

# Maine Parent Guide to Autism Spectrum Disorders

Booklet 3: Resource Guide for Maine Families



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

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**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.

## Table of Contents

Resources .....	6
Advocacy and information.....	6
Assistive technology (AT) .....	8
Autism apps.....	9
Autism education and training .....	9
Developmental evaluation centers.....	10
Early intervention and educational services.....	10
Maine Child Development Services (CDS) sites .....	11
Employment .....	11
Family support .....	12
Health and human services.....	14
Legal assistance.....	15
Recreation and camps.....	16
Respite .....	17
Transition to adulthood.....	18
Wandering registries .....	19
Autism safety.....	20
Recommended books .....	24
Common abbreviations .....	28
Glossary .....	30

**T**he final booklet of this series, the *Resource Guide for Maine Families*, was developed as a tool to assist individuals and families in gathering additional information and identifying needed services and support. While the primary focus of this resource guide is on Maine service providers, agencies and nonprofits, we also included listings of key federal and national resources. This resource guide is not all inclusive, however, as we chose to include organizations and providers likely to provide the most direct assistance to families in search of services and support.

We encourage you to explore the resources listed in this guide and work with your child's team to develop an education and service plan that is right for your family. We hope you will come back to this guide time and again as your child grows older and your family needs change.

Also included in this volume are safety tips for your family, a listing of books recommended by Maine Partnership parents and interested professionals, a compilation of common abbreviations you may encounter, and a glossary of terms to help you navigate the world of special education and disability services. We hope you find these tools useful for your family.

All phone numbers, email addresses, and website information were current at the time of this printing. However, contact information changes from time to time and agencies and organizations may alter their services. We apologize for any errors. Notify us so that updates can be made to future volumes.

*We invite you to contact MAIER to be placed on our mailing list for e-newsletters, event announcements and other items of interest to Maine families affected by autism spectrum disorders.*

“ I find being a parent of a child with autism challenging; I often don’t know why he acts like he does and I don’t know how to help what he is feeling. I am not inside his head and body, and because he doesn’t have the ability to voice what is bothering him, so much is unknown.

There are still people in this day and age who do not understand or accept those with autism spectrum disorders. They think our son acts out just because he’s being a brat ... That may be true sometimes, but everything a typical child feels, he feels dozens of times stronger. I can’t understand or explain what he goes through, even as his mother and the one who knows him best.

It hurts me that he is misunderstood or looked at as odd, when, in actuality, we all have some strange behaviors, just in differing degrees. I get sad that he might not be accepted. Thankfully, Jamie has a small group of friends; the other children enjoy his company and like his fun and joking sweetness. Some can perceive that he is different — especially his girl-friends — and they often treat him in a motherly way. His boy-friends like that he is a very physical kid that loves trains and cars, and they enjoy his funny way of doing and saying things.

Because Jamie has fought so hard, from his birth to now, each and every victory is precious. Learning new skills, making friends, understanding and using language appropriately, reading books by himself, writing and coloring, making up his own math problems to solve, using swings and slides (which has taken years of conditioning); each one of these things is a gift. I take great joy in his achievements, most being simple and natural things for typical children yet are hard fought for us.

I do not wish for him to be different, because all those things about him, including his autism, are part of what makes him special. And he is perfect the way he was created.”



## Resources

### Advocacy and information

#### **211 Maine:** *211maine.org*

211 Maine is a comprehensive statewide directory of Maine health and human services available by calling 2-1-1 or through this website. Connect with a trained call specialist by phone or find answers online to state health and human services questions and/or assistance in locating needed help and resources.

Phone: 211

#### **AccessMaine.org**

Access Maine is a website dedicated to providing a variety of information and resources for Maine citizens with disabilities, including housing, transportation, employment, advocacy, and other topics related to independent living. The site includes links to other Maine-based resources.

#### **Autism Society of Maine (ASM):** *asmonline.org*

The Autism Society of Maine provides education and resources to support the valued lives of individuals on the autism spectrum and their families, including downloadable information sheets and booklets on a variety of topics, brochures, an online referral database, and special programs including Sibshops, support groups and special events. ASM is a local chapter of the Autism Society.

Phone: 800.273.5200; Email: [info@asmonline.org](mailto:info@asmonline.org)

#### **Center for Community Inclusion and Disability Studies (CCIDS)/University of Maine:** *ccids.umaine.edu*

CCIDS brings together the resources of the university and Maine communities to enhance the quality of life for individuals with developmental disabilities and their families. This includes interdisciplinary education, research and evaluation, community engagement through outreach education and technical assistance, and dissemination of information and resources through publications and presentations.

Phone: 800.203.6957; Email: [ccidsmail@umit.maine.edu](mailto:ccidsmail@umit.maine.edu)

#### **Centers for Disease Control/Autism Spectrum Disorder:** *cdc.gov/ncbddd/autism/index.html*

Centers for Disease Control/Autism Spectrum Disorder is a federal resource for information on autism including basic facts, screening and diagnosis, treatments, research studies, statistics and tracking, scientific articles and free downloadable materials.

#### **Centers for Disease Control/Learn the Signs. Act Early:** *cdc.gov/ncbddd/actearly*

Centers for Disease Control/Learn the Signs. Act Early is a federal website devoted to helping parents



track their child's development from birth to 5 years and encourages early action if they suspect autism or other developmental disabilities. The site provides detailed information on developmental milestones and suggestions for action for parents with concerns. Downloadable tools and materials are available.

**Cromwell Center for Disabilities Awareness:** *cromwellcenter.org*

The Cromwell Center for Disabilities Awareness offers free programs to Maine elementary schools and communities to help improve sensitivity, understanding, compassion and acceptance of persons with disabilities. Teacher resources and lesson plans for various grade levels help create a deeper understanding of persons with disabilities as important community members.

Phone: 207.775.9955

**Maine Autism Institute for Education and Research (MAIER):** *umaine.edu/autisminstitute*

MAIER offers education and training about evidence-based practices for professionals working with children and families with autism spectrum disorders, including undergraduate and graduate courses, and professional development workshops. For families seeking assistance, the institute offers services, resources and information, support and guidance, and tools to contribute to awareness regarding their children with ASD. A partnership of the University of Maine College of Education and Human Development and the Maine Department of Education. *Contact MAIER to be placed on their mailing list for e-newsletters, event announcements and other items of interest to Maine families affected by ASD.*

Phone: 207.581.2352; Email: [maineautisminstitute@maine.edu](mailto:maineautisminstitute@maine.edu)

**Maine Developmental Disability Council:** *MaineDDC.org*

The Maine Developmental Disability Council is a partnership of people with disabilities, their families, and agencies who identify barriers to community inclusion, self-determination and independence. The council acts to effect positive change through advocacy, training, demonstration projects and support for other inclusive and collaborative systemic change activities.

Phone: 800.244.3990, Email: [info@maineDDC.org](mailto:info@maineDDC.org)

**Maine Parent Federation (MPF):** *startingpointsforme.org*

The Maine Parent Federation is a community for families of children with disabilities. MPF provides information and assistance on a broad range of topics, help with referrals, one-on-one telephone support, parent-to-parent connections, training and an online resource database. MPF will match individuals with a family support navigator who is an experienced parent from their area, and can offer support for meetings, and help in understanding state laws, accessing services and identifying resources.

Phone: 800.870.7746; Email: [parentconnect@mpf.org](mailto:parentconnect@mpf.org)

**Pine Tree Society:** *pinetreesociety.org*

The Pine Tree Society is dedicated to helping people in Maine with disabilities lead rich, socially connected lives. Services include assistive technology, communication, community supports and accessible recreation. For persons with ASD, Pine Tree Society offers case management, an autism transition program, communication supports, adult life skills and community engagement, and a summer camp for both children and adults.

Phone: 207.443.3341; Email: [info@pinetreesociety.org](mailto:info@pinetreesociety.org)

**State of Maine/Disability Services:** *maine.gov/dhhs/oads/disability*

The State of Maine's Disability Services is an index of state services for children and adults with disabilities, including case management, crisis services, supported employment, guardianship, MaineCare, person-centered planning, a provider directory and residential services.

