

The University of Maine

DigitalCommons@UMaine

General University of Maine Publications

University of Maine Publications

6-1-2018

Maine Parent Guide to Autism Spectrum Disorders Booklet 4 : Resource Guide for Maine Families

Maine Autism Institute for Education and Research

Follow this and additional works at: https://digitalcommons.library.umaine.edu/univ_publications



Part of the [Developmental Neuroscience Commons](#), [Early Childhood Education Commons](#), and the [Special Education and Teaching Commons](#)

Repository Citation

Maine Autism Institute for Education and Research, "Maine Parent Guide to Autism Spectrum Disorders Booklet 4 : Resource Guide for Maine Families" (2018). *General University of Maine Publications*. 3443. https://digitalcommons.library.umaine.edu/univ_publications/3443

This Book is brought to you for free and open access by DigitalCommons@UMaine. It has been accepted for inclusion in General University of Maine Publications by an authorized administrator of DigitalCommons@UMaine. For more information, please contact um.library.technical.services@maine.edu.

Maine Parent Guide to Autism Spectrum Disorders

Booklet 4: Resource Guide for Maine Families



Maine Parent Guide to Autism Spectrum Disorders

Booklet 4: Resource Guide for Maine Families

Maine Autism Institute for Education and Research
5766 Shibles Hall, Room 303, 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 non-discrimination policies: 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 2nd edition. Our continued hope is to provide an easy-to-follow roadmap for Maine parents and caregivers who suspect their child may be at risk for an autism spectrum disorder (ASD) 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

Tony Abbiati

Jessica Archer

Connor Archer

Nikki Becker

Cathy Dionne

Karen Grotton-Pelletier

Felicia Kasprzak

Kathleen Leopold

April Poulsen

Laurie Robichaud

Niki Sheafe

Cheryl Stalilonis

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.

“*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.”



Table of Contents

- Resources 1
 - Advocacy and information..... 1
 - Assistive technology (AT)4
 - Autism apps..... 5
 - Autism education and training5
 - Developmental evaluation centers..... 5
 - Early intervention and educational services.....6
 - Maine Child Development Services (CDS) sites6
 - Employment7
 - Family support8
 - Health and human services.....10
 - Legal assistance..... 11
 - Recreation and camps..... 11
 - Respite 13
 - Sibling support..... 13
 - Transition to adulthood.....14
 - Wandering registries 16
- Augmentative and alternative communication16
- Promoting personal safety 18
- Safety tips.....21
- Recommended books24
- Common abbreviations27
- Glossary29

The 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.

Resources

Advocacy and information

211 Maine

Web: 211maine.org; **Phone:** 211

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.

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)

Web: asmonline.org; **Phone:** 800.273.5200; **Email:** info@asmonline.org

The ASM provides education and resources to support the valued lives of individuals on the autism spectrum and their families. ASM provides downloadable information sheets, booklets on a variety of topics, brochures, an online referral database, adult and teen social groups, autism awareness packets for educators, law enforcement, doctors, dentist, and general awareness. ASM's Autism Information Specialist program helps families navigate the system in their local area by providing a support person to work directly with them. There is no charge for these service. ASM also runs two summer camps for children with ASD and a family retreat weekend. ASM is an affiliate of the Autism Society of America.

Center for Community Inclusion and Disability Studies (CCIDS)/University of Maine

Web: ccids.umaine.edu; **Phone:** 800.203.6957; **Email:** ccidsmail@umit.maine.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.

Centers for Disease Control/Autism Spectrum Disorder

Web: 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

Web: 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

Web: cromwellcenter.org; **Phone:** 207.775.9955

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.



Disability Rights Maine

Web: drme.org; **Phone:** 800.452.1948; **Email:** advocate@drme.org

Agency dedicated to ensuring autonomy, inclusion, equality, and access for people with disabilities in Maine. DRM offers support, advocacy, and legal assistance to individuals and families related to your legal rights under federal and state laws protecting persons with disabilities.

