



Navigating Autism Supports and Services

A guidebook for parents and caregivers

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For accessible formats of this information or assistance with additional equal access to human services, write to ASD.DHS@state.mn.us, call 651-431-4300, or use your preferred relay service. ADA1 (2-18)

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Questions about your child's development?

Because every child is unique, each learns and grows differently. However, children also tend to develop in similar ways. These developmental milestones can help parents and caregivers act if something is not quite right. If you're wondering whether your child's development is typical or not, learn about developmental milestones, then ask a doctor or other specialist. Don't wait. Early intervention programs can make a big difference.

The [First Steps: Pathway to learning, playing and growing, DHS-6751L \(PDF\)](#) provides a summary of key developmental milestones that babies and toddlers should be achieving. It also has tips, tools and guidance to help your child's development. In addition, it describes what resources are available to parents and caregivers who have questions or concerns about their child's development.

You can also [screen your child](#) and take the results with you to your doctor's appointment to help you feel prepared for the conversation. Before the visit you can explore [Help Me Grow Minnesota](#) to access services and supports through your local school district. You do not need a referral or a medical diagnosis to access these resources.

Medical diagnosis and next steps

After you or your child receives a diagnosis of autism spectrum disorder (ASD), the next step is to identify available services and supports. People with ASD or related conditions may need a variety of supports and services over the course of their lifetime.

With so many different therapy options available, choosing services that are right for your child and family can be overwhelming. The amount of information you receive and decisions you have to make can be a complicated process and confusing at times.

Here are six steps to help you navigate the process:

1. Get organized
2. Educate yourself
3. Set goals for your child and family
4. Explore program eligibility rules and healthcare coverage options
5. Ask questions to get services and supports that work for you and your child
6. Call on your natural and existing networks for support

Get organized

It can be helpful to keep a record of who is on your child's team. You may be seeing professionals from a variety of disciplines, as well as an educational team and likely staff from the county and advocacy organizations. It can be difficult to keep track of appointments and contact information.

You may also be asked for and receive a lot of information. It may be helpful to develop a system for organizing this information. Some may find it helpful to create a binder or other filing system; while others may use some type of notebook or electronic application. You might be thinking, but I know all that information and I know my child so well. That is true, however, it can be overwhelming when you are being asked questions over and over again.

Have a method for documenting your child's milestones, doctor and other professional recommendations, appointments, concerns, celebrations and for keeping important documents. Keep a record of therapy options you try and how your child responds to each one.

Some find it helpful to maintain a log of the calls and messages you have received and sent. Find a scheduling or calendar system to help you keep track of all these meetings, and to serve as a reference. You will be serving as your child's primary case manager and lifelong advocate. Staying organized will help you.

Educate yourself

It is important to have a solid understanding of autism spectrum disorder (ASD), including the signs and symptoms, screening and diagnostic procedures, core symptoms, intervention methods and evaluations of their outcomes. Even though you may hear conflicting recommendations from parents, teachers, and other professionals, listen to what they say. Then, do your own research and determine the best options for your child and family. Never be afraid to ask questions.

- Visit the [Minnesota Autism Resource Portal](#) on the internet. It has a lot of helpful information and resources.
- Take the online [ASD Strategies in Action](#) training. Request a free subscription by contacting ASD.DHS@state.mn.us
- Read books
- Read research articles
- Determine your eligibility and healthcare coverage options
- Review information and resources that summarize your options.

Set goals for your child and family

Professionals and educators will set goals for your child, however it is important for you to also determine what goals are a priority for you and your family. Ask yourself what skills you would like to develop or enhance as a parent or caregiver to best meet your child's needs. Write these goals down and bring them to treatment planning meetings.

Monitor your child's progress with these goals. This will help you make decisions about your child's intervention plan. If you don't see progress in these goal areas, this is important to discuss with your child's intervention provider. Changes may need to be made. It is also important to keep track of changes at home, such as a new diet or supplement or any significant changes to the child's home life such as a sibling being born or a move.

Explore program eligibility rules and health care coverage options

Almost all services and supports have rules about who is eligible to receive them. Many programs charge fees. Programs and services can be organized into three categories.

- **Educational services:** The first step to receive services through schools is to request an educational determination. This means the school arranges for a specialist to assess your child. If the assessment shows your child could benefit from additional educational services, an Individualized Education Plan would be written to specify different services and supports your child needs. For more information, download [Overview of Medical Identification and Educational Determination of ASD DHS-6751M \(PDF\)](#)
- **Medical identification:** The first step here is to schedule an appointment with your child's primary medical doctor to discuss your concerns. Some children benefit from services that are considered part of health care. These can include speech therapy, occupational therapy and physical therapy. For these, you will need to get a referral from your child's doctor. Some private health insurance plans will cover the costs of these services. If not, families can apply for Medical Assistance (MA). If you qualify, MA will pay for special services and supports for your child. If your income is too high, you may be able to pay a monthly fee and have your child's health care covered through a federal government plan called [TEFRA](#). More information about the medical pathway is also in [Overview of Medical Identification and Educational Determination of ASD DHS-6751M \(PDF\)](#)
- **Home and community services:** The first step here is to talk to someone at your county or tribal social services office and see if your family would benefit from a case manager. Case managers help people with developmental disabilities and behavioral health conditions. They assess a person's needs and help connect the person and family to appropriate community resources. They use a tool called the MnChoices Assessment and Support Plan. It helps identify potential services, such as personal care assistance (PCAs), the Early Intensive Development and Behavioral Intervention (EIDBI) benefit and more.