Phone: 207.287.9200 or 888.568.1112

## **Assistive technology (AT)**

**All Tech:** *alltech-tsi.org*

All Tech provides in-person or virtual consultations, assessment, training, and technical assistance to identify and provide technology solutions to educational, daily living, communication, and workplace challenges experienced by people of all ages and abilities. All Tech supports assistive technology, augmentative/alternative communication, universal design, accessible instructional materials and computer accessibility.

Phone: 207.321.6080 (Portland), 207.947.9180 (Bangor); Email: [info@alltech-tsi.org](mailto:info@alltech-tsi.org)

**Maine CITE:** *mainecite.org*

Maine CITE is a Maine Department of Education program designed to help make assistive technology and universally designed technology more available to Maine children, adults and seniors. Maine CITE provides information and support for technology used in employment, education, community living and information technology.

Phone: 207.621.3195; Email: [iweb@mainecite.org](mailto:iweb@mainecite.org)

**Mainely Access:** *mainelyaccess.com*

Mainely Access is a private company staffed by rehab professionals to provide adaptive technology services in Maine. Its primary focus is persons of all ages with visual impairments, but also offers training for speech recognition packages and those using alternatives to the standard computer keyboards and mouse.

Phone: 207.650.8151 or 207.650.8343

**University of Maine Farmington Assistive Technology Collection:** [www2.umf.maine.edu/kcmcl/at](http://www2.umf.maine.edu/kcmcl/at)

The University of Maine Farmington Assistive Technology Collection provides introduction to assistive technology, instruction in and/or evaluation of equipment, and general information about assistive technology. Many items can be borrowed for home, school or therapeutic use. Located in UMF's Kalikow Curriculum Materials Center of UMF, this resource is free to individuals with disabilities and their families.

Phone: 207.778.7895; Email: [web-mantor@umf.maine.edu](mailto:web-mantor@umf.maine.edu)

## Autism apps

**Autism Apps from iTunes:** [itunes.apple.com/us/app/autism-apps/id441600681?mt=8](https://itunes.apple.com/us/app/autism-apps/id441600681?mt=8)

This free app provides a comprehensive list of apps used with and by people diagnosed with autism and other special needs. Apps are categorized for easy searching and include links to information and pricing. Reviews by parents, specialists, and users are available. This app is compatible with iPads, iPhones and iPod Touch.

## Autism education and training

**Maine Autism Institute for Education and Research (MAIER):** [umaine.edu/autisminstitute](http://umaine.edu/autisminstitute)

MAIER is a partnership between UMaine's College of Education and Human Development and the Maine Department of Education. MAIER offers education and training about evidence-based practices for professionals working with children and families with autism spectrum disorders, including undergraduate and graduate courses. The institute offers services, resources and information, support and guidance, and tools to contribute to awareness regarding their children with ASD for families. Contact MAIER to be placed on their mailing list for e-newsletters, event announcements and other items of interest to Maine families affected by ASD.

Phone: 207.581.2352; Email: [maineautisminstitute@maine.edu](mailto:maineautisminstitute@maine.edu)

**Kennebec Valley Community College:** [kvcc.me.edu/Pages/Education/Education-Home](http://kvcc.me.edu/Pages/Education/Education-Home)

Kennebec Valley Community College offers undergraduate courses related to educating/working with children with ASD and an associate degree for applied science in autism studies.

Phone: 207.453.5822

## Developmental evaluation centers

*This is not a complete listing; talk with your pediatrician for a diagnostic center in your area.*

### **Augusta: Edmund N. Ervin Pediatric Center, Maine General Health**

*[mainegeneral.org/Pages/Care-and-Services-A-Z/Children-s-Health/Edmund-N-Ervin-Pediatric-Center.aspx](http://mainegeneral.org/Pages/Care-and-Services-A-Z/Children-s-Health/Edmund-N-Ervin-Pediatric-Center.aspx)*

Phone: 207.623.6500

### **Bangor: Eastern Maine Medical Center Pediatric Specialty Clinics**

*[emmc.org/pediatric-services.aspx](http://emmc.org/pediatric-services.aspx)*

Phone: 207.973.7520

### **Farmington: Franklin Memorial Hospital Developmental Pediatrics**

*[fchn.org/franklin-health/pediatrics](http://fchn.org/franklin-health/pediatrics)*

Phone: 207.778.0482

### **Portland: The Barbara Bush Children's Hospital at Maine Medical Center, Developmental-Behavioral Pediatrics**

*[mmc.org/mmp\\_spcare.cfm?id=5688](http://mmc.org/mmp_spcare.cfm?id=5688)*

Phone: 207.662.5522

### **Waterville: Edmund N. Ervin Pediatric Center, Maine General Health**

*[mainegeneral.org/Pages/Care-and-Services-A-Z/Children-s-Health/Edmund-N-Ervin-Pediatric-Center.aspx](http://mainegeneral.org/Pages/Care-and-Services-A-Z/Children-s-Health/Edmund-N-Ervin-Pediatric-Center.aspx)*

Phone: 207.872.4303

## Early intervention and educational services

### **Maine Child Development Services (CDS)/Maine Department of Education:** *[maine.gov/doe/cds](http://maine.gov/doe/cds)*

CDS provides services for families/caregivers who have young children (birth through 5 years) suspected of having, or diagnosed with special needs. Regional CDS sites provide screenings and evaluations, case management and direct instruction to families, and arrange for early intervention, special education, and related services to qualifying children. See CDS listings to find an office serving your area.

Phone: 207.624.6600

### **Office of Special Services/Maine Department of Education:** *[maine.gov/doelspecial](http://maine.gov/doelspecial)*

The Office of Special Services provides oversight and support for the delivery of all special education services in Maine under the federal Individuals with Disabilities Education Act (IDEA), including Part C (birth-to-3 years) and Part B (age 3-to-20 years).

Phone: 207.624.6600

### **Maine Association for Community Service Providers (MACSP):** *[meacsp.com](http://meacsp.com)*

MACSP is an association of organizations that provide support and services to children and adults with

developmental and other cognitive disabilities. Organizations work with Maine state bureaus, offices and departments to provide quality services to Maine people. Member directory listings for service providers throughout Maine. Contact MACSP for assistance finding local service providers.

Phone: 207.623.5005

### **Maine Child Development Services (CDS) sites**

To determine the CDS site serving your city/town: [maine.gov/doe/cds/families](http://maine.gov/doe/cds/families) or call 877.770.8883

#### **CDS State IEU**

111 Sewell St., 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 Ave., Oxford, ME 04270  
Phone: 207.743.9701; Fax: 207.743.7063

#### **CDS PEDS**

163 Silver St., 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 St., Machias, ME 04654  
Phone: 207.255.4892; Fax: 207.255.6457

#### **CDS Midcoast**

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

#### **CDS Two Rivers**

250 State St., 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

## **Employment**

**Camp CARDNE (Center for Autism and Related Disorders New England):** [campcardne.shutterfly.com](http://campcardne.shutterfly.com)

Camp CARDNE is a five week summer work apprenticeship experience for students 16 years and older with ASD. Each apprentice earns a daily stipend while working, and learns about money management such as budgeting and saving. Limited scholarship assistance may be available.

Phone: 603.502.5260; Email: [CARDNE@maine.rr.com](mailto:CARDNE@maine.rr.com)

**Employment for ME:** *employmentforme.org*

Employment for ME provides helpful information and resources about employment and initiatives in Maine for youth and adults with disabilities, including information for youths in transition (e.g., accommodations, rights, money management). The website is a collaboration between MDHHS, Maine Department of Labor, and the Muskie School of Public Service.

Phone: Office of Aging and Disability Services, 207.822.0328

Phone: Bureau of Rehabilitation Services, 207.623.7963

**Maine Bureau of Rehabilitation Services:** *maine.gov/rehab*

Maine Bureau of Rehabilitation Services is a gateway to services and support for Maine citizens with disabilities for accessing employment, gaining independence and supporting community integration. Services include job training, vocational rehabilitation services and other resources for employment.

Phone: 207.623.6799

**Maine CareerCenter:** *mainecareercenter.com*

Maine CareerCenter provides services and resources for youths age 14–21 years to gain training and employment opportunities that help teens — including those with disabilities — learn skills while still in high school. The centers also provide opportunities and resources for Maine adults seeking career exploration and training. Centers are located across the state and services are free to Maine workers.