Maine Autism Institute for Education and Research (MAIER)

Web: umaine.edu/autisminstitute;

Phone: 207.581.2352;

Email: maineautisminstitute@maine.edu

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.*

Maine Developmental Disability Council

Web: MaineDDC.org; **Phone:** 800.244.3990; **Email:** info@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.

Maine Parent Federation (MPF)

Web: mpf.org; **Phone:** 800.870.7746; **Email:** parentconnect@mpf.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. All programs, services, and resources are free to families and do not require qualifying factors in order to receive assistance.

Pine Tree Society

Web: pinetreesociety.org; **Phone:** 207.443.3341; **Email:** info@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.

State of Maine/Disability Services

Web: maine.gov/dhhs/oads; **Phone:** 207.287.9200 or 888.568.1112

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.

Assistive technology (AT)

Maine CITE

Web: mainecite.org; **Phone:** 207.621.3195; **Email:** iweb@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.

Mainly Access

Web: mainlyaccess.com; **Phone:** 207.650.8151 or 207.650.8343

Mainly 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.

Pine Tree Society

Web: pinetreesociety.org; **Phone:** 207.386.5930; **Email:** ncohen@pinetreesociety.org

Pine Tree Society offers comprehensive individualized services including Assistive Technology assessments and consultations and ongoing support.

Spurwink ALLTECH

Web: spurwinkalltech.org; **Phone:** 207.535.2017 (Portland); **Email:** ALLTECHinfo@spurwink.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.

University of Maine Farmington Assistive Technology Collection

Web: www2.umf.maine.edu/kcmc/at; **Phone:** 207.778.7895; **Email:** web-mantor@umf.maine.edu

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.

Autism apps

Autism Apps from iTunes

Web: 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)

Web: umaine.edu/autisminstitute; Phone: 207.581.2352; Email: maineautisminstitute@maine.edu

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.

Kennebec Valley Community College

Web: kvcc.me.edu/Pages/Education/Education-Home; Phone: 207.453.5822

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.

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

Web: 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

Web: emmc.org/pediatric-services.aspx; Phone: 207.973.7520

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

Web: mainehealth.org/barbara-bush-childrens-hospital/services/developmental-behavioral-pediatrics;
Phone: 207.662.5522

Early intervention and educational services

Maine Child Development Services (CDS)/Maine Department of Education

Web: maine.gov/doe/cds; Phone: 207.624.6600

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.

Maine Child Development Services (CDS) sites

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

CDS State Intermediate Education Unit

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



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 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

Maine Association for Community Service Providers (MACSP)

Web: meacsp.com; **Phone:** 207.623.5005

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.

Office of Special Services/Maine Department of Education

Web: maine.gov/doe/specialed; **Phone:** 207.624.6600

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).

Inclusive Schooling

Web: inclusiveschooling.com

Website developed by two special education faculty to support administrators, educators and parents who wish to create more caring, creative inclusive schools for all learners. Offers live and online courses, workshops, presentations and support. Contact Inclusive Schools through their website.

Employment

Camp CARDNE (Center for Autism and Related Disorders New England)

Web: campcardne.shutterfly.com; **Phone:** 603.502.5260; **Email:** CARDNE@maine.rr.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.

Employment for ME

Web: employmentforme.org; **Phone:** Office of Aging and Disability Services, 207.822.0328;

Phone: Bureau of Rehabilitation Services, 207.623.7963

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.

Maine Bureau of Rehabilitation Services

Web: maine.gov/rehab; **Phone:** 207.623.6799

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.

Maine CareerCenter

Web: mainecareercenter.com; **Phone:** 888.457.8883

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.

Family support

Autism Safety Education & Training (ASET)

Web: aset911.com; **Phone:** 207.415.1392; **Email:** nbrown623@aol.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.*

Autism Society of Maine

Web: asmonline.org; **Phone:** 800.273.5200; **Email:** info@asmonline.org

The ASM provides education and resources to support the valued lives of individuals on the autism spectrum and their families. ASM provides downloadable information sheets, booklets on a variety of topics, brochures, an online referral database, adult and teen social groups, autism awareness packets for educators, law enforcement, doctors, dentist, and general awareness. ASM’s Autism Information Specialist program helps families navigate the system in their local area by providing a support person to work directly with them. There is no charge for these service. ASM also runs two summer camps for children with ASD and a family retreat weekend. ASM is an affiliate of the Autism Society of America.

