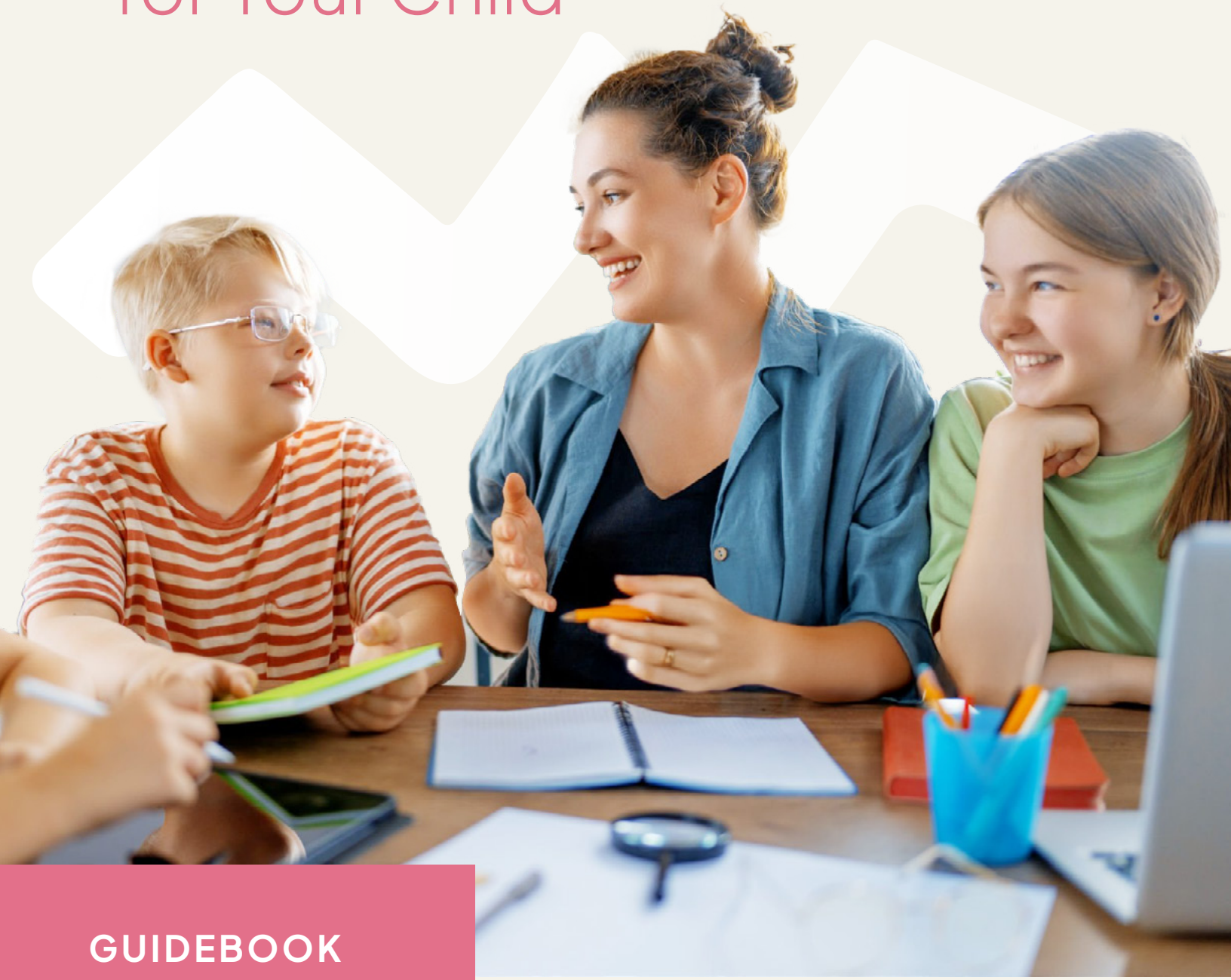
Navigating a New Autism Diagnosis for Your Child

HERE TO SUPPORT YOU • HERE TO SUPPORT YOU •



GUIDEBOOK

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RESOURCES

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Multiple center locations
in Massachusetts
Open between 8:00am – 4:30pm

Introduction and Overview

Welcome to the autism community!

You may be feeling many different emotions as you embark on this journey with your child, and we want to assure you that all of your feelings are valid. Whether you were expecting to join this community or not, there is so much to learn, and this can be overwhelming for any parent or caregiver. We hope that this guidebook will provide helpful information and support as you process your child's autism diagnosis and navigate next steps.

Combining perspectives of autistic individuals, parents of children with autism, and professionals in the autism space, this guide offers practical tips and starting points while recognizing that every family's journey is unique.

Please explore this guide at your own pace and keep your individual values and priorities at the forefront. No one knows your family better than you!

Most importantly, please remember that your child is still a child and that your most important jobs are still to love them, keep them safe, and accept and celebrate them for who they are. This does not change with an autism diagnosis.

We hope you find encouragement and practical support in this guide, and we wish you and your family the very best on this journey!

Key Terms

You have probably been hearing a lot of new words related to autism and we know it can be hard to understand what everything really means. Here are some words you will find in this guidebook, and what we mean by them.

Accommodations
Accommodations are changes to the environment, tools, or expectations that help a child learn, communicate, and participate in ways that work best for them.

Applied Behavior Analysis (ABA)
ABA is an approach to autism care that focuses on teaching new skills and reducing barriers to learning by using structured and individualized methods.

Autism/Autistic
Autism is a natural difference in how a person thinks, learns, and experiences the world. Someone who is diagnosed with autism can be identified as autistic—this is called identity-first language, and it is preferred by many individuals in the autistic community. Others prefer person-first language, which instead identifies someone as a person with autism. This guidebook uses both in an effort to validate individual preferences.

Evidence-based
Interventions and practices that are grounded in scientific research, guided by clinical expertise, and shaped by the preferences and needs of the individuals they support.

