

NAVIGATING
AUTISM SPECTRUM DISORDER

A comprehensive guide for families

BOSTON MEDICAL CENTER

The Autism Program

The Autism Program at Boston Medical Center is here to support you and your family as you navigate Autism Spectrum Disorder (ASD).

For more information about our support, please visit **www.bmc.org/autism**. For patients of Boston Medical Center who are interested in learning about our "Autism Friendly" hospital initiative, visit us at **www.bmc.org/visiting-us/autism-friendly-initiative**

✉ autismprogram@bmc.org

www.bmc.org/autism

☎ 617.414.3842

BOSTON MEDICAL CENTER

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This guide uses QR codes!

Throughout this guide, all necessary links and forms will be available in the form of QR codes. To access them, open the camera app on your smart phone, aim it at the code, and follow the link that pops up! You can also click directly on the codes if you are viewing this guide on a computer. *Note that some devices may require you to download a QR reader (free) from the app store

Finding Accurate Stories

At the point of receiving a diagnosis for your child, you may be wondering where to turn next. While there is a lot of information available about ASD on the internet, we caution you to **choose your sources wisely.** Not every source will provide information that applies to your specific situation, and in some cases, the information is just simply incorrect.

It can be helpful to ask your child's doctor as well as other families who are navigating an autism diagnosis if they have **recommended websites or readings.** Below, we have curated some of our favorite websites for accessing clear, digestible and accurate information about ASD and related resources.

"My advice for families is to be easy on yourself and your kid. Even though there's so much emphasis on achievement and success, life's more about being happy and fulfilled."

Click or Scan with Phone

BMC Autism Program

CDC

Mayo Clinic

Academy of Pediatrics

Autism Research

It's Important to Remember

- Autism is a **SPECTRUM**, meaning no two people are going to present with the same strengths, challenges, likes or dislikes.
- While ASD is often diagnosed in childhood, it is a **LIFELONG** condition.
- Some individuals may always be **IMPACTED** by a diagnosis in some way, even if they do not need significant support.

- Autism is different, **NOT LESS.**
- Autism doesn't **LOOK** a certain way, it is sometimes referred to as an "invisible diagnosis" as it cannot be "seen."
- "Treatment" for autism is educational/therapeutic. There are no **MEDICAL** interventions for ASD, like a specific medication or treatment in a hospital.

FAQs

Receiving an autism diagnosis for your child can be overwhelming. You may experience a range of emotions, from confusion, to disbelief, sadness, fear, or even relief. It is important to know that **all of these feelings are normal,** and talking them through with people you trust can help you sort through your thoughts, questions and determine next steps. **Remember that you are not alone.**

Below, we have shared some of the most common questions that families ask when navigating a new diagnosis.

QUESTION

What caused my child's autism?

FACT

There is **no one specific cause** of Autism Spectrum Disorder. Researchers continue to find evidence pointing to a combination of genetic, environmental, and biological factors. What is important to remember is that **autism is not caused by something a parent does or does not do.** There are a few genetic syndromes associated with ASD (for example, Rett syndrome and Fragile X syndrome) where the genetic cause is known. You can also choose to follow up with a genetic counselor to get more information about potential genetic causes or linkages to ASD.

Genetic Testing

FAQs

QUESTION

What is the treatment for autism? Is there a medication my child can take?

FACT

There is **no medical treatment** for autism, and there are no medications that treat all of the core symptoms of the diagnosis. "Treatment" for autism is educational and therapeutic in nature, focused on teaching in a way that is individually tailored for your child. Many therapies and supports focus on building **functional communication** and **independent skills**, providing behavioral support, exploring sensory needs and promoting social skills. Because every child's individual strengths and challenges vary, each will need a different combination of programs and services to match their unique learning and social profile. Early and intensive services can lead to significant progress, though learning can and should occur across the lifespan. **It is important to talk with your child's clinicians and school team to determine which services and supports would be most beneficial for them.**

Autism Facts

It can be helpful to understand which therapies are evidence-based and those that need more research or are untested. The following websites may be helpful as you explore these topics:

Autism Science Foundation

National Standards

Science in Autism

FAQs

QUESTION

Will my child always have this diagnosis?