Bullying and Individuals with Special Needs

Web: 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

Web: gearparentnetwork.org; **Phone:** 800.264.9224

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.

Maine Autism Institute for Education and Research/Maine Family Partnership (MAIER/MFP)

Web: umaine.edu/autisminstitute/maine-family-partnership; **Phone:** 207.581.2352;

Email: maineautisminstitute@umaine.edu

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. MAIER's online Resource Center (umaine.edu/autisminstitute/resources) offers links to important Maine and National Resources as well as links to reliable information related to family life (e.g., peer relationships, puberty, sleep, bullying, and other developmental concerns). *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.*

Maine Parent Federation (MPF)

Web: mpf.org; **Phone:** 800.870.7746; **Email:** parentconnect@mpf.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. All programs, services, and resources are free to families and do not require qualifying factors in order to receive assistance.

National Autism Association/Autism Safety/Bullying

Web: 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

Web: 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

Web: maine.gov/dhhs/ocfs/cbhs; **Phone:** 207.624.7900

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.

Katie Beckett Option/Maine DHHS

Web: maine.gov/dhhs/ocfs/cbhs/eligibility/katiebeckett.html; **Phone:** 207.624.7900

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.

Maine Department of Health and Human Services (DHHS)

Web: maine.gov/dhhs; **Phone:** 207.287.3707

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

MaineCare/Maine DHHS

Web: maine.gov/dhhs/mainecare.shtml; **Phone:** 207.287.3707

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.

Office of Child and Family Services/Maine DHHS

Web: maine.gov/dhhs/ocfs/cbhs/services/case-management.html; **Phone:** 207.624.7900

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).

Legal assistance

Disability Rights Maine

Web: drme.org; Phone: 800.452.1975; Email: advocate@drme.org

Agency dedicated to ensuring autonomy, inclusion, equality, and access for people with disabilities in Maine. DRM offers support, advocacy, and legal assistance to individuals and families related to your legal rights under federal and state laws protecting persons with disabilities.

Pine Tree Legal Assistance

Web: ptla.org; Phone: See website for your local office or call the Portland office, 207.774.8211

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.

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

Web: campcapella.org; Phone: 207.843.5104

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.

Camp CARDNE

(Center for Autism and Related Disorders New England)

Web: campcardne.shutterfly.com; Phone: 603.502.5260; Email: CARDNE@maine.rr.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.

Camp STRIVE

Web: pslstrive.org/camp; Phone: 207.774.6278

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.

Camp Summit (Farmington)

Web: asmonline.org/programs/summer-camp.aspx;

Phone: 800.273.5200; **Email:** info@asmonline.org

Free summer day camp for children aged 5–15 years old with autism spectrum disorders. Offered by the Autism Society of Maine (ASM), this two-week day program focuses on developing communication skills and peer relationships in a social settings. Activities include crafts, outdoor play, swimming, and field trips. FMI or to request an application, visit their website, call, or email ASM.

Camp Waban

Web: waban.org; **Phone:** 207.324.7955; **Email:** camp@waban.org

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.

Finding the Pieces Summer Camp (Biddeford)

Web: asmonline.org/programs/summer-camp.aspx;

Phone: 800.273.5200; **Email:** info@asmonline.org

A collaboration of ASM, the University of New England, and the City of Biddeford, this FREE summer day camp is for children in K–5 with autism spectrum disorders in York County. Held two weeks in August, this day program provide an enriching summer camp experience for children who have autism that celebrates differences and provides opportunities to interact with peers both on and off the spectrum. Activities include arts and crafts, sports and games, swimming, and field trips. FMI or to request an application, visit the ASM website, or call or email ASM.

Maine Special Olympics

Web: specialolympicsmaine.org; **Phone:** 207.879.0489

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.

Pine Tree Camp

Web: pinetreesociety.org/children-and-families/pine-tree-camp; **Phone:** 207.443.3341

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.