Neurodiversity
Neurodiversity is the idea that everyone's brain works differently, and that those differences are a natural and valuable part of human diversity.

Occupational Therapy (OT)
Occupational Therapy helps children develop daily life skills, such as dressing, eating, playing, and using their hands effectively. OT also often supports children with their sensory needs and processing.

Physical Therapy (PT)
Physical Therapy helps children strengthen their muscles, improve balance, and develop movement skills for everyday activities like walking, running, climbing, and playing.

Self-Advocacy
Recognizing and expressing one's own needs, preferences, and feelings, whether by using words, gestures, or other forms of communication.

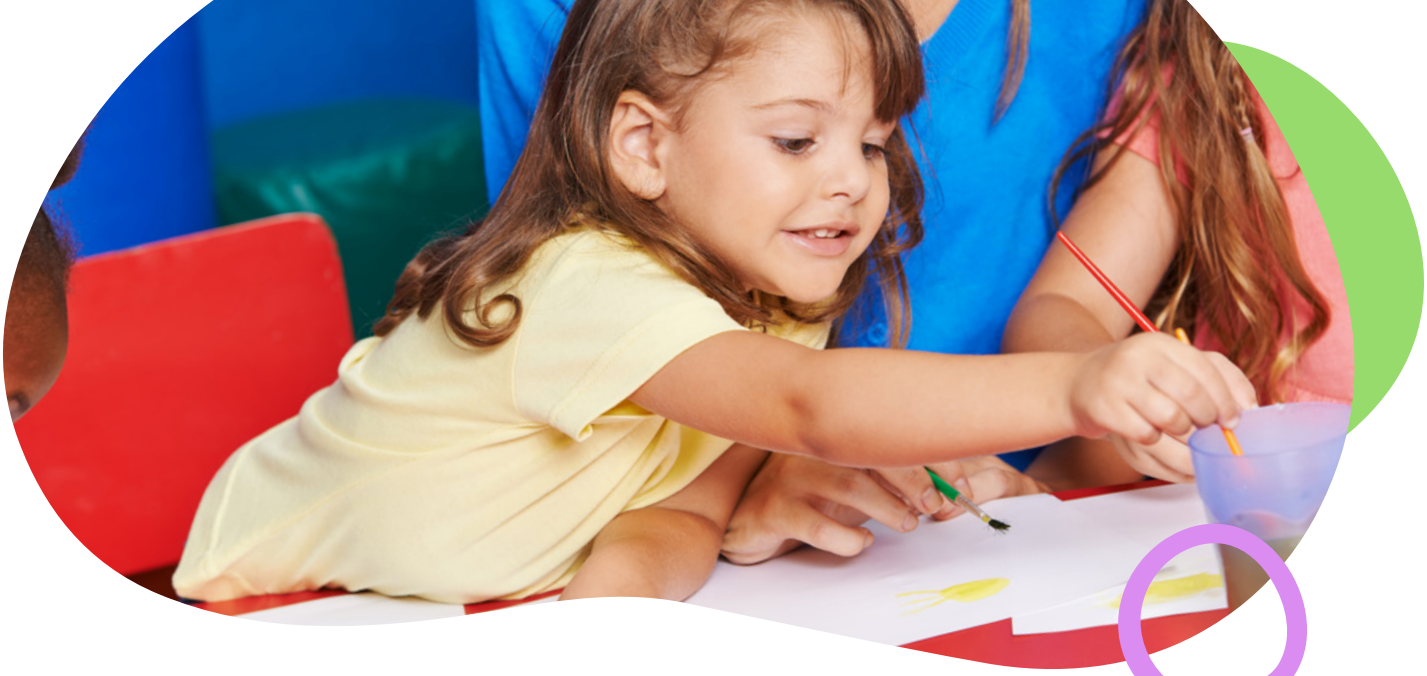
Sensory Regulation
A child's ability to manage and respond to sensory input (such as sounds, textures, or movement) in a way that supports attention, comfort, and participation in daily activities.

Speech-Language Therapy
Speech-Language Therapy helps children build communication skills, including speaking, understanding, using gestures, and interacting with others. This applies to children who communicate verbally, as well as to children who communicate in other ways such as using gestures, sign language, pictures, or a communication device.

Support Group
A support group is a gathering of people with shared experiences who come together to offer encouragement, advice, and understanding.

Support Network
A support network is the group of people—such as family, friends, professionals, and community members—who offer emotional, practical, and informational help to a child and their caregivers.

Target Skills
Specific skills a child is learning, such as making requests, taking turns, or brushing their teeth, based on their unique needs and goals.



New Diagnosis Frequently Asked Questions

Q **My child just received a diagnosis of autism. What should I do first?**

It can be overwhelming to receive a new diagnosis for your child, and you are likely experiencing many different feelings. While it is great that there is lots of information about autism available, it can be hard to know where to begin. It is ok to take some time to process in whatever way works best for you before diving into information and resources.

When you are ready, you might want to learn more about the variety of programs and resources for which your child and family may now be eligible. Please see page 18 of this guidebook for some key starting points.

One of the best things you can do, especially early on, is to connect with people who have been where you are and with people who understand your child's experiences. These connections will help you find support, information, and validation as you begin this journey.

Your local Parent Training and Information Center and Autism Support Center are wonderful places to start. Many offer support groups and opportunities for you to connect directly with experienced caregivers. You can find more information about these resources on pages 19–21 of this guidebook.

In addition to other parents and caregivers, autistic adults can be a wonderful resource to learn more about the autistic experience. There are specific recommendations on pages 22–23 of this guidebook to help you get started.

WHAT MATTERS MOST

Keep in mind that there are an infinite number of different perspectives on, and ways of, experiencing autism, and that your journey with your child is unique. Take what you need, leave what you don't, and remember that this will evolve as you move forward.

How do I know which services are a good fit for my child?