ANSWER

There is **no "cure"** for autism, and individuals may in some way, shape or form be impacted by the diagnosis across their lifespan. While there is no crystal ball that predicts what the **developmental trajectory** is going to look like for any specific child, we know that autistic individuals can go on to college, have careers, have families, and live independently. The way your child "looks" or presents at the point of a new diagnosis will likely not be the same as they grow, develop and gain new skills.

How Do I Tell My Child?

QUESTION

I don't know if I want to tell anyone about my child's diagnosis. I'm worried about how they will react. What should I do?

ANSWER

If, when and how you choose to share your child's diagnosis with anyone is a **personal choice.** In some cases, sharing your child's autism diagnosis will allow for additional services to be put in place (i.e. sharing with your child's school district or an outside service provider). Sharing a diagnosis with your child can be helpful toward their understanding of what makes them unique. It can also support their **advocating for themselves as they get older.**

It can be helpful to talk with your child's clinicians and others that you trust about how you might approach sharing the diagnosis.

Disclosing Autism

Early Signs of ASD

Autism Spectrum Disorder (ASD) is a complex developmental disorder that can impact social interaction, communication and behavior. While "symptoms" of autism can look different for each person, it is typically categorized by challenges in the areas of **social communication** and **restricted or repetitive patterns of behaviors, interests, and/or activities.** ASD is considered a "spectrum" disorder, meaning that no two people are alike.

Some of the early signs of ASD, especially in young children, include:

Social Communication and Interaction Skills

- Uninterested in or difficulty playing with peers
- Variability in verbal communication skills and/or unique use of language (ex. repetition)
- Difficulty understanding sarcasm or conversation nuances

Restricted or Repetitive Behavior

- Lack of eye contact, little/no response to their name, lack of pointing or showing and sharing behaviors
- Playing in a manner that is repetitive (ex. spinning the wheels of a car)
- Having difficulty transitioning from one activity to the next

Other Characteristics

- A loss of skills that they once had
- Unusual reactions to sensory stimulus (ex. avoiding touch, covering ears in loud places, or seeming to have a high pain tolerance)

Diagnostic Criteria

For your child to be diagnosed with ASD, they must meet the diagnostic criteria in the **Diagnostic and Statistical Manual of Mental Disorders (DSM-5)** published by the American Psychiatric Association in 2013. There are two domains that are considered:

1. Social communication
2. Fixated interests and repetitive behavior or activities

The ASD diagnosis also includes a **severity scale** from mild to severe that is meant to clarify how much support an individual needs to navigate the social and behavioral activities of their lives.

It is important to know that a **severity rating** is based on just a snapshot of time, and not indicative of how much progress your child will make over time.

The Diagnostic Process

ASD is diagnosed by a clinician who has specialized training in child development and behavior (e.g. **Developmental Behavioral Pediatrician, Neurologist, Psychologist, Nurse Practitioner** etc). It is an observational diagnosis in that it cannot be diagnosed by a medical test like a brain scan or blood test.

A **clinician** who specializes in assessing for Autism Spectrum Disorder will interview the child's caregiver, teachers and therapists about the child's behavior.

01

They will do an assessment of your child's **skills, strengths,** and **challenges** while hearing any concerns that you have about your child's development.

02

Through these processes, they will either **diagnose or rule out** an ASD diagnosis, sharing other concerns they may have about your child's development. They may also recommend services and support that you should explore for your child.

03

Myths vs. Facts

MYTH

Autism can be cured.

FACT

Autism is a **lifelong condition.** Tailored services and interventions, especially in childhood, can cultivate important skills and ideally lead to as independent a life as is achievable. However, ASD is not something that can be "cured."

MYTH

Autism is only seen in boys.

FACT

While autism is four times more common in boys than in girls, **both girls and boys can receive an ASD diagnosis**. A behavior called **"masking"** can occur in females, where they may camouflage or hide symptoms or behaviors that are seen by others as problematic. This "masking" of their autistic traits or symptoms can make it more challenging to diagnose, and lead to them being diagnosed later in life.

Myths vs. Facts

MYTH

All individuals with autism either have a low IQ or "savant" like ability..