Respite

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

Web: namimaine.org/?page=FamilyRespite; **Phone:** 207.622.5767; **Email:** respite@namimaine.org

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.

Sibling support

Autism Society of Maine/Sibling resources

Web: asmonline.org/library; **Phone:** 800.273.5200

ASM offers several books from their lending library that address sibling and family issues, and are free to borrow.

Organization for Autism Research

Web: researchautism.org/how-we-help/families/sibling-support

The OAR website offers free, downloadable guides specifically for teens, young children, and parents to address living with a sibling with ASD.

Sibling Support Project

Web: siblingssupport.org

National program dedicated to concerns of brothers and sisters of people with special needs. Online resources include suggested reading, online support groups, workshops, and information on Sibshops-peer support groups for school-age siblings.

Transition to adulthood

Alpha One

Web: alphaonenow.org; Toll-free: 800.640.7200

Phone (South Portland): 207.767.2189;

Phone (Bangor): 207.941.6553;

Toll-free: 800.300.6016

Phone (Presque Isle): 207.764.6466;

Toll-free: 800.974.6466

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.

Autism Society of Maine (ASM)

Web: asmonline.org; Phone: 800.273.5200;

Email: info@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.

Employment for ME

Web: employmentforme.org;

Phone: Office of Aging and Disability Services, 207.822.0328; Phone: Bureau of Rehabilitation Services, 207.623.7963

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.

High School & Beyond: A Guide to Transition Services in Maine.

Web: maine.gov/dhhs/ocfs/cbhs/transition-adulthood.shtml; **Phone:** 207.624.7900.

An online, downloadable guide to transition resources and planning information useful to Maine youth, young adults and their families. Download a copy or contact the Office of Child and Family Services to request a copy.

Maine Coalition for Housing and Quality Services

Web: maineparentcoalition.org; **Phone:** 207.879.0347

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.

Maine Department of Health and Human Services (DHHS)/Office of Aging and Disability

Web: maine.gov/dhhs/oads; **Phone:** 207.287.3707

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

Links to specific State of Maine webpages related to transition:

Maine Care Waiver/DHHS: maine.gov/dhhs/oads/index.shtml

Guardianship/DHHS: maine.gov/dhhs/oads/laps-guardianship/guardianship.html

Maine Department of Labor/Vocational Rehabilitation: maine.gov/rehab

Maine Parent Federation (MPF)

Web: mpf.org; **Phone:** 800.870.7746; **Email:** parentconnect@mpf.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. All programs, services, and resources are free to families and do not require qualifying factors in order to receive assistance.

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. Check with your local Police Department or Sheriff's Office for a Wandering Registry near you as more are being added each year.

Cape Elizabeth Police Department Wandering

Database: capeelizabeth.com/services/public_safety/police_services/client_wandering_database.html

Lincoln, Somerset and Waterville Wandering

Database: helpautismnow.com/databases_cont.html

Penobscot Regional Communication Center

Wandering Registration:

penobscotrcc.com/wanderer-database

Rockland Police Department:

rocklandmaine.gov/municipal/departments/police/client-wandering-database/

Sagadahoc County Communications:

sagcounty.com/departments/communications/wanderer-program/

Waldo County/Knox County Wandering

Database: helpautismnow.com/databases_cont_2.html

Augmentative and alternative communication

We are grateful to Jennifer Seale, Ph.D., CCC-SLP of the University of Maine, Communication Sciences and Disorders, for her time and expertise in providing the following information.

Augmentative and alternative communication (AAC) is a term used to describe ways that people can communicate without the use of spoken language (i.e., alternative), or in addition to it (i.e., augmentative). AAC can help individuals tell others information and also understand things more easily. For example, sign language, pointing, head nods and facial expressions can be used to communicate information. Another example is a visual schedule (e.g., daily planners, reminders on a smartphone),

which can improve an individual's ability to understand what is expected of them.