It is important to consider that a child does not need services just because they are autistic. While they may experience and interact with the world differently, their way of interacting with the world is not inherently wrong or in need of correction. However, in many cases, high quality services can be an important part of supporting the development of a child with autism. You may have received recommendations for Applied Behavior Analysis (ABA), speech-language therapy, occupational therapy (OT), and/or physical therapy (PT) at the time of your child's diagnosis, and it can feel difficult to know where to start.

First, consider the specific areas in which your child seems to need support. For example:

- Do they become frustrated when they are unable to communicate their wants and needs?
- Do they struggle with different textures, loud noises, or self-care tasks such as toothbrushing and toileting?

You may also think about what is difficult for you when caring for your child. For example:

- Perhaps you are unsure of how to respond to your child when they are distressed.
- Maybe you feel that you could use support in finding ways to play with your child that you both enjoy.

Remember that services should support both you and your child in learning new skills and in identifying and implementing accommodations.

Once you have identified where your family needs support, you may consider some logistics. For example:

- What type of insurance coverage does your family have?
- What type of scheduling works for your family?
- Page 11 of this guidebook include starting points and suggested questions to ask when exploring potential service providers.

WHAT MATTERS MOST

Remember that your family is unique, that it is ok to do what works for you, and that this may be different than what works for other families.

Will my child catch up? Will they be ok?

Many parents and caregivers ask these questions as they process their child's diagnosis and begin to wonder what the future holds. Your feelings and worries are valid and also, your child is perfect just the way they are! They were autistic before being officially diagnosed, and they will continue to be autistic because it's a big part of what makes them the amazing person that they are.

As you learn more about autism and connect with other caregivers, it will become easier to recognize and appreciate your child's unique strengths and interests. There are also many autistic adults sharing their stories publicly, and it can be very helpful to learn from them and hear their perspectives. You can find a list of some autistic adults who share their stories on pages 22–23 of this guidebook.

You may choose to seek services to support your child's development and to assist you in understanding and responding to their needs. You can love and accept your child for who they are and still want to help them develop skills and strategies that are meaningful for them. Remember that it is also important to learn what accommodations your child needs and to support them in self-advocating for those accommodations.

In determining when to target specific skills and when to accommodate, it can be helpful to think about whether a particular goal truly benefits your child or whether it serves to make those around them more comfortable. The way your child learns, interacts, and experiences the world may always be different from non-autistic peers and there is nothing wrong with that!

WHAT MATTERS MOST

An autism diagnosis does not mean that there is something wrong with your child. Embrace their unique strengths and needs and, with your support, your child will thrive just as they are and will develop skills to navigate the world on their terms.

Q Should I tell my child about their diagnosis?

Yes! The sooner your child knows that they are autistic, the sooner they can begin to develop an understanding of themselves and to build community.

Think of it this way: if your child is not aware of their diagnosis and inevitably starts to notice that they learn and interact differently than other people, they may feel like they are simply less intelligent or less likeable. If they have been empowered with the knowledge of their diagnosis, this may help them understand why they are different and why that is ok. It can also help them start connecting with other autistic people who can validate their experiences.

Of course, information should be presented at a developmentally appropriate level. For children who may not be ready for a focused conversation, reading books with autistic characters can be a great way to start introducing the idea. The conversation can evolve as your child grows.

Not every child will react in the same way when told that they are autistic, and the most important thing you can do is to let them know that you love them exactly as they are and that you are there for them no matter what. The words you say to your child become their inner voice as they grow up, so you have a big impact on how they will view themselves. Affirm their identity and way of being, and they will be in the best position to grow into an adult with a strong sense of self and the confidence to advocate for their needs.

WHAT MATTERS MOST

Telling your child that theyare autistic will help them understand themselves, embrace their identity, and gain confidence in who they are. This will enable them to develop a strong sense of self and to build their community.

Choosing Service Providers for Your Family

The process of choosing service providers will look different for every family, and we hope that this guide gives you confidence and practical tips as you get started. The right provider should meet your family's unique needs and, most importantly, they should truly CARE. To help you evaluate your options, consider these five key factors when looking for a provider who C.A.R.E.S. :

COST

For most families, cost and insurance coverage are important factors. Here are some considerations:

- Start by contacting your insurance provider to ask about covered services and out-of-pocket costs. Your insurance provider may also be able to provide you with a list of providers who are in-network.
- When you reach out to potential providers, confirm that they are in-network to be sure you are covered.
- Providers offer varying degrees of support around navigating insurance, and this may be something to consider when choosing whether or not to work with them.

APPROACH

Think about what type of programming you are looking for and what qualities are important to you. Here are some considerations:

- Certain provider characteristics may be important to you. For example: Is it important to you that the provider's approach is evidence-based? Is it important to you that the provider is responsive to the lived experiences of people like your child?
- You may want to note the language that each provider uses when speaking about children and families like yours, and think about how their language aligns with your values and perspective.
- Consider asking about the provider's or program's commitment to their own training, ongoing supervision, and continuous improvement.
- Consider asking the provider to share how they will determine what to work on with your child.

RESOURCES

Direct services are just one component of supporting an autistic child and their family, and it can be challenging to navigate everything on your own. You may want to find out if a provider will be helpful to your family in connecting with other resources and supports. Here are some questions you might ask:

- Does the provider maintain relationships with other community providers and help with referrals as needed?
- Can the provider help you find resources such as local support groups?

ENGAGEMENT

A service provider may be an expert in their field, but you are the expert on your child! Family engagement has many benefits for both you and your child, so consider how you will be involved in their care. Avoid providers who don't value caregiver input and involvement! The following questions may help you get a sense of your involvement in any service provider's work with your child:

- How will my input be included in setting goals for my child?
- How often will I be able to communicate directly with my child's provider(s)?
- Will I be able to my give feedback to my child's provider? What actions can I expect in response to any feedback I offer?