FACT

Autistic individuals have a **wide-range of learning capabilities, cognitive skills and IQs**. While some demonstrate above average skill sets in some areas (sometimes called a **"savant skill"**), many simply have strengths and challenges just like anyone else. It is important to remember that intellectual disability is not synonymous with autism and must be evaluated and diagnosed separately from ASD.

MYTH

People with autism do not like to be touched.

FACT

Certain **sensory sensitivities** may occur for some individuals, however, none apply to all. Where one person might not like to be touched, another might seek deep pressure in the form of a hug or a blanket. Where one person might get overwhelmed by loud noises, another may enjoy the auditory input from banging on drums. It can be helpful to pay attention to your own child's specific sensory needs, likes and dislikes.

"I want him to know that he's loved. And that it's okay that he is who he is. It's okay if he's different, or if he finds things difficult. Like, that's okay. It's okay to be yourself."

Myths vs. Facts

MYTH

Individuals with ASD do not feel emotion or seek connection to others.

FACT

This is completely inaccurate. All people with autism have different thoughts, feelings and emotions, even if they communicate these uniquely. Remember that just because someone is not verbalizing an emotion (discomfort, excitement, confusion), it does not mean that they aren't feeling it or expressing it in other ways. Communication does not just relate to spoken words. We communicate with our **bodies, gestures, and expressions**.

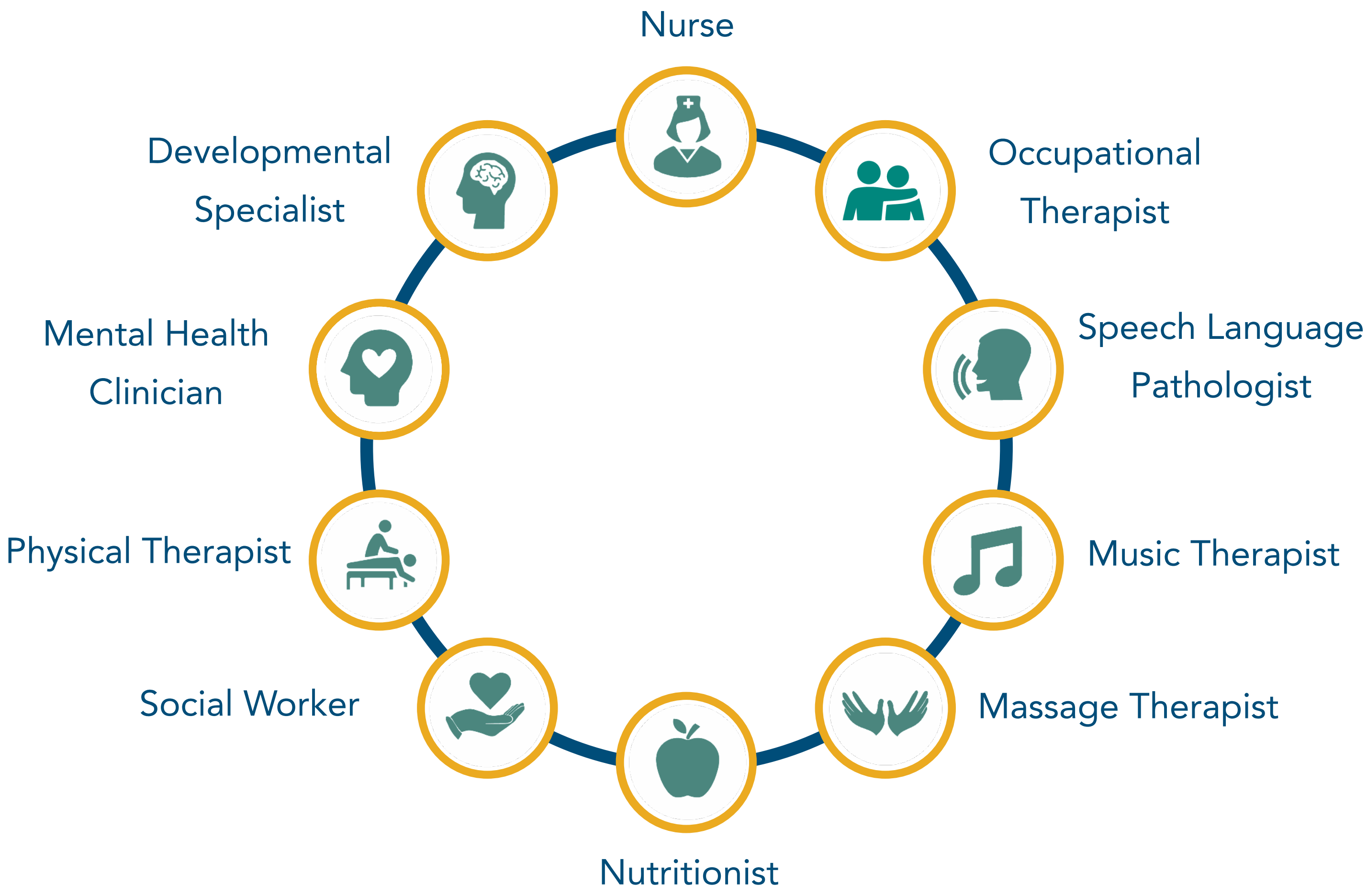
Many autistic individuals seek friendship, love, companionship and connection. While autistic individuals may benefit from being taught techniques for social interactions, it does not mean they are uninterested or incapable of forming a connection to others. It can be particularly helpful to find unique ways of connecting with your child, such as building off of their **interests** and **strengths.**