Phone: 888.457.8883

**“ Know that you are not the only ones going through this and reach out to other parents and support groups. Attend as many workshops or seminars on autism as you can. Reach out to as many resources as possible.”**

## Family support

**Autism Safety Education & Training (ASET):** *aset911.com*

ASET provides resources for families including downloadable forms and handouts about fire safety, wandering, teaching children about first responders and 911 registration forms. Autism training programs for first responders include police, fire/rescue/EMS, 911 dispatchers, as well as school systems and other interested groups. *For safety tips you can use right now, see the “Autism Safety” section of this booklet.*

Phone: 207.415.1392; Email: nbrown623@aol.com

**Autism Society of Maine:** [asmonline.org](http://asmonline.org)

The Autism Society of Maine provides education and resources to support the valued lives of individuals on the autism spectrum and their families, including downloadable information sheets and booklets on a variety of topics, brochures, online referral database, and special programs including Sibshops, support groups, and special events.

Phone: 800.273.5200; Email: [info@asmonline.org](mailto:info@asmonline.org)

**Bullying and Individuals with Special Needs:** [ocali.org/project/bullying\\_and\\_individuals\\_with\\_special\\_needs](http://ocali.org/project/bullying_and_individuals_with_special_needs)

Bullying and Individuals with Special Needs is a series of webpages developed by the Ohio Center for Autism and Low Incidence that feature information, webcasts, and resource lists to increase awareness, provide education, and promote action to address bullying of persons with disabilities.

**Gaining Empowerment Allows Results (G.E.A.R)**

**Parent Network:** [gearparentnetwork.org](http://gearparentnetwork.org)

G.E.A.R. is a parent-run organization for parents of children with disabilities, including emotional and behavioral health needs, offering support through group meetings and phone calls, as well as workshops on topics of interest to parents. Services provided throughout Maine.

Phone: 800.264.9224

**Maine Autism Institute for Education and Research/Maine Family Partnership (MAIER/MFP):** [umaine.edu/autisminstitutel/maine-family-partnership](http://umaine.edu/autisminstitutel/maine-family-partnership)

MAIER institute staff work together with individuals and families affected by ASD to identify issues of concern to Maine families and collaborate on projects to promote greater awareness and understanding, develop tools and resources, address access to services, and support research efforts. Hosts educational and social events to support family-to-family networking, provide information, and strengthen community ties.



Contact MAIER to be placed on their mailing list for e-newsletters, event announcements and other items of interest to Maine families affected by ASD.

Phone: 207.581.2352; Email: [maineautisminstitute@maine.edu](mailto:maineautisminstitute@maine.edu)

**Maine Parent Federation (MPF):** [startingpointsforme.org](http://startingpointsforme.org)

MPF is a community for families of children with disabilities. It provides information and assistance on a broad range of topics, help with referrals, one-on-one telephone support, parent-to-parent connections, and training. MPF will match families with a Family Support Navigator — an experienced parent from their area — to provide support for meetings and help in understanding state laws, accessing services, and identifying resources. An online resource database is available.

Phone: 800.870.7746; Email: [parentconnect@mpf.org](mailto:parentconnect@mpf.org)

**National Autism Association/Autism Safety/Bullying:** [autismsafety.org/bullying.php](http://autismsafety.org/bullying.php)

The National Autism Association/Autism Safety/Bullying website is devoted to information on bullying, specifically when it involves children and teens with ASD. It provides parents with tips and resources for preventing and responding to bullying incidents.

## Health and human services

**Child Behavioral Health Provider List/Maine DHHS:** [maine.gov/dhhs/ocfs/cbhs/provider-list/home.html](http://maine.gov/dhhs/ocfs/cbhs/provider-list/home.html)

The Maine Department of Health and Human Services Child Behavioral Health Provider List provides information about behavioral health providers in each Maine county.

**Children’s Behavioral Health Services/Maine DHHS:** [maine.gov/dhhs/ocfs/cbhs](http://maine.gov/dhhs/ocfs/cbhs)

Maine DHHS’s Children’s Behavioral Health Services provides behavioral health treatment and services for children from birth until their 21st birthday. Services include providing information and assistance with referrals for children and youth with developmental disabilities/delays, intellectual disability, Autism Spectrum Disorders, and mental health disorders.

Phone: 207. 624.7900

**Katie Beckett Option/Maine DHHS:** [maine.gov/dhhs/ocfs/cbhs/eligibility/katiebeckett.html](http://maine.gov/dhhs/ocfs/cbhs/eligibility/katiebeckett.html)

Katie Beckett is a MaineCare option for children with serious health conditions. It is one of the many ways a child can access MaineCare. If a child meets the rules for this option, the child can receive full MaineCare benefits.

Phone: 207.624.7900



**Maine Department of Health and Human Services (DHHS):** *maine.gov/dhhs*

Maine DHHS serves as a gateway to all Maine DHHS programs and services.

Phone: 207.287.3707

**MaineCare/Maine DHHS:** *maine.gov/dhhs/mainecare.shtml*

MaineCare is financial assistance for health care that is available to persons who meet income guidelines and are eligible based on age, family situation, and health care needs. Visit the website or call for information on eligibility, getting an application, or for help with filling out an application.

Phone: 207.287.3707

**Office of Child and Family Services/Maine DHHS:** *maine.gov/dhhs/ocfs/cbhs/services/case-management.html*

The Office of Child and Family Services offers an assessment for eligibility for case management services, develops Individual Service Plans, and services to meet needs. Case Managers work with families to assist with coordination and advocacy of services for your child.

A case management provider list of those contracted with DHHS can be accessed online (*maine.gov/dhhs/ocfs/cbhs/provider-list/home.html*).

Phone: 207.624.7900

## **Legal assistance**

**Disability Rights Maine:** *drcme.org*

Disability Rights of Maine is a protection and advocacy agency for people with disabilities. It provides individuals with information about their rights and service systems, and provides legal services to individuals and groups.

Phone: 800.452.1975

**Pine Tree Legal Assistance:** *ptla.org*

Pine Tree Legal Assistance provides free legal assistance to help Maine people with low incomes. Offices are located across the state. Interactive online tools and resource library guide you to the best resources and information about legal issues including special education, human rights, employment, and disability benefits.

Phone: See website for listing of your local office or call the Portland office: 207.774.8211

## Recreation and camps

*This list is not all inclusive as many summer camps in Maine also serve children with special needs. For more summer camp information, contact the Autism Society of Maine and/or 211Maine (see their listings in this guide).*

### **Camp CaPella:** [campcapella.org](http://campcapella.org)

Camp CaPella is a summer camp located on Phillips Lake in Dedham, Maine, offering camp programs for children and adults with disabilities and their families, designed to foster personal growth and exploration. Activities include swimming, hiking, boating, camp crafts, and nature study.

Phone: 207.843.5104

### **Camp CARDNE (Center for Autism and Related Disorders New England):** [campcardne.shutterfly.com](http://campcardne.shutterfly.com)

Camp CARDNE is a summer camp for children with high functioning Autism or Asperger's Syndrome, located in York, Maine. The program focuses on developing social skills and positive peer relations.

Limited scholarship assistance may be available.

Phone: 603.502.5260; Email: [CARDNE@maine.rr.com](mailto:CARDNE@maine.rr.com)



### **Camp STRIVE:** [pslstrive.org/camp](http://pslstrive.org/camp)

Camp STRIVE is a summer day camp for people in the South Portland area for ages 11–24 with developmental disabilities. The focus is on making friends, playing games and learning valuable skills in a safe, inclusive environment. The camp includes sports and games, cooking, arts and crafts, and field trips.

Phone: 207.774.6278

### **Camp Summit:** [asmonline.org/news.asp?article=3920](http://asmonline.org/news.asp?article=3920)

Camp Summit is the Autism Society of Maine's summer day camp for children ages 5–15 with ASD. Camp is held in Farmington, Maine during July and August for two separate two-week sessions. Attendees focus on the development of communication skills and peer relationships in a social setting. Call for information or to request an application.