SCHEDULE

You may have received a recommendation that your child receive a certain number of hours of services. While this is important information and guidance to have, you can (and should!) also consider what is manageable and realistic for your family. There may or may not be alignment between the recommendation and what is feasible for your family, and that's ok. Every family is different, and you need to do what is right for your family and child.

- When speaking with potential providers, take note of how flexible they are willing to be with the number of hours your child will receive services and the schedule for services.
- Take note of how the provider explains the reasoning for their recommendations. Do their explanations seem clear and reasonable to you?

WHAT MATTERS MOST

Remember that when you make a decision about a service provider, you are doing the best you can with the information you have at the time. Give yourself grace if a service provider does not work out for any reason!

Suggested Questions to ask Potential Service Providers

- Do you accept my insurance? Will you assist with preauthorization?
- What are your scheduling options?
- What is your cancellation policy?
- Who are the people providing services? What are their experiences and credentials?
- What kind of training and supervision do your providers receive?
- What research or evidence are your services based on?
- How do you ensure that you're hearing the perspectives of people with lived experience?
- How do you determine what goals to work on?
- What does a typical session look like?
- Can I observe my child's sessions?
- What happens if my child becomes distressed during a session?
- How will I know how my child is doing?
- When and how do you update goals as my child progresses?
- When and how can I communicate with the person/people working with my child?
- Will you make suggestions for things I can do to support my child at home?
- How do you gather feedback from families? What do you do with that feedback?
- If I have a concern about my child's services or about their provider, what steps can I take?
- Do you offer any supports or resources for children and families beyond direct services?
- Do you help with referrals to other providers if needed?

WHAT MATTERS MOST

Remember that these questions are just suggestions to get you started. There may be other things that are important to you, and there may be questions on this list that are not as important to you. Finding service providers who fit your needs will be an individual process, and you should trust that you know your child and family best!

Neurodiversity & Autism Services

Every child is unique, and so is every family's approach to finding support. Some families feel most comfortable with providers who embrace a neurodiversity-affirming approach, while others may prioritize different qualities in a provider. What matters most is finding the right fit for your child and family.

What Does It Mean to Be Neurodiversity-Affirming, and Why Does It Matter?

Neurodiversity-affirming providers recognize autism as a natural variation in how people think, communicate, and experience the world, and not as something to be fixed or corrected. These providers focus on supporting autistic children in ways that respect their needs, strengths, and self-identity. Instead of focusing on teaching compliance with adult directions or teaching to mask (hide) autistic traits, neurodiversity-affirming approaches emphasize self-advocacy, communication in all forms, sensory regulation, and accommodations that help children thrive. Choosing this type of provider can help ensure that your child receives respectful and supportive care that nurtures their wellbeing and confidence.

WHAT MATTERS MOST

Each family's journey is unique, and learning about neurodiversity-affirming care can help inform the choices you make. Research shows that affirming a child's identity and needs can positively impact their self-esteem, mental health, and long-term wellbeing. If this mindset and approach is new to you, exploring it with an open mind can help ensure your child receives respectful and supportive care that nurtures their confidence and growth.

Questions to Ask

When meeting with a potential provider, you may want to determine if their approach aligns with your values and goals. Consider asking:

- How do you support a child's communication, including non-speaking communication?
- How do you approach sensory needs and regulation?
- How do you encourage self-advocacy and autonomy for autistic children?
- How do you handle behaviors that may be expressions of distress?
- Do you use rewards or consequences to shape behavior? If so, how?
- How do you involve families in setting goals and strategies?
- How do you ensure that therapy is respectful of a child's needs and identity?
- What are your thoughts on the neurodiversity movement and affirming practices?

Safety Considerations

Safety can be a major concern for many caregivers of autistic children due to risks associated with running or wandering away from caregivers (called elopement), water safety, mouthing or eating nonfood items, and overall challenges around understanding danger. This may or may not be the case for you and your child but, if it is, here are some recommended steps to take when making a plan for your child's safety. You can find more specifics, including helpful checklists, on pages 24–29 of this guidebook.

Please remember that even the very best safety features and most thorough preparedness cannot replace appropriate adult supervision, which may look different for an autistic child than it does for same-age peers. Be sure that a responsible adult who is aware of your child's safety-related needs is supervising them at all times.

Auditing and Observation at Home

Home Audit

A good way to start is to complete a safety audit of your home. Carefully check every room—and other areas such as hallways—inside of your home, as well as all outdoor areas, taking notes about potential hazards along the way. Imagine yourself in your child's shoes as you complete the audit to assess what is likely to catch their attention and what they can access. You can find a safety audit checklist on pages 24–25 of this guidebook.

Home Observation

In addition to this, you may want to spend some time observing your child and making note of safety issues that arise. It may be helpful to notice any triggers—such as loud noises, certain clothing, and specific situations—that may increase the risk of elopement and other potentially dangerous behaviors.

Safety Problem-Solving

When you observe a dangerous behavior, try to determine what the purpose of that behavior is for your child. For example, if your child is eloping, could it be because their environment is too loud? Think about some replacement behaviors to help your child have their needs met in a safer way. For example:

- If your child tends to elope when the environment is too loud, you could offer them noise-cancelling headphones.
- If they often chew nonfood items, a safe and durable chewy tube may work as a safe replacement.

It is important to remember that there is a reason behind each of your child's behaviors, and that addressing this must involve more than just trying to get them to stop through compliance-based methods or rewards and consequences. Remind yourself that figuring out how to meet your child's needs in ways that help reduce dangerous behaviors will involve time, patience, and trial and error. This is why it is so important to maximize safety in their environment while going through this process.