Early Intervention (EI)

Early Intervention (EI) is a free state/federal program that focuses on the development of children from birth to age three and their families. Anyone can refer a child to EI including caregivers themselves. Children qualify for EI services based on **assessments, risk factors, a documented disability, and clinical judgment.**

Services are offered in the **"natural environment"** (such as home, daycare, preschool, and/or community locations).

Types of EI Professionals



- Nurse
- Occupational Therapist
- Speech Language Pathologist
- Music Therapist
- Massage Therapist
- Nutritionist
- Social Worker
- Physical Therapist
- Mental Health Clinician
- Developmental Specialist

EI contracts with **Specialty Service Providers** (**SSPs**), such as ABA agencies, to provide additional services for those with an ASD diagnosis.

Some sites may have **Parent Groups, Toddler Groups, and Parent-Child Groups**.

Resources to find SSPs in Massachusetts are listed below:

Local EI Programs

Family TIES

Special Education

State and federal laws mandate that all school-aged children (3-22) with disabilities have access to a "free and appropriate public education," also known as **FAPE.**

These laws include:

- **The Individuals with Disabilities Education Act (IDEA)**
- **Section 504 of the Rehabilitation Act**

Boston Public Schools

Special Education Guide

Children who are eligible for special education services can enter the school on their 3rd birthday at any time during the calendar year and do not need to wait until the start of the academic year each fall.

Advocacy Reminder:
Keep logs and copies of all communications and correspondences with the school.

Individualized Education Program (IEP)

When a child reaches age 2.5, EI will assist families in the transition to the local school district for special education services through an **Individualized Education Program (IEP).**

Laws mandate eligible students receive an Individualized Education Program (IEP) to meet their unique needs in the **"least restrictive environment" (LRE)** and that no child may be denied school services because of their disability.

IEP's are reviewed annually with formal assessments being conducted every three years. It is important to know that you can reconvene the special education team to discuss your child's progress and concerns at any time.

IEPs should also state whether or not the child will receive transportation to and from school, and **extended school year (ESY) summer services**.

Individualized Education Program (IEP)

IEP Services include: Speech and language therapy, occupational therapy, physical therapy, ABA, social skills and more.

Special classroom settings (i.e. a disability general, disability specific, autism specific or ABA based classroom), "integrated" or "inclusive" setting, or "general education" setting with supports.

"Service grid" refers to one of the last pages of the IEP that outlines the exact services the student will receive through special education. Each service in the grid is also accompanied by a start and end date, a frequency/duration, and how the service connects to IEP goals.

"Direct services" refer to supports/therapies that are directly provided to the student 1:1 or in a group setting and focus on particular IEP goals and objectives.

"Indirect services" refer to supports/services that are provided as a consultation to other professionals working with the student (such as the student's teacher) that focus on particular IEP goals and objectives.

"As a parent, YOU are the best advocate for your child. Legally, you are entitled and must be informed of all services available to your child. The greater your involvement and voice, the greater the outcome!"