Phone: 800.273.5200

**Camp Waban:** [waban.org/camp-waban-sanford-maine.aspx](http://waban.org/camp-waban-sanford-maine.aspx)

Camp Waban is a fully accessible summer camp located on Bauneg Beg Lake in Sanford, Maine. Available for rental by individuals, families, group homes, schools and organizations serving children and adults with disabilities and their families and caregivers. Campers must be accompanied by family or staff who are expected to be responsible for them. Activities include swimming, boating, basketball, music, arts and crafts, accessible nature trails and more.

Phone: 207.324.7955; Email: [camp@waban.org](mailto:camp@waban.org)

**Maine Special Olympics:** [specialolympicsmaine.org](http://specialolympicsmaine.org)

Maine Special Olympics is an organization that provides year-round sports training and athletic competition in a variety of Olympic-type events for children and adults with intellectual disabilities. It provides opportunities for participants to develop physical fitness, demonstrate courage, experience joy and participate in sharing of gifts, skills and friendship with their families, other Special Olympics athletes, and the community.

Phone: 207.879.0489

**Pine Tree Camp:** [pinetreesociety.org/camp.asp](http://pinetreesociety.org/camp.asp)

Pine Tree Camp is a summer camp located in Rome, Maine, for children and adults with physical and/or developmental disabilities. It offers both overnight and day camp opportunities as well as Camp Communicate, a camp experience for children who use high-tech devices to communicate.

Phone: 207.443.3341

## Respite

**National Alliance on Mental Illness/Maine (NAMI) Family Respite Program:**

[namimaine.org/?page=FamilyRespite](http://namimaine.org/?page=FamilyRespite)

The NAMI Family Respite Program offers families statewide short-term relief (respite) from the responsibilities of caring for a child with significant developmental delays, and behavioral or emotional disorders. NAMI provides support, education and advocacy to those impacted by mental illness.

Phone: 207.622.5767; Email: [respite@namimaine.org](mailto:respite@namimaine.org)

**Respite for ME:** [respiteforme.com](http://respiteforme.com)

Respite for ME is a statewide program funded by the Maine DHHS to provide respite care to families. The program offers caregivers a much needed, short-term break from the day-to-day demands of caring for and raising a child with special needs.

Phone: 207.622.5767

## Transition to Adulthood

### **Alpha One:** *alphaonenow.com*

Alpha One is a center for independent living for people with disabilities. Alpha One offers a variety of independent living services to enable independence in all aspects of life. Offices are located in South Portland, Bangor and Presque Isle. Alpha One supports advocacy and innovation to promote independent living.

Phone (South Portland): 207.767.2189; Toll-free: 800.640.7200

Phone (Bangor): 207.941.6553; Toll-free: 800.300.6016

Phone (Presque Isle): 207.764.6466; Toll-free: 800.974.6466

### **Autism Society of Maine (ASM):** *asmonline.org*

The Autism Society of Maine provides education and resources to support the valued lives of individuals on the autism spectrum and their families, including online resources and a borrowing library of books on transitioning to adult life, support and social group listings, and information specialists. ASM is a local chapter of the Autism Society.

Phone: 800.273.5200

Email: [info@asmonline.org](mailto:info@asmonline.org)

### **Employment for ME:** *employmentforme.org*

Employment for ME provides helpful information and resources about employment and initiatives in Maine for youth and adults with disabilities. It includes information for youths in transition (e.g., accommodations, rights, money management). The website is a collaboration between MDHHS, Department of Labor, and the Muskie School of Public Service.

Phone: Office of Aging and Disability Services, 207.822.0328

Phone: Bureau of Rehabilitation Services, 207.623.7963

### **Maine Coalition for Housing and Quality Services:** *maineparentcoalition.org*

Maine Coalition for Housing and Quality Services is a parent-initiated coalition dedicated to creating a system of quality housing and personal supports for adults with special needs. Parents and advocates working together to implement a lifelong continuum of care for people with developmental disabilities.

Phone: 207.879.0347

### **Maine Department of Health and Human Services (DHHS)/**

#### **Office of Aging and Disability:** *maine.gov/dhhs/oads/disability*

The Office of Aging and Disability is the gateway to DHHS programs and services for persons with disabilities.

Phone: 207.287.3707

## Links to specific State of Maine webpages related to transition:

**Maine Care Waiver/DHHS:** [maine.gov/dhhs/oads/disability/ds/MaineCare](http://maine.gov/dhhs/oads/disability/ds/MaineCare)

**Guardianship/DHHS:** [maine.gov/dhhs/oads/guardianship](http://maine.gov/dhhs/oads/guardianship)

**Maine Department of Labor/Vocational Rehabilitation:** [maine.gov/rehab](http://maine.gov/rehab)

**Maine Parent Federation (MPF):** [startingpointsforme.org](http://startingpointsforme.org)

MPF is a community for families of children with disabilities. Information and assistance on a broad range of topics including the transition to adult living is provided. MPF assists with referrals, one-on-one telephone support, parent-to-parent connections, and training. An online resource database is available. MPF will match families with a Family Support Navigator, who is an experienced parent from the area, and can offer support for meetings, help in understanding state laws, assistance accessing services, and identifying resources.

Phone: 800.870.7746; Email: [parentconnect@mpf.org](mailto:parentconnect@mpf.org)

## Wandering registries

Wandering registries provide free database registration with local law enforcement agencies to provide a critical network of real-time information about your child, including a photograph, to responders in the event of a wandering incident. Registration provides valuable time-saving information to law enforcement.

**Lincoln, Somerset and**

**Waterville Wandering Database:**

[helpautismnow.com/databases\\_cont.html](http://helpautismnow.com/databases_cont.html)

**Penobscot Regional Communication**

**Center Wandering Registration:**

[penobscotrcc.com/wanderer-database](http://penobscotrcc.com/wanderer-database)

**Waldo County/Knox County Wandering**

**Database:** [helpautismnow.com/databases\\_cont\\_2.html](http://helpautismnow.com/databases_cont_2.html)



## Autism safety

**T**he following safety information was authored and provided by Autism Safety Education & Training (ASET), located in Portland, Maine. Matt Brown, the owner and founder of ASET, is a seasoned law enforcement officer and parent of a teenage son with ASD who has trained many first responders in Maine over the last 10 years. We encourage you to contact ASET with any safety questions you may have regarding your family member with ASD.

Individuals with autism are at a much higher risk of placing themselves in a dangerous or even potentially life-threatening situation, such as wandering or becoming a victim of a crime. Often persons with ASD do not develop a natural sense of danger, and as a result, can place themselves in harm's way. They may meltdown when experiencing sensory overload or when forced to process information, questions or instructions too quickly. These characteristics can create dangerous situations when interacting with first responders, particularly police, who often have little training in this area.

For all of these reasons, families and caregivers of persons affected by autism spectrum disorder (ASD) should be proactive when it comes to ensuring their loved one's safety at home, in school or in the community. The following is a summary of safety issues in each of those three environments, as well as a list of some crucial action items you can implement immediately.

## Home safety

- Deadbolt doors and lock windows.
- Secure all poisonous substances and keep medications in a lock box.
- Keep all firearms properly secured and store ammunition in a separate location.
- Identify water sources and other dangers near your dwelling and within your community (including pools) should your child with ASD wander from the home.
- Be extra vigilant during summer months regarding wandering. Follow this link for a great resource for wandering information: [awaare.org](http://awaare.org).





- Inform neighbors, caregivers, family members, and local first responders of potential safety issues and needs.
- Prepare a home escape plan in the event of fire, and practice often. Additional fire safety tips can be found online ([asmonline.org/programs\\_law\\_fire.asp](http://asmonline.org/programs_law_fire.asp)).
- Be aware that in an emergency situation, such as fire in the home, your child with ASD may retreat to their favorite hiding spot. Report these potential hiding spots to first responders in the event of an actual emergency.
- Identify specific behaviors of your child that may lead them to harm within your home.
- Prepare and post a “911 Script” in the event of an emergency. Download a template at

*[aset911.com/wp-content/uploads/2014/11/911-script-for-parents.pdf](http://aset911.com/wp-content/uploads/2014/11/911-script-for-parents.pdf).*

## **Community safety**

- Ensure your child has some form of identification since they may be unable to ask for help.
- Have your child meet local first responders in a stress-free setting. They should explore equipment and see them in uniform.
- Be aware that individuals with ASD may show aggression or self-injurious behavior. Traveling and any non-routine situations may induce this behavior.
- Be aware that individuals with ASD may have a distorted sense of danger and may not



understand the consequences of their actions. Identify specific behaviors that may cause injury while out in the community.