AAC is also useful for assisting some individuals with autism navigate social situations. AAC does not prevent speech or language development. In fact, research suggests AAC improves access to language and facilitates development and growth in the following areas:

- Expression
- Understanding
- Self-regulation
- Social skills
- Literacy
- Academic and employment skills

AAC services are traditionally performed by a

licensed speech-language pathologist (SLP) who has specialized in the evaluation, learning and AAC strategy maintenance processes. A full evaluation can last anywhere from 1–3 hours. Oftentimes, this process is broken into intervals of time that an individual can tolerate. Parents, siblings, teachers, peers and other important individuals in his or her life can play a role in the evaluation process by identifying the ways in which the individual is already able to communicate information and the areas of need, which in turn guides the evaluation process.

After the evaluation, the SLP will make a recommendation for AAC tools and strategies based on the outcomes of their findings. An SLP may recommend more than one AAC technique for individuals. For example, if a computer with specialized communication software breaks down, it becomes important to have a backup system.

AAC also includes high technology devices (i.e., computers and tablets) that can support various communication functions. These high technology devices are often expensive and require a doctor's referral for evaluation, and a prescription for the device, to supplement the SLPs full evaluation report. These are submitted to third-party payers (i.e., Medicare, Medicaid, insurance) who can then approve or deny funding requests. If your request is denied, your SLP can initiate an appeals process. Once a device is obtained, your SLP will provide treatment aimed at language development and other skills related to AAC use.

AAC systems are never an either/or consideration; this means that individuals using

sign language or pen and paper strategies may also benefit from the use of high technology equipment. In fact, having multiple ways of communicating is common for everyone. Additionally, individuals with autism may need AAC in some contexts but not in others, which can be related to fluctuating processing or speech skills. Individuals are never too old, too young, too impaired or too verbal to be considered for AAC services. If you're interested in exploring AAC options for your child, talk with your SLP about initiating the AAC evaluation process.



Promoting personal safety

Our thanks to Karen Grotton-Pelletier, LCPC, and Certified Instructor for radKids, for her knowledge and expertise in providing the following information on personal safety. To learn more about radKids children's safety programs and access their resources, visit radkids.org.

All parents worry about protecting their children from dangerous situations and teaching them the skills to respond effectively to threats in their environment. Parents of children on the autism spectrum have some additional challenges to consider. Many children with autism don't seem to have quite the same built in "radar" when it comes to danger or threat detection, and differences in sensory processing may inhibit effective responding in the area of safety (for example, choosing what to attend to while crossing the street or discerning intent from someone's body language). That being said, research has shown when safety skills are taught in a systematic manner they can be very successful in keeping kids safe. The following steps may be helpful in beginning to teach safety skills:

Assess and Collaborate: Assess your child's strengths, as well as weaknesses, when it comes to personal safety. Think of the situations and circumstances when you tend to be on high alert when it comes to their safety — imagine if you weren't around to guide your child through that situation — what additional skills or plans would

they need to navigate that situation safely? Use this information to guide you in assessing where supplemental skill building is necessary.

Everyone your child interacts with has a role to play in teaching and reinforcing safety skills. When planning for safety, consider involving your neighbors and local law enforcement. Neighbors you trust can be extra sets of eyes to support your child if they are in danger, as well as contacting you if they see your child out alone. Consider speaking with members of your child's treatment team and





school to get their perspectives of concerns across different settings.

Prepare: Once you’ve assessed your child’s safety strengths and areas for skill development, you can begin preparing plans of action regarding how to handle different emergency situations safely. Make sure your child knows his or her full name and address, your name and phone number, who to call for help in a dangerous or scary situation, and how to make that call. Create (and then practice) a home evacuation plan in case of fire or disaster; walk around the neighborhood and identify safe places to go in case of emergency (e.g., neighbor’s house, open store); if your child tends to wander, consider using visual reminders in your home (e.g., STOP signs on doors).

Teach: Actively teach your child safety information in whatever manner works best for your child (social stories, video modeling, pictures or walking through a plan together). Find or create teachable moments throughout the day to reinforce the safety skills you are teaching your child. For example, in a store or other crowded place, ask your child who he or she could go to for help if separated from you.

Knowledge is power: When children have a plan of action, they become empowered in their own safety — learning to replace the fear, confusion, and panic of a dangerous situation with confidence, personal safety skills and self-esteem.