Navigating the IEP: Important Things to Remember

- The entire IEP process, and the services and supports that your child will be provided through their IEP are **completely free**. There are no fees or costs associated with special education services.

- Your child's IEP must be translated into your **preferred language**. You do not need to sign the IEP until you have had a chance to review it in your preferred language.

- You are allowed to bring anyone you would like to an **IEP meeting**, including family members, social workers, therapists or advocates. However, if you are planning to bring an attorney to your IEP meeting, you must notify the school team in advance.

- You are entitled to an **interpreter**, and all meetings should be conducted in your preferred language. If you attend a meeting and an interpreter is not present, you have the right to request that the meeting be canceled and rescheduled.

- If your school district provides you any written documents, including the IEP, know that **you have the right to review the documents before signing**.

- Some families choose to enlist the support of an **advocate or educational consultant** to help support them through the IEP process, or when requesting a change or increase of services.

Special Education Timeline

Enroll your 3+ year old child in public school. **They may already have an IEP**.

↓

Send a letter to the School **OR** Special Education Department requesting a **Team Evaluation** due to your concerns or child's diagnosis.

↓

After receiving the letter, the school district has 5 school days to send a **Consent for Evaluation Form**, which lists all the evaluations to be performed. Check that all the necessary evaluations are included. **SIGN** and **RETURN** it as soon as possible for the evaluation to begin. Common areas of testing are: **Behavioral, Speech, Occupational Therapy, Physical Therapy, Psychological, and ABA**. Testing may happen all on one day or may be **broken up over several dates**.

↓

After receiving the **Consent Form**, the school district has 45 school days to complete evaluations and have the **Team meeting**. After the testing, an IEP meeting will be scheduled. There, you will be given a copy for your records of the testing reports. Each area will report their findings, and a decision about Special Education eligibility or additional services will be made. **You are allowed to disagree with any report, such as rejecting the absence of services.**

↓

You will receive a **final copy of the IEP** 10 school days after the meeting. Make sure to read through the whole document or bring it to your child's pediatrician to help you. You have the option to: **(1) fully accept the IEP, (2) reject the IEP, or (3) partially reject the IEP.** You have 30 days to return the signed IEP.

Special Education Advocacy

Mass DLC

Disability Law Center:
A private, non-profit organization responsible for providing protection and advocacy for the rights of Massachusetts residents with disabilities.

617-723-8455

FCSN

Federation for Children with Special Needs:
A center for parents and parent organizations to work together on behalf of children with special needs and their families.

617-236-7210

Mass Advocates

Massachusetts Advocates for Children:
Provides advocacy and legal assistance regarding educational issues for parents of children with special needs.

617-357-8431

Volunteer Lawyers

Volunteer Lawyers Project:
Provides legal representation to families from lower income households in Boston through the pro bono services of private attorneys and paralegals.

617-423-0648

Resources for Teens and Young Adults

At age 14, youth are invited to participate in their Individualized Education Plan (IEP) meetings, and it is around this time that we **encourage families to start thinking about what life after high school might look like**. Navigating the transition to adulthood can be overwhelming. Here are a few resources for your family to explore as you're considering plans and action steps:

Transition Timeline

Safer Dating

Age of Majority

Got Transition

The **Asperger and Autism Network** has lots of great programming and resources for teens and adults on the autism spectrum including **support groups, life-coaching, training and events**.

AANE

BMC Resources

Outpatient Therapies

Families can access **outpatient therapies** through their health insurance plans. **You should contact your insurance provider to learn specific details about what is covered under your plan.**

Children with disabilities in MA **can apply for Mass Health Secondary insurance** to help cover the cost of outpatient services. This can be helpful if your primary insurance does not cover a particular therapy or if you have a number of co-payments for various therapies your child is receiving.

Outpatient Services

Applied Behavior Analysis, or ABA, is an intensive therapy known for its success in supporting individuals of any age with Autism Spectrum Disorder (ASD) and other developmental disabilities. ABA can support development in the areas of **cognition, language, communication, social, and adaptive skills**. ABA services can be provided in school, in the home and through ABA centers.

Secondary Insurance

Everyday ABA Video Series

The Autism Program at BMC partnered with New England ABA to develop a **free 6-part parent training series** focused on helping parents and caregivers implement ABA in everyday life, accessible above.