- Be aware that individuals with ASD may be able to tolerate significant pain or other sensations such as extreme temperatures. Ensure your child is appropriately dressed for the weather when out in the community.
- Designate one person that is responsible for your child's safety while out in the community.

## School safety

- Notify the school if your child has a tendency to wander and places they might go.

(Download a template at [aset911.com/wp-content/uploads/2014/10/Parent-to-school-safety-letter.docx](http://aset911.com/wp-content/uploads/2014/10/Parent-to-school-safety-letter.docx)).

- Have safety strategies specific to your child's needs included in IEP.
- Advocate for your school to have a wandering response plan in place. ([aset911.com/wp-content/uploads/2014/02/School-Safety-and-Autism-handout.pdf](http://aset911.com/wp-content/uploads/2014/02/School-Safety-and-Autism-handout.pdf))
- Be proactive about bullying. Keep a close watch on social networking communication. For more information, visit [stopbullying.gov](http://stopbullying.gov).

## Teen safety

- Be aware that individuals with ASD are more likely to be bullied and victims of sexual abuse. Keep a close watch on Internet activities to identify potential bullying and any inappropriate sexual behaviors.
- Consider monitoring software for the computer and handheld devices.
- Individuals with ASD can often be more susceptible to manipulation. They may not understand the devious motives of others, and as a result, can find themselves in legal trouble.
- Be aware that illegal drugs may be used to decrease social anxieties. Be watchful and consider random drug testing.

## Immediate action items for parents and caregivers

- Register your child with local law enforcement. A sample form is available at [aset911.com/](http://aset911.com/)



*wp-content/uploads/2014/02/autism-registration-form-shortened.pdf.*

- Teach water safety at an early age and provide swim lessons.
- Be fully informed of all the various safety issues that impact individuals with ASD including dangers within the home/neighborhood/school.
- Inform your child's school of your specific safety concerns relative to individuals with ASD, particularly wandering and meltdown behaviors (Download a sample letter at [aset911.com/wp-content/uploads/2014/10/Parent-to-school-safety-letter.docx](http://aset911.com/wp-content/uploads/2014/10/Parent-to-school-safety-letter.docx)).
- Advocate for Autism Safety Training in your community ([aset911.com](http://aset911.com)). Bring a copy of "Why Your Community Needs this Training" to schools and first responder agencies (Download at [aset911.com/wp-content/uploads/2013/07/Why-Your-Community-Needs-Autism-Safety-Training.pdf](http://aset911.com/wp-content/uploads/2013/07/Why-Your-Community-Needs-Autism-Safety-Training.pdf)).
- Consider GPS tracking devices if the individual has a tendency to wander. Some examples of these devices are provided at [friendshipcircle.org/blog/2014/01/15/7-tracking-devices-to-find-a-lost-child-with-autism](http://friendshipcircle.org/blog/2014/01/15/7-tracking-devices-to-find-a-lost-child-with-autism).
- Promote RF (Radio Frequency) tracking technology within your community (such as Project Lifesaver International [projectlifesaver.org](http://projectlifesaver.org)). Your local law enforcement agency could have the ability to use highly specialized tracking equipment utilizing proven RF Frequency technology to

locate missing individuals. This equipment is costly, however, and would require an upfront investment to bring to your community. Start advocating now.



## Recommended books

These books have been recommended by parents, professionals and practitioners who have found them useful or helpful in some way. Many have been written by individuals with ASD and/or their families. We encourage you to explore these listings for more information, insights from other families, and helpful guidance for family members of all ages.

Andron, L. (2001). *Our journey through high functioning autism and Asperger syndrome*.

Philadelphia, PA: Jessica Kingsley Publishers.

Barnett, C. (2013). *The spark: A mother's story of nurturing, genius, and autism*. Random House.

Barron, J. & Barron, S. (2002). *There's a boy in here: Emerging from the bonds of autism*. Arlington, TX: Future Horizons.

Birch, J. (2002). *Congratulations! It's Asperger syndrome*. NY: Jessica Kingsley Publishers.

Bonker, E. (2011). *I am in here: The journey of a child with autism who cannot speak but finds her voice*. Revell.

Collins, P. (2004). *Not Even Wrong — Adventures in Autism*. New York: Bloomsbury.

Davis, B. & Schunick, W. G. (2001). *Breaking Autism's barriers: A father's story*. Philadelphia, PA: Jessica Kingsley Publishers.

Downey, M. K. & Downey, K. (2002). *The people in a girl's life: How to find them, better understand them and keep them*. Philadelphia, PA: Jessica Kingsley Publishers.

Fleisher, M. (2003). *Making sense of the unfeasible: My life journey with Asperger Syndrome*. NY: Jessica Kingsley Publishers

Fleischmann, A. (2012). *Carly's voice: Breaking through autism*. New York: Touchstone.

Fling, E. R. (2000). *Eating an artichoke: A mother's perspective on Asperger syndrome*. Philadelphia, PA: Jessica Kingsley Publishers.

Freedman, J. L. (2007). *Unstrange Minds: Remapping the world of autism*. New York: Basic Books.

Gilpin, W. (2002). *Much more . . . laughing and loving with autism*. Arlington, TX: Future Horizons.

Grandin, T. (1986). *Emergence: Labeled Autistic*. Norvato. CA: Arena Press.

Grandin, T. (1995). *Thinking in Pictures and Other Reports from my Life With Autism*. NY: Bantam Doubleday Dell Publishing.

Hall, K. (2000). *Asperger syndrome, the universe and everything*. Philadelphia, PA: Jessica Kingsley Publishers.

Hart, C. (1989). *Without reason: A family copes with two generations of autism*. NY: Harper & Row Publishers.

- Higashida, N. (2007), translated copyright (2013). *The reason I jump: The inner voice of a thirteen-year-old boy with autism*. New York: Random House.
- Hoopmann, K. (2000). *Blue bottle mystery: An Asperger adventure*. Philadelphia, PA: Jessica Kingsley Publishers.
- Hoopmann, K. (2002). *Lisa and the lacemaker: An Asperger adventure*. Philadelphia, PA: Jessica Kingsley Publishers.
- Hoopmann, K. (2001). *Of mice and aliens: An Asperger adventure*. Philadelphia, PA: Jessica Kingsley Publishers.
- Johnson, C. & Crowder, J. (1994). *Autism: From tragedy to triumph*. Boston, MA: Branden Books.
- Kaufman, B.N. (1994). *Son rise: The miracle continues*. Tiburon, CA: H.J. Kramer, Inc.
- Kedar, I. (2012). *Ido in autismland: Climbing out of autism's silent prison*. Kedar.
- Kephart, B. (1998). *A slant of sun*. NY: W.W. Norton & Company.
- Lawson, W. (2001). *Understanding and working with the spectrum of autism: An insider's view*. Philadelphia, PA: Jessica Kingsley Publishers.
- Ledgin, N. (2002). *Asperger's and self-esteem: Insight and hope through famous role models*. Arlington, TX: Future Horizons.
- Leonard-Toomey, P. (Ed.) (1997). *In our words: Stories by brothers and sisters of children with autism & PDD*. Fall River, MA: Adsum, Inc.
- Martin, E. P. (1999). *Dear Charlie: A guide for living your life with autism — a grandfather's love letter*. Arlington, TX: Future Horizons.
- Maurice, C. (1993). *Let me hear your voice: A family's triumph over autism*. Austin, TX: Pro-Ed.
- McCabe, P., McCabe, E., & McCabe, J. (2002). *Living and loving with Asperger syndrome: Family viewpoints*. NY: Jessica Kingsley Publishers.
- Messner, A. W. (1996). *Captain Tommy*. Arlington, TX: Future Horizons.
- Meyers, D. J. (Ed.) (1995). *Uncommon Fathers Reflections on Raising a Child with a Disability*. Bethesda, MD: Woodbine.
- Meyers, D. J. (Ed.) (1997). *Views from our shoes: Growing up with a brother or sister with special needs*. Bethesda, MD: Woodbine House.
- Myers, D. J. & Vadasy, P. (1996). *Living with a brother or sister with special needs: A Book for sibs*. (2nd Edition). USA: University of Washington Press.
- Mont, D. (2002). *A different kind of boy: A father's memoir about raising a gifted child with autism*. Philadelphia, PA: Jessica Kingsley Publishers.
- Morse, D., Gayhardt, V., & Wallace, R. S. (1998). *At home with autism: Three families' stories*. Stratham, NH: Potential Unlimited Publishing.
- Mukhopadhyay, T. R. (2003). *The mind tree: A miraculous child breaks the silence of autism*. NY: Arcade Publishing.