Considerations Away from Home

Although your child likely spends much of their time at home, it is important to think about their safety in other locations as well. Think about experiences such as riding in the car, staying at a hotel, visiting a park, going to a store, or any other activities that are relevant for your family. Here are some considerations to help you start thinking about what would be useful for keeping your child safe outside of your home:

- If car safety is a challenge, you might look into guards that prevent a child from unbuckling their seatbelt.
- Although it can be painful to imagine, consider what would be helpful if your child wandered away from home or otherwise became separated from you. Items such as ID tags or bracelets and GPS trackers are widely used with autistic children and may be helpful.
- You may want to create a safety checklist to use when visiting places with your child so that you can quickly identify and address potential dangers.

Making a Safety Plan

Now that you have gathered information and gained a clearer understanding of potential safety risks, you can make a plan to address them. You may wish to consider some questions such as:

- What changes need to be made inside of my home?
- What needs to be done in my yard or other areas surrounding my home?
- What does my child need when they are outside of the home?
- Which specific safety items will best meet my child and family's needs?
- How will I get the items that I need to keep my child safe?
- How can I, and other caregivers, keep my child safe in the meantime?

See pages 26–27 of this guidebook for a more detailed list of questions to consider when making a safety plan.

Taking Action

You've identified risks, developed a plan to improve safety, and researched options that are most likely to work for your child and your home. Now you are ready to purchase, or otherwise obtain, necessary items and services.

In addition to purchasing items yourself, you can consider other ways to get what you need. Maybe you have friends or family members who have things to pass along, or a local "Buy Nothing" group where items are being offered. You could also ask other parents of children with autism and/or your child's service providers if they know of lower-cost ways to obtain safety items or services such as swim lessons. Some organizations offer grants that can be used for this purpose, so consider looking into those as well. See pages 28–29 of this guidebook for a checklist of potential safety items.

WHAT MATTERS MOST

While all caregivers must take steps to ensure their child's safety, this can be a much more complex and challenging responsibility when caring for an autistic child. Increased worries about safety and the need to be hypervigilant at all times can impact the mental and physical wellbeing of caregivers. Building a strong support network and getting connected with local organizations can help you find support and respite when you need it.

Building a Support Network

All caregivers benefit from a strong support system that provides social connection, validation and advice, assistance navigating difficult times, and help with practical needs such as childcare. This type of support is even more important for caregivers of children with autism, but unfortunately can also be more challenging to build and maintain. As with anything else, your personal preferences and needs are important to take into consideration. We all prefer different types of relationships and that is ok!

Maintaining Existing Relationships

If you already have a support system of family and friends, you may be wondering how to maintain relationships with them while helping them understand the evolving needs of your child and family. Some common barriers to maintaining relationships with existing friends and family include feeling like they can't relate to your experiences, having a reduced capacity to stay connected due to caregiving responsibilities, and managing other peoples' discomfort with your child's diagnosis and needs.

It can be helpful to keep in mind that most people are doing their best to be supportive and understanding, but they may not know how to do that in a way that is most meaningful for you and your family. They may need some help to recognize what is helpful and what is not, and you might experience a variety of responses to that. Some people will be willing and able to be flexible and others may not have that capacity.

Tips to Maintain Relationships

- **Give people time and space to learn**
  Just as you want people to recognize that you and your child are doing your best, try to consider that they are most likely doing their best as well—even if their best is not what you want or need at the time.

- **Communicate and set boundaries**
  Tell people what you and your child need in order to participate in events or gatherings and to feel included. You can feel confident in doing so by reminding yourself that you are not asking too much. You are advocating for the valid needs of your child and family, and that is important.

- **Share information**
  When people feel like they don't understand and don't know what to do, they will tend to pull away. Ask if they are open to learning more and how they prefer to do so—for example, through conversation, books, articles, podcasts, or other ways.

- **Enlist the help of a supportive person**
  You may not have the time or capacity to share information and resources with people to help educate them about your family's needs. This is understandable! If you have a friend or family member who is looking for ways to help, having them connect with less informed or supportive friends and family can be a great way for them to meaningfully support you.

Building New Relationships

In addition to maintaining your existing support network, it can be very helpful to form new relationships. You will likely find that other parents and caregivers of autistic children are strong sources of support and validation. Remember that you are not alone on this journey, and there are many people in your local area and beyond who understand how you are feeling. There are both formal ways to get connected and informal steps you can take to increase your chances of finding a supportive community of people who "get it."

Tips to Build New Relationships

- Contact your local Parent Training and Information Center and/or Autism Support Center, and ask them if they offer any programs to facilitate caregiver to caregiver connections or mentorship—many of them do!
- Look up your city or town's Special Education Parent Advisory Council (SEPAC) and connect with them by sending an email, joining their mailing list, or attending a meeting. Offerings will vary by location, but this is a great way to meet other local parents. Your child does not need to be attending school for you to get involved.
- Search for local social media groups for parents and caregivers of autistic children, and consider joining. You may want to review the rules and take some time to read and observe in the group to get a feel for it before jumping in. Not every group will be the right fit, but you can find incredibly supportive spaces on social media and this can be more accessible for busy caregivers. You could also consider joining groups that invite parents and caregivers to ask questions of autistic adults.
- Explore local Special Olympics programming and accessible or adaptive recreation opportunities. If you see something that seems like a potential fit for your family, give it a try! Many families point to these activities as the places they have found the most support and connection.
- Look for local events that are advertised as inclusive and/or sensory-friendly, and attend the ones that work for you. The above tips will also help you connect with people and organizations that know about these types of events.
- Fenced and otherwise inclusive playgrounds can also be a great place to meet families like yours, due to the increased accessibility and safety features.

WHAT MATTERS MOST

Building and maintaining relationships can be challenging, especially when you are caring for an autistic child, but taking steps to do so will give you the best opportunities to find both practical and emotional support. Along the way, you will likely find yourself being a source of that support for others and that can also be fulfilling and empowering. You are not alone!

Conclusion and Feedback

Thank you for taking the time to read this guidebook! We hope it has been helpful and that you will continue to refer back to it as you move forward with your child.

When you are ready, the remaining pages of this guidebook include the resources and lists mentioned throughout.