Outpatient Therapies

Speech-Language Therapy addresses challenges with language and communication. It can help people with ASD improve their **verbal and nonverbal and social communication** with the goal of helping the individual communicate in more useful and functional ways.

Occupational Therapy (OT) and **Physical Therapy** focus on a child's hand and finger skills **(fine motor)**, large muscle **(gross motor)**, and sensory needs.

Total Communication Interventions, sometimes referred to as **Alternative and Augmentative Communication (AAC)** involves using language, vocalizations, pictures and gestures as well as sign language.

Cognitive Behavioral Therapy (CBT) is a form of treatment with a licensed provider focusing on **thought process, behavior, coping skills, and learning strategies** around implementing those learned skills. If you think your child might benefit from meeting one on one with a therapist, a list of providers can be found on the **Psychology Today** website.

Family Support

Raising a child with Autism Spectrum Disorder can be overwhelming and isolating. You should know that you are not alone. It can be helpful to find a support system that works for you—whether those are **family support groups, community centers, or online forums.**

Connecting with other families can serve as an important reminder and source of comfort as you manage the many complexities of seeking services and caring for your child. A good starting place is to contact your **local autism support center** for a list of current parent support groups in your area.

Services offered at Autism Support Centers

- Information and Referrals
- Lending Library
- Speaker Series
- Family Events
- Camp Listings
- Newsletters
- School Vacation Programs

Did you know that Facebook groups are a great virtual space for getting tips, resources and ideas from other families who have walked through this experience?

Facebook has groups for parents/caregivers of autistic individuals and groups for individuals with autism. Check your local community or national pages to find a group that might be a good fit.

Autism Support Centers

MA Parents of Autism

Asperger/ Autism Network

Boston Autism Moms & Dads

Family Support

Autism Support Centers can be one of the most helpful resources for families. These centers offer **information and referrals, parent training, workshops and specialized programs for children, teens and adults.** Centers are often staffed by caregivers who have a child with ASD, and are there to explain what services and supports your child and family might benefit from.

01

Autism Alliance

(508) 652-9900

02

HMEA's Autism Resource Central

(508) 835-4278

03

Vinfen

(617) 441-1800

04

Lifeworks

(781) 762-4001

06

Community Autism Resources

508) 379-0371

05

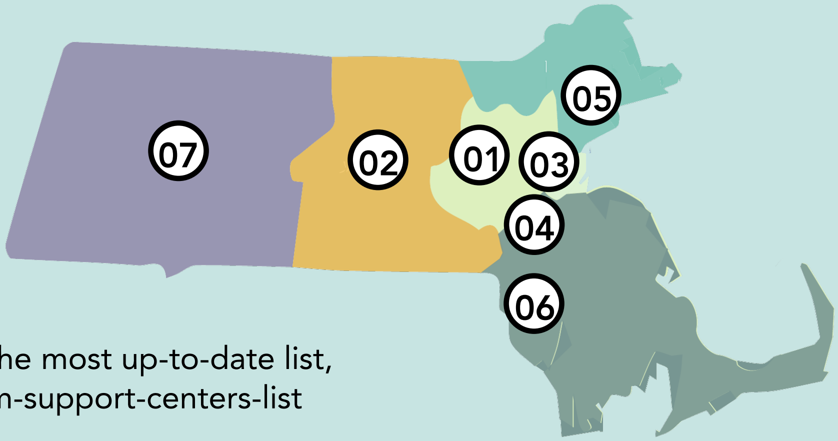
Northeast Arc

(978) 777-9135

07

Autism Connections

(413) 529-2428



This information is subject to change. For the most up-to-date list, go to: www.mass.gov/service-details/autism-support-centers-list

Sibling Support

Research shows that siblings describing their own experiences consistently mention their parent's **reactions, acceptance, and adjustment** as their most significant influence on having a brother or sister with a disability.

"When raised with sensitivity, understanding, and permission to be honest about their feelings, siblings often grow to be powerful advocates – not only for their brothers and sisters, but for everyone in the autism community."

Sibling support resources can look like **social stories, support groups, special 1:1 time with parents, and counseling.** Siblings may benefit from meeting other peers who are growing up in similar households. Our favorite resources are listed to the right.