- Newport, J. & Newport, M. (2002). *Autism-Asperger's & sexuality: Puberty and beyond*. Arlington, TX: Future Horizons.
- Notbohm, E. (2012). (2nd Edition). *Ten things every child with autism wishes you knew*. Arlington, TX: Future Horizons.
- Ogaz, N. (2002). *Buster and the amazing daisy: Adventures with Asperger syndrome*. Philadelphia, PA: Jessica Kingsley Publishers.
- Overton, J. (2003). *Snapshots of autism: A family album*. NY: Jessica Kingsley Publishers.
- Park, C. C. (2001). *Exiting Nirvana: A daughter's life with autism*. NY: Little, Brown & Company.
- Park, C.C. (1982). *The Siege: The First 8 Years of an Autistic Child*. Canada: Little, Brown, & Company Limited.
- Peers, J. (2003). *Asparagus Dreams*. NY: Jessica Kingsley Publishers
- Powers, M. D. (Ed.) (1989). *Children with autism: A parent's guide*. Bethesda, MD: Woodbine House.
- Prince-Hughes, D. (Ed.) (2002). *Aquamarine blue: Personal stories of college students with autism*. Athens, OH: Swallow Press/ Ohio University Press.
- Prince-Hughes, D. (2004). *Songs of the gorilla nation: My journey through autism*. NY: Harmony Books.
- Pyles, L. (2001). *Hitchhiking through Asperger syndrome*. Philadelphia, PA: Jessica Kingsley Publishers.
- Rankin, K. (2000). *Growing up severely autistic: They call me Gabriel*. Philadelphia, PA: Jessica Kingsley Publishers.
- Reed, D. (1996). *Paid for the privilege: Hearing the voices of autism*. Madison, WI: DRI Press.
- Romkema, C. (2002). *Embracing the sky*. Philadelphia, PA: Jessica Kingsley Publishers.
- Rosenblatt, A. I. & Carbone, P.S. (Eds.). (2013). *Autism Spectrum Disorders: What every parent should know*. Elk Grove Village, IL: American Academy of Pediatrics.
- Satkiewicz-Gayhardt, V., Peerenboom, B., & Campbell, R. (1998). *Crossing bridges: A parent's perspective on coping after a child is diagnosed with Autism/PDD*. Stratham, NH: Potential Unlimited Publishing.
- Schneider, E. (1999). *Discovering my autism: Apologia Pro Vita Sua (with apologies to Cardinal Newman)*. Philadelphia, PA: Jessica Kingsley Publishers.
- Schneider, E. (2002). *Living the good life with autism*. Philadelphia, PA: Jessica Kingsley Publishers.
- Schulze, C.B. (1993). *When Snow Turns to Rain: One Family's Struggle to Solve the Riddle of Autism*. Rockville, MD: Woodbine House.
- Seroussi, K. (2000). *Unraveling the mystery of Autism and Pervasive Developmental Disorder: A mother's story of research and recovery*. NY: Simon & Schuster.

- Shaw, J. (2002). *I'm not naughty – I'm autistic: Jodi's journey*. Philadelphia, PA: Jessica Kingsley Publishers.
- Shore, S. (Ed.). (2004). *Ask and tell: Self-advocacy and disclosure for people on the Autism Spectrum*. Shawnee Mission, KS: Autism Asperger Publishing Co.
- Shore, S. (2001). *Beyond the wall: Personal experiences with Autism and Asperger's Syndrome*. Shawnee Mission, KS: Autism Asperger Publishing Co.
- Stacey, P. (2003). *The Boy who loved windows*. U.S.A.: First Da Capo Press.
- Stehli, A. (1995). *Dancing in the rain*. Westport, CT: Georgiana Organization, Inc.
- Stehli, A. (1991). *The wound of a miracle: A child's triumph over Autism*. New York: Avon Books.
- Stone, F. (2004). *Autism — the eighth colour of the rainbow: Learn to speak autistic*. NY: Jessica Kingsley Publishers.
- Thierfeld Brown, J., Wolf, L., King, L. & Bork, G. R. (2012). *The Parent's Guide to College for Students on the Autism Spectrum*. Shawnee Mission, KS: AAPC Publishing.
- Willey, L. H. (1999). *Pretending to be normal: Living with Asperger's Syndrome*. Philadelphia, PA: Jessica Kingsley Publishers.
- Williams, D. (1998). *Autism and sensing: The unlost instinct*. Philadelphia, PA: Jessica Kingsley Publishers.
- Williams, D. (1996). *Autism: An inside-out approach*. Philadelphia, PA: Jessica Kingsley Publishers.
- Williams, D. (2004). *Everyday heaven*. NY: Jessica Kingsley Publishers.
- Williams, D. (2002). *Exposure anxiety — the invisible cage: An exploration of self-protection responses in the autism spectrum*. Philadelphia, PA: Jessica Kingsley Publishers.
- Williams, D. (1998). *Like colour to the blind*. Philadelphia, PA: Jessica Kingsley Publishers.
- Williams, D. (1992). *Nobody nowhere: The extraordinary autobiography of an autistic*. NY: Avon Books.
- Williams, D. (2004). *Not just anything: A collection of thoughts on paper*. NY: Jessica Kingsley Publishers.
- Williams, D. (1994). *Somebody's somewhere: Breaking free from the world of autism*. New York: Times Books.

## Common abbreviations

Below is a listing of some common abbreviations you may encounter when accessing educational, social and developmental services.

<b>AAC:</b> Assistive and Augmentative Communication	<b>ESY:</b> Extended School Year
<b>ABA:</b> Applied Behavior Analysis	<b>FAPE:</b> Free Appropriate Public Education
<b>ADA:</b> Americans with Disabilities Act	<b>FBA:</b> Functional Behavior Assessment
<b>ADD:</b> Attention Deficit Disorder	<b>FERPA:</b> Family Educational Rights and Privacy Act
<b>ADHD:</b> Attention Deficit Hyperactivity Disorder	<b>ID:</b> Intellectual Disability
<b>APE:</b> Adapted Physical Education	<b>IDEA:</b> Individuals with Disabilities Education Act
<b>ASD:</b> Autism Spectrum Disorder	<b>IEE:</b> Independent Educational Evaluation
<b>ASL:</b> American Sign Language	<b>IEP:</b> Individualized Education Program
<b>BCABA:</b> Board Certified Assistant Behavior Analyst	<b>IFSP:</b> Individualized Family Service Plan
<b>BCBA:</b> Board Certified Behavior Analyst	<b>ITP:</b> Individual Transition Plan
<b>BIP:</b> Behavioral Intervention Plan	<b>LD:</b> Learning Disability
<b>CCM:</b> Community Case Manager	<b>LCPC:</b> Licensed Clinical Professional Counselor
<b>CDC:</b> Centers for Disease Control	<b>LCSW:</b> Licensed Clinical Social Worker
<b>CDS:</b> Child Development Services	<b>LEA:</b> Local Education Agency
<b>CHIP:</b> Child Health Insurance Program	<b>LRE:</b> Least Restrictive Environment
<b>CM:</b> Case Manager	<b>LSH:</b> Language, Speech and Hearing Specialist
<b>DD:</b> Developmental Disability	<b>LSW:</b> Licensed Social Worker
<b>DHHS:</b> Department of Health and Human Services	<b>MA:</b> Mental Age
<b>DOE:</b> Department of Education	<b>M-CHAT:</b> Modified Checklist for Autism in Toddlers
<b>DT:</b> Developmental Therapy/Therapist	<b>MH:</b> Mental Health
<b>EBP:</b> Evidence-based practice	<b>MUSER:</b> Maine Unified State Education Regulations, Revised
<b>ECS:</b> Early Childhood Services	<b>NCLB:</b> No Child Left Behind
<b>EI:</b> Early Intervention	<b>OADS:</b> Office of Aging and Disability Services
<b>ESDM:</b> Early Start Denver Model	<b>ORS:</b> Office of Rehabilitation Services
<b>ESEA:</b> Elementary & Secondary Education Act	<b>OT:</b> Occupational Therapy/Occupational Therapist