If you are looking for additional support or assistance with resources, please feel free to contact the Family Support team at ANNA (Allied Network for Neurodevelopmental Advancement). You can call (617) 307–3989 or email ashley@annaautismcare.com and we will be happy to assist you.

Enjoy your incredible child and always remember that you are exactly who they need. You are doing great!

Resources

Massachusetts Insurance and Financial Resources

Insurance

Your child is eligible for secondary MassHealth, known as CommonHealth, based on their autism diagnosis. There can be a monthly premium based on your income, and there is an associated Premium Assistance program to help offset these costs.

In addition to covering out of pocket expenses, CommonHealth has other benefits such as coverage for incontinence products starting at age 3.

You can find additional information at: https://www.mass.gov/info-details/masshealth-commonhealth and https://www.mass.gov/info-details/masshealth-premium-assistance-pa

The Autism Insurance Resource Center is a wonderful support in navigating the complicated insurance system, with particular expertise in CommonHealth and Premium Assistance for families of children with autism. You can find them at: https://massairc.org/

Department of Developmental Services (DDS)

DDS offers family support and funding for supplemental services for autistic individuals and their families. One component of this is the Children's Autism Waiver Service Program which provides eligible children ages birth through nine with intensive in-home services and supports. Please note that DDS eligibility does not guarantee access to all available services, as this can be dependent on available funding and other factors. Learn more at: https://www.mass.gov/orgs/department-of-developmental-services

Supplemental Security Income (SSI)

SSI provides monthly financial assistance for parents of children with disabilities, including autism, whose income falls within the eligibility limits. Learn more at: https://www.mass.gov/info-details/eligibility-for-ssi-and-ssdi

Massachusetts Parent Training and Information Center

Federation for Children with
Special Needs (FCSN)
The Schrafft Center
529 Main Street, Suite 1M3
Boston, MA 02129

E-mail: info@fcsn.org
Website: https://fcsn.org/

Toll-Free: (800) 331–0688 (in MA only)
Phone: (617) 236–7210 (V/TTY)

- English – Option 1
- Spanish – Option 2
- Haitian-Creole & French – Option 3
- Portuguese – Option 4
- Mandarin & Cantonese – Option 5
- Vietnamese – Option 6
- Russian – Option 7
- All other languages – Option 8
- ASL and captioning available

The Federation for Children with Special Needs (FCSN) has a strong commitment to language access and offers a wide range of supports and engagement opportunities for all families of children with disabilities, including:

- Parent Training and Information Center offering workshops and trainings
- Caregiver to Caregiver Respite Network
- Parent to Parent Program
- Information Center providing special education support and guidance
- School Finder
- Family Advisor Program
- Parent Consultant Training Institute
- Family Voices for assistance navigating healthcare systems
- Transition support for young adults and their families

Massachusetts Autism Support Centers

Metro Region Autism Support Centers

Advocates, Inc./Autism Alliance of Metrowest (children and families)

1881 Worcester Rd.
Framingham, MA 01701
(508) 652–9900
AutismAlliance@Advocates.org
www.autismalliance.org

Vinfen Autism Support Center (children and families)

1208A VFW Parkway, Suite 202
West Roxbury, MA 02132
(617) 206–5902 or (617) 562–4094
AutismSupports@vinfen.org
www.vinfen.org/asc

Lifeworks Autism Support Center (children, adults and families)

89 Clapboardtree St.
Westwood, MA 02090
(781) 762–4001
autismsupportcenter@lifeworksarc.org
www.lifeworksarc.org/service/adult-autism-support-center/

Northeast Region Autism Support Centers

Northeast Arc/The Autism Support Center (children and families)

6 Southside Rd.
Danvers, MA 01923
(978) 777–9135
ascstaff@ne-arc.org
www.ne-arc.org/services/autism-and-specialty-aba-services/autism-support-center

Northeast Arc/Adult Autism Support Center (adult 18+ and families)

100 Independence Way, Suite D3,
Liberty Tree Mall
Danvers, MA 01923
(978) 624–2603
adultautism@ne-arc.org
www.ne-arc.org/services/autism-and-specialty-aba-services/adult-autism-support-center

Central/West Autism Support Centers

HMEA: Autism Resource Center of Central Massachusetts (children, adults and families)

712 Plantation St.
Worcester, MA 01605
(508) 835–4278
autism@hmea.org
www.autismresourcecentral.org

Pathlight: Autism Connections (children, adults and families)

(413) 585 8010
www.autismconnectionsma.org

Springfield Office
220 Brookdale Dr.
Springfield, MA 01104

Northampton Office
11 Village Hill Rd.
Northampton, MA 01060

Berkshire Office
75 South Church St., Suite 402
Pittsfield, MA 01202

Greenfield Office
101 Munson St.
Greenfield, MA 01301

Southeast Region Autism Support Centers

Within the Southeast Region, Community Autism Resources is the Children's Autism Center. In each catchment area, there is a Family Support Center with an Adult Autism Navigator that takes the place of an adult Autism Center.

