Part C services, a second visit will be scheduled. This visit can be in your child’s natural environment, at the CDS office, or at any location that is most convenient for your family. The Service Coordinator and one other professional will be present for this visit, and it begins with a Routines-Based Interview (RBI). This is a conversation that allows you to discuss your child’s strengths and challenges within his typical daily routines and activities. From this, you will develop a list of outcomes that you would like to work on during your child’s time in EI.

At the end of this visit, the Individualized Family Service Plan (IFSP) is finalized by identifying how the outcomes will be measured, which EI Team member will serve as the Primary Service Provider (PSP) and how often the visits will occur. By law, the IFSP must be developed within 45 days of the referral being made to CDS.

Once the IFSP has been developed, Routines-Based Home Visits must begin within 30 days. These visits include evidence-based services provided within your child’s natural environment.

The PSP will help you identify and learn strategies to address the outcomes identified on your child’s IFSP within the context of her daily routines and activities.

Your family and PSP will have access to additional support from other members of the Early Intervention Team (EIT) if needed. The EIT may include Special Educators, a Speech/Language Pathologist, an Occupational Therapist, a Physical Therapist, a Teacher of the Deaf, and a Social Worker.

Your child’s IFSP is reviewed *at least* every six months through meetings held in your child’s natural environment or at the CDS office, when requested by the family. When your child nears her third birthday, the Service Coordinator will begin the process of transitioning her from Part C to Part B services, if eligible.

Early childhood special education (Part B)

Currently, CDS provides services to preschool-aged children (3–5 years) with developmental delays and/or disabilities in accordance with Part B of IDEA. CDS ensures that identified children receive a Free Appropriate Public Education (FAPE). Part B services must take place in the Least Restrictive Environment (LRE) and with typically developing peers to the maximum extent possible. (For more information on these Special Education Laws and terms, see following sections of this guide.)

Once your referral is received at your regional CDS site, an IEP Case Manager will call you to gather further information about your concerns and about

“*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.*”

– Maine Parent

your child’s overall development within the five developmental domains (Cognitive, Communication, Motor, Social/Emotional, and Adaptive). They may also contact whomever made the referral (if not the family) to gather more information, if needed.

At this point, there are three potential outcomes: CDS determines the referral does meet the criteria for a special education referral and the file would be closed; CDS determines further screening needs to be completed to determine what evaluations (if any) are necessary; CDS refers your child to the IEP Team for evaluations.

Once your child is referred to the IEP Team, the IEP Case Manager presents the information to the Early Childhood Special Education Team (ECSET). The ECSET usually includes Case Managers, a Speech/Language Pathologist, an Occupational Therapist, and Special Educators. However, it may also include a Physical Therapist, a Teacher of the Deaf (TOD), and/or a Social Worker if needed. The team makes their recommendations for evaluations based on the information collected in the referral. The IEP Case Manager then mails the appropriate forms to the parent to review and sign.

Once you have signed and returned the consent for the evaluations, CDS has 60 days to complete the evaluations, send copies of the evaluations to you, and hold an IEP meeting to determine your child’s eligibility for Special Education Services.

If your child is eligible for services, an Individualized Education Program (IEP) is developed for your child by the team. The IEP is a legal document that outlines your child’s strengths and needs, identifies goals your child will be working on, and lists Special Education and Related Services that will be provided by CDS. This may include Specially Designed Instruction (SDI), Speech Therapy, Transportation, Physical Therapy (PT), Occupational Therapy (OT), Consultation, etc. Parents must approve and sign the IEP.

CDS has 30 days to implement the IEP once parental consent for Special Education Services is received. These services may take place in an early childhood setting, in the service provider’s location, or in a special education program, as determined and agreed upon in the IEP.

IEPs are reviewed annually and at other times throughout the year *upon request* (including at parent



“Our son’s first day of school scared us because we were so worried how others would treat him. It turned out he loves school, which makes us worry less, but we will always worry.”

– Maine Parent

request). Re-evaluations are completed at least every 3 years to re-establish eligibility for services; however, they may be completed sooner if necessary.

In the fall prior to your child becoming eligible for kindergarten (if you are planning to enroll your child in public school), CDS begins the process of informing your public school that your child will be entering their school system. The following spring, CDS will schedule and conduct a “CDS to Public School Transition” meeting at the public school district in which your child resides.