5 radKIDS Plans

To share with children



If ANY Grown Up you don't know comes up and tries to talk with you, **What's Your Plan?** *Keep a Safe Distance, and go to a Safe Zone or to another Grown Up you trust. Remember: All radKIDS know it is not your job to help a Grown Up YOU don't know.*



If ANY Grown Up /Adult you don't know or trust ASKS YOU for help or OFFERS you ANYTHING without MOM or DAD's permission, **What's Your Plan?** *radKIDS say, "NO" in a LOUD VOICE and RUN to a Safe Zone or Grown Up you Trust and tell them because radKIDS know: It is not their job to help a Grown Up it's a Grown Up's job so tell a Grown Up you TRUST.*



If ANYONE you don't know approaches you in a CAR and asks you for help or directions, **What's Your Plan?** *radKIDS Know it is not their job to help a Grown Up so, They say, "NO" and always stay 3 GIANT STEPS back from the car and RUN to a Safe Zone.*



If ANYONE touches you then asks you to keep it a SECRET or tells you something BAD will happen to you or someone you love. **What's Your Plan?** *radKIDS Know: No One has the right to hurt you or touch you because you are SPECIAL so radKIDS say "NO" and "RUN to a Safe Zone" and TELL Because they know it is a TRICK and not their fault.*



If ANYONE grabs you or tries to take you away, **What's Your Plan?** *Yell Loud, "NO", HIT HARD and RUN FAST to a Safe Zone because all radKIDS Know, NO One Has the Right to Hurt You, You CAN STOP THEM and It's not your FAULT so you can Tell.*

Used with permission of radKids®

Safety tips

The 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.
- 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/resources/fire-safety.aspx).
- 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.

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).



- 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)
- Be proactive about bullying. Keep a close watch on social networking communication. For more information, visit 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/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).
- Advocate for Autism Safety Training in your community (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).
- 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.
- Promote RF (Radio Frequency) tracking technology within your community (such as Project Lifesaver International 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.

Endow, J. (2006). *Making lemonade: Hints for autism's helpers*. Cambridge WI: Cambridge Book Review Press.

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.

- 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. (2002). *Lisa and the lacemaker: An Asperger adventure*. Philadelphia, PA: Jessica Kingsley Publishers.
- Kedar, I. (2012). *Ido in autismland: Climbing out of autism's silent prison*. Kedar.
- 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.
- Martin, E. P. (1999). *Dear Charlie: A guide for living your life with autism — a grandfather's love letter*. Arlington, TX: Future Horizons.
- McCabe, P., McCabe, E., & McCabe, J. (2002). *Living and loving with Asperger syndrome: Family viewpoints*. NY: Jessica Kingsley Publishers.
- 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.
- 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.
- Peers, J. (2003). *Asparagus Dreams*. NY: Jessica Kingsley Publishers
- 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.
- 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.
- 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.
- Stansell, L. (2017). *No more chasing normal: The emotional guide for parents of children with autism, Down Syndrome, and all other disabilities*. Charleston, SC: CreateSpace Independent Publishing Platform.
- 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.
- Volk, D. (2015). *Chasing the rabbit: A Dad's life raising a son on the spectrum*. Charleston, SC: CreateSpace Independent Publishing Platform.
- Wiley, L. H. (1999). *Pretending to be normal: Living with Asperger's Syndrome*. 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. (2004). *Not just anything: A collection of thoughts on paper*. NY: Jessica Kingsley Publishers.

Common abbreviations

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

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

OT: 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: 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
Behavior Analyst Certification Board: bacb.com
Center for Autism and Related Disorders (CARD): centerforautism.com
Indiana Institute on Disability and Community: iids.indiana.edu
National Autism Center: nationalautismcenter.org
National Professional Development Center on Autism Spectrum Disorder: autismpdc.fpg.unc.edu





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.



THE UNIVERSITY OF
MAINE

Maine Autism Institute
for Education and Research

5766 Shibles Hall, Room 306, Orono, ME 04469-5766
207.581.2352 • Fax: 207.581.2428
maineautisminstitute@maine.edu • umaine.edu/autisminstitute