Community Autism Resources (children and families)

33 James Reynolds Rd., Unit C
Swansea, MA 02777

Northern Area

Bridgewater Office
120 Main St.
Bridgewater, MA 02324
(508) 379–0371 / (800) 588–9239
www.community-autism-resources.com
barbaradomingue@community-autism-resources.com

Brockton Area

The Arc of Greater Brockton
1250 West Chestnut St.
Brockton, MA 02301
(508) 583–8030
www.thearcofgreaterbrockton.org
info@thearcofgreaterbrockton.org

Fall River Area

People Inc.
1 Father DeValles Blvd., Suite 401
Fall River, MA 02723
(774) 488–5325
www.peopleinc-fr.org
familysupport@peopleinc-fr.org

Cape Cod and the Islands Area

Kennedy-Donovan Center
294 Quaker Meeting House Rd.
Sandwich, MA 02537
(508) 745–3590
www.kdc.org

New Bedford Area

Better Community Living
5 Ventura Dr.
Dartmouth, MA. 02747
(508) 999–4300
www.bettercommunity.com

Plymouth Area

Plymouth County Family Support Inc.
118 Long Pond Rd., #100
Plymouth, MA 02360
(508) 927–4520
www.pcfamilysupport.org
info@pcfamilysupport.org

South Coastal Area

Advocates, Inc.
1189 R North Main St.
Randolph, MA 02368
(781) 767–3048
http://southcoastalfamilysupport.org/

Taunton/Attleboro Area

The Arc of Bristol County
141 Park St.
Attleboro, MA 02703
(508) 226–1445
www.arcnbc.org

Autistic Perspectives

Many Autistic individuals are sharing their stories, which is incredibly valuable in furthering our understanding of autism. While this is not an exhaustive list, it includes a diverse range of individuals with varied experiences and perspectives.

Jordyn Zimmerman

Jordyn is non-speaking and did not receive access to augmentative communication until age 18. She holds a Master of Education from Boston College and is dedicated to ensuring that everyone has access to effective communication. The documentary film This Is Not About Me tells Jordyn's story of growing up autistic and nonspeaking.
→ https://www.jordynzimmerman.com/

Tiffany Hammond

Tiffany is a keynote speaker, consultant, advocate, and mother to two boys with the same diagnosis. Drawing on a Master's in Developmental Psychology as well as her lived experience, she explores concepts related to Autism and Intersectionality with a focus on the Black Autistic experience.
→ https://www.fidgetsandfries.co/

Morénike Giwa Onaiwu

Morénike is a multiply disabled and neurodivergent global human rights and disability scholar, author, advocate, and parent in a multicultural and neurodiverse biological and adoptive family. Morénike utilizes lived and learned experience to advance accessibility and inclusion with an emphasis on intersectionality.
→ https://advocacywithoutborders.org/morenikego/

Jules Edwards

Jules is an indigenous disability justice advocate and writer who experiences disability and neurodivergence through multiple lenses, including as a parent of neurodivergent children. She presents on topics including culturally responsive practices, parenting, universal design, and educational and workplace inclusion.
→ https://autistictyping.com/

Joy F. Johnson

Joy is a behavior analyst and advocate whose work is informed by her personal experiences with ableism and racism within societal and educational systems. Her AFA (Autistics for Autistics) scholarship fund aims to bridge the gap between the Autistic community and the field of Applied Behavior Analysis.
→ https://joyfjohnson.com/

Danny Whitty

Danny is a nonspeaking writer and advocate who uses Spelling to Communicate (S2C) and also identifies as an apraxic, neurodivergent, immigrant, and half-Asian person. He is a published author and poet, as well as an advocate who is particularly committed to sharing the perspectives of nonspeaking autistics.
→ https://dannywithwords.com/

Ly Xīnzhèn Zhǎngsūn, J.D.

Ly Xīnzhèn's work centers on the intersections of disability, queerness, race, gender, class, nation, and migration. They are a consultant, advocate, and the Director of Public Policy at the National Disability Institute. Ly Xīnzhèn is also the Founding Executive Director of the Autistic People of Color Fund.
→ https://lydiaxzbrown.com/

Andrew Arboe

Andrew is a keynote speaker and self-advocate with particular expertise in supporting autistic individuals and their families around employment, driving and transportation, and transition to adulthood. He is a member of various Boards including the Neurodiversity Employment Network and Disability Rights Connecticut.
→ https://andrewarboe.weebly.com/

Kieran Rose

Kieran is an international speaker, consultant, mainstream and academic author, and father to three autistic children. He specializes in Autistic Masking, Autistic Burnout and Autistic Identity, and believes in the importance of conveying the collective story of many Autistic voices in his work to promote understanding of the Neurodiversity Paradigm.
→ https://theautisticadvocate.com/

Jennifer Cook

Jennifer is an autism advocate, author of nine bestselling books, and the on-camera expert for Netflix's Love on the Spectrum U.S. An alumna of Brown and Columbia universities, she has presented at the White House and to royal audiences in Europe. Jennifer believes in supporting people of all ages in improving relationships and unzipping hidden social rules.
→ https://www.jenniferotooleauthor.com/

Dr. Kerry Magro

Kerry is an award-winning speaker, bestselling author, movie consultant, and nonprofit founder and CEO, who credits his success to a supportive family and quality services in his childhood. His organization "KFM Making a Difference" provides college scholarships for adults with autism.
→ https://kerrymagro.com/

Lyric Rivera

Lyric is a trans-nonbinary self-advocate, author, consultant, and voice behind the internationally recognized NeuroDivergent Rebel blog. They have a diverse business background, working with organizations of all sizes to advance inclusion and autonomy of neurodivergent people, and are known as the creator of the #AskingAutistics hashtag.
→ https://neurodivergentrebel.com/

Autistic Women & Nonbinary Network (AWN)

AWN's mission is centered on dispelling misinformation and stereotypes about autism in order to reduce stigma and fear, while providing support and resources for Autistic women, girls, nonbinary and trans people of all genders, Two Spirit people, and all people of marginalized genders or of no gender.
→ https://awnnetwork.org/

Learn From Autistics

Learn From Autistics aims to connect parents with Autistic voices, recognizing that this population is underrepresented in public conversations around autism and that the Autistic community includes many varied perspectives.
→ https://learnfromautistics.com/

Autistic Self Advocacy Network (ASAN)

ASAN is a nonprofit disability rights organization run by and for autistic individuals. Through policy and legal advocacy, educational resources, and leadership training, ASAN works to advance equal rights, access, and opportunities for autistic people.
→ https://autisticadvocacy.org/

Home Safety Audit

Below are some things you may want to look for as you complete a safety audit of your home. Considering these questions can help you plan next steps, such as rearranging things in the home or acquiring necessary items. Please remember that you know your child best, so some of these may not apply and there may be additional things to consider for your family:

Entry and Exit Points

- [ ] How many doors and windows do you have? Are they secure?
- [ ] Can your child open them?
- [ ] What type of handle/knob/closure do they have?