**PBS:** Positive Behavioral Supports  
**PCP:** Person Centered Plan/Primary Care Provider  
**PDD, PDD-NOS:** Pervasive Developmental Disorder- Not otherwise specified  
**PECS:** Picture Exchange Communication System  
**PL:** Public Law  
**PSP:** Primary Service Provider  
**PT:** Physical Therapy/Physical Therapist  
**RSU:** Regional School Unit  
**RTI:** Response to Intervention  
**SAD:** School Administrative District  
**SAU:** School Administrative Unit

**SI:** Sensory Integration or Specialized Instruction  
**SIB:** Self-injurious Behavior  
**SLP:** Speech Language Pathologist  
**SOP:** Summary of Performance  
**SP:** Speech Pathologist  
**SPED:** Special Education  
**SPL:** Service Provider Location  
**SSA:** Social Security Administration  
**SSDI:** Social Security Disability Income  
**SSI:** Supplemental Security Income  
**ST:** Speech Therapy  
**VR:** Vocational Rehabilitation



## Glossary

This listing includes some of the most common terms you will encounter as you access educational, social, and developmental services.

### A

**Adapted Physical Education (APE):** A carefully designed physical education program for a student with a disability, based on a comprehensive assessment, and designed to give the student the skills necessary for a lifetime of rich leisure, recreation, and sport experiences to enhance physical fitness and wellness.

**Adaptive behavior:** The ability to adjust to new experiences, interact with new people and participate in new activities and experiences.

**Adaptive equipment:** Furniture and other positioning support that can be used to help a child maintain comfortable and appropriate posture and functioning when sitting, standing or moving.

**American Sign Language (ASL):** A complete, complex language that uses signs made by moving the hands combined with facial expressions and postures of the body to communicate.

**Americans with Disabilities Act (ADA):** A federal law that guarantees equal opportunity for people with disabilities in employment, public accommodation, transportation, government services and telecommunications.

**Applied Behavioral Analysis (ABA):** Applied Behavior Analysis is treatment used to teach new behaviors or to reduce challenging behaviors by applying interventions based upon the principles of learning theory. Careful observation, intervention and documentation are used to demonstrate that the interventions employed are responsible for improvements in behavior.

**Asperger's Syndrome (AS):** Prior to changes made in the DSM-5 published in 2013, AS was classified as an autism spectrum disorder characterized by average to above-average cognitive function, deficits in communication and social language (pragmatics) and, sometimes, a limited range of interests or obsessive interest in a particular topic, such as weather, train schedules or car models. Currently (in the DSM-5), this diagnosis is encompassed within the diagnostic code for Autism Spectrum Disorder.

**Assistive and Augmentative Communications (AAC):** Additional materials, supports, equipment and/or electronic devices that help people communicate when their spoken language is not sufficient for communicating their needs.

**Assistive technology:** Electronic as well as non-electronic materials, equipment and devices designed to help people with disabilities play, learn, communicate, move around and carry out activities of daily living at home, at school and in the community.



**Attention Deficit Disorder (ADD):** A condition referring to excessive difficulty in concentrating and focusing or extreme distractibility.

**Attention Deficit Hyperactivity Disorder (ADHD):** The diagnostic term used to describe people who have excessive difficulty in concentrating and focusing, extreme distractibility or over activity, and sometimes including disruptive behavior or aggression.

**Autism:** A condition marked by developmental delay in social skills, language, and behavior, which is often present in children with varying degrees of severity. See Autism Spectrum Disorders.

**Autism Behavior Checklist (ABC):** Diagnostic tool for identifying autism in children.

**Autism Spectrum Disorders (ASD):** DSM-5 diagnosis encompassing persistent deficits in social communication/interactions and restrictive, repetitive patterns of behavior, interests, or activities. An ASD diagnosis should also include a designated “level of severity” based on the level of support required. Prior to the DSM-5 (published in 2013) the diagnostic criteria for ASD encompassed the following five disorders: Autistic Disorder, Asperger’s Syndrome, Childhood Disintegrative Disorder, Rett’s Syndrome, and Pervasive Developmental Disorder-Not otherwise specified (PDD-NOS).

## B

**Baseline:** The level of function exhibited by a child before instruction is introduced.

**Behavior modification:** The use of a behavioral approach to alter a person’s behavior through positive and negative reinforcement.

## C

**Center for Disease Control (CDC):** U.S. government agency dedicated to the protection of public health and safety through the control and prevention of disease, injury and disability.

**Cognition:** The ability to perceive, think, reason and analyze.

**Cognitive ability:** An individual’s intellectual ability or the cumulative skills of knowing and understanding.

**Communication notebook:** A notebook sent with a student (typically a special education student or young student) to and from school by which parents and teachers maintain daily communication.

**Comprehensive evaluation:** A complete assessment of a child, based on educational, psychological, social and health status conducted by a team of professionals and accompanied by information from parents and teachers.

**Congenital condition:** A condition existing at birth.

**Cue:** A physical or verbal/vocal gesture that prompts a person to speak, perform an activity, or behave in particular way.

## D

**Developmental delay:** A slower rate of development in comparison to the majority of children of the same age when comparing developmental milestones (i.e., sitting, walking, talking).

**Developmental Disability (DD):** A condition that impairs physical or cognitive development.

**Developmental milestones:** Skills that are associated with a certain age of achievement; e.g., when a baby begins to crawl or say his/her first words.

**Diagnosis:** The name of the disorder identified after an evaluation. Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) is the most recent update to the American Psychiatric Association classification and diagnostic tool; published in 2013. Used by clinicians to diagnose and classify mental health disorders.

**Due Process Hearing:** A legal hearing where parents present evidence that a school district is not effectively educating their child. Under IDEA, parents have the right to request a due process hearing if they cannot resolve a dispute with the school district related to their child's IEP.

## E

**Early Denver Start Model (ESDM):** A comprehensive early intervention approach for children with ASD, ages 12–48 months. 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). This model of intervention places a strong emphasis on positive emotional interactions for the child.

**Echolalia:** Repeating back something said to you. Delayed echolalia is repeating it later. Both behaviors are found in many individuals with autism. Functional echolalia is using a quoted phrase in a way that has shared meaning, for example, a child who sings the Barney jingle to ask for a Barney videotape, or says “Get your shoes and socks” to ask to go outside.

(The) Education for All Handicapped Children Act (EAHCA): See “Public Law 94-142”.

**Executive function:** The ability to plan, organize and follow through with activities. Also includes the ability to inhibit actions, delay responses, make appropriate choices and shift one's attention. Individuals with ASDs, learning disabilities and other neurological conditions often have deficits in executive function.

**Expressive language:** Any spoken language, vocalizations, gestures or other means by which a person is able to communicate to others.

## F

**Fine motor skills:** Generally refers to the small movements of the hands, wrists, fingers, feet, toes, lips and tongue.

**Free and Appropriate Education (FAPE) :** The Section 504 regulation requiring a school district to provide a “free appropriate public education” (FAPE) to each qualified person with a disability who is in the school district’s jurisdiction, regardless of the nature or severity of the person’s disability.

**Functional Behavioral Assessment (FBA):** A process based largely on observation in which problem behaviors are addressed and analyzed. Causes and functions of the behavior are identified. Then a behavior intervention plan (BIP) based on a specific, individualized profile is developed and, ideally, implemented across settings in order to minimize or stop inappropriate behaviors.