Sibling Resource Packet

Sibling Support Project

Sibling Support Network

Governmental Benefits

There are many community resources to help your family and child with day to day support, information and sometimes additional funding and benefits.

Department of Developmental Services

The Department of Development Services (DDS) is a state-run agency that provides person centered supports for individuals with intellectual and **developmental disabilities (IDD)** including ASD.

DDS works with children with IDD and ASD to connect families with support programs/centers, supplemental educations services, and other specialized programs. DDS also works with adults with IDD and ASD to connect with employment, day programs and community and residential supports.

Your local autism support center can assist you in **applying for DDS** or you can access a copy of the application through this link:

DDS Application

Governmental Benefits

Supplemental Security Income

Supplemental Security Income (SSI) provides financial benefits to families due to a child's disability, depending on the household income. You can apply **here** or by phone at 800-772-1213.

Insurance Resource Center for Autism and Behavioral Health

The Insurance Resource Center for Autism and Behavioral Health provides resources for families regarding their **medical insurance plans** and **autism and behavior treatments.**

The center can also help families apply for MassHealth or MassHealth Secondary and help you navigate any insurance barriers for autism treatment that may arise.

Mass AIRC

Autism Insurance Guide

MassHealth Coverage Guide

Establish A Routine

Create a Schedule

Children thrive with **structure** and **consistency.** Creating a written and/or picture schedule as part of your routine can support maintaining structure.

Add Tasks

Start to fill in your schedule with **consistent eating, sleeping, and hygiene routines.** Add in other activities around these specific routines.

Break into Steps

Be specific about what needs to be done for each activity. Breaking activities into **smaller steps** and using pictures can help support your child's understanding.

Set Goals

Goals should be **specific** and **realistic** for you and your family. What do you want your child to accomplish each day?

Feeding, Toileting, Safety, and Sleeping

Feeding

Feeding problems occur more frequently in children with ASD. Check out these resources to learn more about how to manage picky eating and be sure to follow up with your child's physician.

Autism & Picky Eating

BMC Picky Eating Handout

Safety

Safety is a common concern for families as many autistic children have difficulty understanding safety rules and may engage in behaviors like running away from caregivers, trying to open windows and doors independently, or speaking to strangers. Setting up safeguards to secure your home and teach your child how to be safe can ease anxiety Learn more from our safety guide below!

Safety Guide

Toileting

Potty training is a process that takes time and patience. Consult these resources for ways to know if and when your child is ready, and how you might approach training in a step-by-step manner.

When is a child ready?

Toilet Training 101

Sleeping

Many autistic children struggle with **sleep issues**, including falling asleep, staying asleep, or waking up too early. Sleep is important for a growing mind and body and disruptions can affect the entire family. These resources can help build and maintain healthy sleep habits.

"I Can Sleep By Myself" Story

WebMD: Sleep Problems

Transitions

Transitions can be difficult for children, especially when a preferred activity transitions into an activity your child does not enjoy. Ensure each activity has a **clear beginning** and **end.** Review the schedule with your child at the start and end of each activity, so they know what comes next.

Choose how you will notify your child of the transition. Use **visual cues** and **timers** prior to transitioning. Our suggested apps for visual timers and schedules are listed below.

Tiimo Planner

Choice Works

My Routine

Remember The Milk

KAZUTIME

Visual Schedule Planner

Done Habit Tracker

Pick your battles! Brushing teeth every day may be something you need to prompt and reinforce, but maybe you can decide to let go of whether your child's clothes match. Choose to address the skills that are most important to you, your child and their evolving needs.

Encourage Desired Behavior

Once your routines have been set, identify **easy to deliver rewards** for your child to earn by following through with their routine. What does your child really want to play with or do during the day?

Keep these items out of reach until your child has completed the **identified tasks**. Provide them with the item or activity immediately after they have "earned" it.

Set **clear expectations** for engaging with this reward. How long will your child be allowed to engage with the activity?

Throughout the day, provide your child with **more praise** instead of negative consequences or reprimands. You want your child to learn that the best way to get your attention is by **following expectations**.

"If more people understood autism, I believe that the young people who are on the spectrum would feel more accepted and not so much as outsiders."

Notes