Furniture

- [ ] How many doors and windows do you have?
- [ ] Are they secure?
- [ ] Can your child open them?
- [ ] What type of handle/knob/closure do they have?

Appliances

- [ ] Are stove/oven controls accessible to your child?
- [ ] Can your child access and open things like the refrigerator, freezer, oven, dishwasher, washing machine, dryer, or toilet?
- [ ] Is the TV in reach and is it secured to prevent tipping?

Cabinets

- [ ] Which ones can your child reach and open, and what's inside of them?
- [ ] Can your child climb to reach others?
- [ ] Which items need to be moved and which cabinets need to be secured?
- [ ] For those that need to be secured, what type of handle/knob do they have?

Electrical and Miscellaneous

- [ ] Are there wires that your child can reach?
- [ ] Are there outlets that need to be covered to improve safety?
- [ ] Do you have blinds with long cords that could pose a safety risk?

Stairs

- [ ] Is your child able to freely access the stairs?
- [ ] Can they safely navigate them in both directions?
- [ ] Is there a railing for them to hold?

Small and/or Toxic Items

- [ ] Are there accessible nonfood items that your child might put in their mouth?
- [ ] Are some of them small enough to be a choking risk?
- [ ] Are some toxic if ingested?
- [ ] How can these be secured to improve safety?

Hazardous Items

- [ ] Where do you store items such as medications, cleaning supplies, pet food, knives, scissors, other sharp objects, firearms, matches, lighters, alcohol, cannabis, or other items that may pose a safety risk?
- [ ] How can you ensure that these items are always secured and out of reach?

Sharp Edges

- [ ] Do you have tables, cabinets, furniture, bricks around a fireplace, or other items with sharp edges that could potentially injure your child?

Outdoor

- [ ] Do you have a pool and is it secured?
- [ ] Is there a pond or other body of water on or near your property?
- [ ] Are there tools or outdoor appliances that are accessible to your child?
- [ ] Is there a shed or other storage area where the child could hide or become trapped?
- [ ] If your yard is fenced, is your child able to open the gate(s)?

Making a Safety Plan

Now that you have gathered information and gained a clearer understanding of potential safety risks, you can make a plan to address them. Consider the following questions:

What needs to be done in my home and yard?

- What needs to be locked or otherwise secured?
- Do I need alarms for entry/exit points?
- Are there visual aids that would help, such as laminated stop /go signs?
- What needs to be moved?
- What needs to be installed?

What else will help keep my child safe?

- Should my child wear an ID tag and/or GPS tracker?
- Do I need safety items for the car?
- Does my child need swimming lessons?
- Do I and/or other caregivers need First Aid and CPR Training in case of choking or other emergencies?

What specific items or services need to be purchased or otherwise obtained?

- What locks and security features will be compatible with my home's specific doors, windows, cabinets, appliances etc.?
- What will be secure enough that my child can't remove or unlock it?
- What kind of ID tag and/or GPS tracker will my child tolerate wearing?

What will I, and other caregivers, do in the meantime to keep my child safe?

Taking Action

Here are examples of items, actions, and services that may enhance safety. Please keep in mind that all may not apply to your family and there may be additional things you need:

Needed	Not Needed		Completed
○	○	Out of reach locks for all exterior doors (including sliders) and windows	
○	○	Out of reach locks for interior doors as needed	
○	○	Alarms for doors and windows	
○	○	Visual aids such as red “STOP” and green “GO” signs or stickers	
○	○	Anchors to secure all furniture (including TVs) to the wall	
○	○	Adjustments to furniture type and layout to decrease climbing	
○	○	Removal of furniture such as storage chests that could trap your child inside	
○	○	Locks for appliances such as the refrigerator, freezer, oven, dishwasher, washing machine, dryer, and toilet	
○	○	Rearranging of cabinets and other storage areas to ensure hazardous items are out of reach and secured	
○	○	Cord protectors to hide cords and cables	
○	○	Outlet covers	
○	○	Cord cleats, winders, or retractors to keep long cords of window blinds out of reach	
○	○	Child-height railing for stairs	
○	○	Safety gates for the top and bottom of staircases	
○	○	Removal of small items that pose a choking hazard	
○	○	Removal of potentially toxic items that your child may put in their mouth	
○	○	Safe and durable sensory chew toys	
○	○	Out of reach lock for gates that serve as entry/exit points to the yard	

Needed	Not Needed		Completed
○	○	Secure storage for hazardous items such as medications, sharps, firearms, cleaning supplies, matches and lighters, pet food, alcohol, and other substances	
○	○	Soft bumpers/edge protectors for sharp edges of furniture, fireplace bricks, etc.	
○	○	Exterior fencing	
○	○	Out of reach lock for pool gate	
○	○	Out of reach lock for gates that serve as entry/exit points to the yard	
○	○	Removal of tools, grills, and other hazards from areas accessible to your child	
○	○	Out of reach locks for sheds and other outdoor storage	
○	○	ID tag or bracelet for your child	
○	○	GPS tracking device for your child	
○	○	Seatbelt buckle guards	
○	○	Child safety harness	
○	○	Portable/removable locks and alarms for doors in hotels or other homes	
○	○	Swim lessons for your child (and caregivers if applicable)	
○	○	First Aid and CPR Training for all caregivers	
○	○	Clear safety plans for both inside and outside the home for all potential caregivers	
○	○	Safety checklist to use when visiting new places	

Find us online at

ANNAAUTISMCARE.COM

ANNAAUTISMCARE.COM

intake@annaautismcare.com / (617) 693-5767

Multiple center locations
in Massachusetts
Open between 8:00am - 4:30pm

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