## G

**Gross motor skills:** The use of one’s large muscles to move, such as walking, running, hopping and jumping.

## H

**High-functioning Autism (HFA):** Although not officially recognized as a diagnostic category in the DSM-5, HFA refers to individuals with ASDs who have near-average to above-average cognitive abilities and can communicate through receptive and expressive language.

**Hypertonia:** Increased tension or stiffness in the muscles.

**Hypotonia:** Low muscle tone.

## I

**Identification:** Evaluation of a child as a candidate for special education services. This process requires proper screening and assessment to confirm if a child has an ASD or another disorder.

**Inclusion:** The concept that students with disabilities should be integrated with their non-disabled peers; also referred to as mainstreaming.

**Independent Education Evaluation (IEE):** An educational evaluation conducted by an agency/evaluator outside the school district. Parents have the right to obtain an IEE, however, it is most often at their own expense.

**Individual Transition Plan (ITP):** A plan to facilitate the transfer of a student from one setting to another, such as a different classroom, school or to adult services.

**Individualized Education Plan (IEP):** An educational plan that outlines special education and related services specifically designed to meet the educational needs of student with a disability.

**Individualized Family Service Plan (IFSP):** Similar to IEP, but is the service plan that outline services for an individual with a disability from birth until three years.

**Individuals with Disabilities Act (IDEA):** A federal law that established the rights of children with identified disabilities to get a free, appropriate public education in the least-restrictive environment.

## J

**Joint attention:** Sharing one's experience of looking at an object or event by making eye contact with another person, following gaze, gesturing and pointing.

## L

**Language, Speech and Hearing Specialist (LSH):** a professional service provider who plans and provides speech, language, and hearing assessments and therapy to referred students.

**Least Restrictive Environment (LRE):** To the maximum extent appropriate, children with disabilities are to be educated with children who are not disabled. Alternative placement can occur only when the nature or severity of the child's disability is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily.

**Low-functioning Autism (LFA):** Although not officially recognized as a diagnostic category in the DSM-5, LFA refers to individuals with autism with an IQ of less than 80.

## M

**Magnetic Resonance Imaging (MRI):** A non-invasive diagnostic medical tool that creates detailed images of the selected body structures or organs using a magnetic field, radio wave pulses and a computer.

**Mental Age (MA):** An assessment of intellectual functioning based on the average standard for

children of the same chronological age.

### **Modified Checklist for Autism in Toddlers**

**(M-CHAT):** A checklist used by general practitioners for children 16–30 months to assess their risk for ASD. Depending on the results for the M-CHAT, children may be referred for additional assessment.

**Motor planning:** The ability to think through and physically carry out a task from beginning to end.

## N

**Neuro-motor:** A process involving both the nervous system and the muscles.

**Neurotypical (NT):** A term sometimes used by persons with autism to describe people who are not on the autism spectrum.

## O

**Objectives:** The intermediate steps in an IEP that must be taken to reach annual goals.

**Occupational Therapy/Occupational Therapist (OT):** Therapy focusing on fine motor skills, (e.g. picking up small objects, writing) or managing activities of daily living (dressing, eating); An Occupational Therapist (OT) focuses on creating strategies and adaptations to better manage self-care, play, and social interactions. An OT is the professional who provides Occupational Therapy.

**Office of Civil Rights (OCR)/DOE:** Agency of the U.S. Department of Education that focuses on ensuring equal access to education and the protection of civil rights of children in public schools.

## P

**Perseveration:** Obsessive-like, continued immediate repetition of a behavior.

### **Pervasive Development Disorder/ Pervasive Development Disorder-Not Otherwise Specified:**

(PDD, PDD-NOS or PDD/NOS) Prior to changes made in the DSM-5 (2013), PDD and PDD/NOS were classified as an autism spectrum disorder characterized by the presence of some, but not all the defining symptoms of autism. Currently encompassed by the diagnosis of Autism Spectrum Disorder in the DSM-5.

### **Physical Therapy/Physical Therapist (PT):**

Therapy to help develop muscle strength, coordination, mobility, and/or basic motor skills. A Physical Therapist (PT) is the professional who provides physical therapy.

**Pica:** Persistent eating of nonfood items, such as paper, dirt, etc., that have no nutritional value.

### **Picture Exchange Communication System**

**(PECS):** Augmentative/alternative communication intervention package that used pictures to facilitate and teach communication.

**Proprioception:** The awareness of where one's body and extremities are and with movement through space.

**Public Law 94-142:** Also known as The Education for All Handicapped Children Act of 1975 (EAHCA). The U.S. Federal law that provides the funds to states that maintain certain standards in

their education of children with disabilities; i.e., by providing a free and appropriate education in a least restrictive environment.

## R

**Receptive language:** The comprehension of spoken and written communication and gestures.

**Regression:** The loss of skills that have already been learned.

**Reinforcement:** Reinforcement is when a behavior is increased or maintained by the consequences that follow that behavior; reinforcement can be either positive or negative.

**Respite care:** Care provided by an individual or institution to a child with a disability so that the primary caretakers, usually parents, can have a break. Sometimes respite care is funded by state agencies.

## S

**SCERTS Model:** A comprehensive, multidisciplinary educational model developed by Barry Prizant and Emily Rubin to address the needs of students with ASDs and related challenges. The acronym stands for Social Communication, Emotional Regulation, and Transactional Support, which are the cornerstones of this approach.

**Seizure:** Involuntary movement or changes in consciousness brought on by bursts of electrical activity in the brain.

**Self-help skills:** Daily skills such as self-feeding, dressing, bathing, and other tasks that are necessary to maintain health and well-being.

**Self-injurious Behavior (SIB):** Self-inflicted behaviors such as head-banging, hand-biting, or scratching, that inflict harm or injury to oneself.

**Self-stimulation (stimming, stereotypy):** A term for behaviors whose sole purpose appears to be to stimulate one's own senses, such as rocking one's body, hand-flapping, spinning, echolalia. Many people with autism report that some "self-stims" may serve a purpose for them, such as for calming, help with concentration, or to shut out an overwhelming sound.

**Sensorimotor:** Pertaining to brain activity other than automatic functions (respiration, circulation, sleep) or cognition. Sensorimotor activity includes voluntary movement and the senses like sight, touch and hearing.

**Sensory Integration (SI):** How our brains perceive sensory information, process it, and report back to us what is happening.

**Special Education (SPED):** Specialized and personalized instruction of a child with disabilities, designed in response to educational disabilities determined by an evaluation.

**Speech-Language Pathologist (SLP):** Professional who specializes in the evaluation and treatment of communication disorders and swallowing disorders.

**Supplemental Security Income (SSI):** An income-based federal program that pays benefits to individuals with disabilities with limited income and resources.

**Supported employment:** Work performed by persons with cognitive, physical, or emotional challenges that involve an adapted environment and/or additional support staff.

## T

**Tactile defensiveness:** Extreme physical sensitivity to certain touch, textures and sensations.

**Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH) Model:** A program model using evidence-based practices to treat and educate persons with ASDs. Developed at the University of North Carolina, Chapel Hill, TEACCH incorporates respect for individual differences, respect and inclusion of parents and various professionals, and input from individuals with ASDs to develop skills, and promote learning and independence.

## V

**Verbal I.Q.:** The score resulting from various tests involving verbal tasks, such as understanding written material and answering general knowledge questions.

## Glossary References

*Diagnostic and statistical manual of mental disorders: DSM-5, (2013).* 5th ed. Arlington

VA: American Psychiatric Association.

Association for Science in Autism Treatment:  
[asatonline.org](http://asatonline.org)

Behavior Analyst Certification Board: [bacb.com](http://bacb.com)

Center for Autism and Related Disorders  
(CARD): [centerforautism.com](http://centerforautism.com)

Indiana Institute on Disability and Community:  
[iide.indiana.edu](http://iide.indiana.edu)

National Autism Center: [nationalautismcenter.org](http://nationalautismcenter.org)

National Professional Development Center on  
Autism Spectrum Disorder: [autismpdc.fpg.unc.edu](http://autismpdc.fpg.unc.edu)



# 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.