Team meetings

Parents play an important role at all IFSP and IEP team meetings, yet they can be overwhelming. Experienced parents suggest the following:

- Take a friend or advocate with you for support, to take notes, or to help clarify information.
- Be prepared to ask questions about things you don’t understand
- Be firm about your priorities for your child

Ultimately, the IFSP or 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 IFSP/IEP before services can begin. If your child qualifies for EI services, they are provided at no cost to you. However, if your child has insurance (including Medicaid), 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 Services, U.S. Department of Education Handout Services (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/spced/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)

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.

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 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. 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.

“ 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.”

– Maine Parent

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 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. Your child has already been found eligible for services, and these services have been provided prior to entering public school. Your child will be transitioned into public school with her existing services, 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 a succession of less restrictive evidence-based practices or interventions with insufficient efforts 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.

Parents have the right to challenge any decision by calling a hearing. For more information see the Maine Parent Federation fact sheets (<http://mpf.org/resources.html>) 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

“ 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.”

– Maine Parent

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 important members of the IEP team and experts on your own child. You are encouraged to include others 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 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, and who will be attending. Schools must inform parents that they may invite people to the meeting who have knowledge or special expertise about your child or can provide support to families (e.g., ASM or MPF support person or other advocate).

As a parent, you can also request an IEP meeting at any time.



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 you plan to attend.** 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, ask to reschedule the meeting at a time 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. If a draft of the IEP is available, you can ask to have a copy so that you can review it before the meeting. However, it is illegal for the school to have completed the IEP prior to this 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.

“*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.*”

– Maine Parent

- **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 to the IEP meeting.
- **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:

- greatschools.org/gk/iep-for-autism
- understandingspecialeducation.com/IEP-tips.html
- mpf.org/resources.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
- 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
- Child’s educational placement

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 or disagree with the IEP and to file an appeal. At this time, the team is required to hold another IEP meeting to discuss your concerns. If changes cannot be agreed upon at this time, a mediation process will begin and attorneys may be contacted to represent the school and family. Disability Rights Maine (DRME) (drme.org) offers families assistance from their advocates and attorneys in representing your child’s educational rights. Contact DRME by phone (800.452.1948) FMI and assistance.

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 is transitioning from an early intervention program/services, then he has an IFSP (Individualized Family Service Plan). An IFSP may transfer into an IEP once your child starts public school, or you and 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 school team. Each provider (i.e., speech therapist, occupational therapist, etc.), will give a description of your child’s status in her current services, and make recommendations for services to be carried over into the school setting. The school staff will ask questions, describe the school setting, and discuss how they will accommodate the needs of your child.

The Autism Society of Maine and the Maine Parent Federation both offer free support and assistance to families in navigating educational issues, including IEPs. A support person can be assigned to guide you through the IEP process, help you organize information in preparation for meetings, and attend meetings with you if needed. Contact the ASM or MPF using the information located at the end of this volume, or see *Volume 4: Resource Guide*.

“*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.*”

– Maine Parent

Step 7: Implementing an IEP

After an IEP is agreed upon, you will be given a copy of the IEP, as well as the names of all teachers and related service providers working with your child.

Teachers and related 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 school must implement services outlined in the IEP no later than 30 days after agreed upon.

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 you did at the initial meeting.

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. 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 Autism Society of Maine and the Maine Parent Federation offer assistance to parents faced with IEP disagreements and Disability Rights Maine assists parents in addressing grievances with your school, including representing your child in court, if needed. See the Resource listings at the end of this volume for contact information for these supports.

Step 10: Re-evaluation

At least every three years your child must be re-evaluated for special education. This evaluation is often called a triennial. The purpose of this review is to determine 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).

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

“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.”

– Maine Parent

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 Free and Appropriate Public Education (FAPE) mean for your child?

- Every child must receive a public school education at no cost 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:

- 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
- Assistance from a paraprofessional (e.g., educational technician)

- Alternative grading system or use of a pass-fail system
- Scheduled or additional breaks
- Specialized instruction
- 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.

What does Least Restrictive Environment (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.
- 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 a child is placed in a more restrictive setting, all efforts must be made to include the child with disabilities in as many activities with their peers as soon as possible. These activities might include recess, physical

education class, music class, lunch time and other extra-curricular activities.

What LRE does NOT mean:

- That 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.
- That your child will remain in the general education environment. If a more restrictive environment is deemed most appropriate at this time, the school must return your child, with needed supports, to the general classroom and environments as soon as possible.

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 about 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.

“ 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.”

– Maine Parent

Selected references and resources

Special education law

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.

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

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. mfp.org/resources.html

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.



Photo courtesy of Felicia Kasprzak

Autism ribbon used with permission of the Autism Society of Maine

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.