Ask questions to get services and supports that work for you and your child

Selecting services and supports should be based on your child and family's unique strengths and needs. The [Next Steps: Pathway to services and supports for a child recently identified with ASD, DHS-6751J \(PDF\)](#) helps parents and caregivers understand options for their child and what action steps to take in the first year after diagnosis.

The [Pathway to Services and Supports for Autism \(PDF\)](#) provides resources and support information from across health, education and community based resources. The Pathway resource can help anyone at any stage or at any age. The Pathway is also available in [Hmong](#), [Oromo](#), [Somali](#), [Russian](#), [Vietnamese](#), [Karen](#) and [Spanish](#) as well.

The National Research Council recommends intensive therapy to help children with ASD reach their best outcomes. Research intervention options to help you determine with services and supports are right for your child and family. See Access services and supports.

Keep in mind that what may be effective for one child or family, may not be as effective for another. These are important questions to consider before choosing an intervention service.

- Is this intervention method supported by research? In other words, is there scientific evidence to show that this method is effective and validated? There are several sources to help you decide:
 - American Academy of Pediatrics: [Identification, Evaluation, and Management of Children with Autism Spectrum Disorders \(Clinical Report\)](#)
 - Centers for Disease Control and Prevention: [Autism Spectrum Disorder Recommendations and Guidelines](#)
 - [Autism Focused Intervention Resources and Modules](#)
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- What are the advantages and disadvantages of this therapy?
- Is this intervention a good fit for our family? There are many important factors to consider when evaluating intervention services.

- For instance, is the time commitment conducive to your family life? For example, if all caregivers must work, a home-based service during the day isn't likely the best approach.
- In addition, some services are provided in a clinical setting, whereas others are provided in the home. You must consider where your child and family has the most needs and decide where the best environment is for your child to access services. In addition, some therapy approaches are offered in a more structured setting that help to minimize distractions, while others are offered in a more natural play-based setting.
- Cost involved
 - How much does the therapy cost?
 - Are there additional costs to consider (e.g., materials for programming, transportation costs, etc.)?
 - Is this therapy covered by your insurance?
- Does the therapy align with the goals you would like to accomplish for your child and family?
- Is this intervention method appropriate for my child's age and abilities?

Once you have decided on what type of intervention method(s) is appropriate for your child and family, there may be additional considerations when choosing a service provider. There are several intervention providers across the state.

- Is there a provider in my area?
- Will my child need transportation?
- What insurance plans do they accept?
- Do they specialize in ASD?
- What age groups do they serve?
- Do they have a wait time for appointments?
- How successful has the program been for other children? Do they have testimonials or data to support their outcomes? Do they provide regular progress monitoring updates and make program changes and updates based on analysis of data and outcomes of assessments and evaluations.
- Do the staff have education and experience in working with children, youth and young adults with ASD? It is best to have a supervisor or lead therapist that is specifically licensed, certified or trained in the intervention therapy they claim to offer at their agency.
- Do they allow parents and caregivers to be present and observe or participate in therapy service?

- Do they offer family/ caregiver training and counseling services? Does the provider value parent and caregiver input at every step of the treatment planning process?

There are also medications, as well as other types of therapies and supports that may be beneficial to consider. For more information on how to find a provider, visit [Service providers](#).

Keep in mind that these therapies may have varying levels of research to support their effectiveness.

Questions to consider as you evaluate your therapy provider(s):

- Do the provider's goals align with the goals you have for your child and family?
- Do you notice your child demonstrating progress in their day to day activities?
- Does this therapy help to alleviate stress on your family and educate you on helpful strategies you can implement into your daily routines?
- Do you have a functional working relationship and open communication with your child's provider?
- Is your child maintaining and generalizing skills they learn from therapy? This means that they are able to demonstrate the skills they learn across a variety of settings, people and materials, as well as continue the skills over a period of time.
- Do they tailor the treatment plan to the specific needs of my child and family? Do they respect you and your child by listening and adjusting goals or procedures when you have concerns?
- Does your child seem happy when interacting with the provider(s) and appear to be developing helpful skills for them to build independence and functional communication?
- Try out different therapy services and options. Every child is different and will respond differently to different services and supports. You have to determine what is best for your child and family. If you have any concerns, talk to your provider and team. If things don't change, then it may not be the right fit.

Preparing for transition

[Transition](#) can be a challenging time for young people and their families because there is so much unknown. Learning about the resources and supports available, along with the changes that occur when a person enters into adulthood, can help everyone feel more prepared. It is never too early to start preparing for transition into adulthood. The [Next Stage: Pathway to Transition and Long-Term Services and Supports for ASD, DHS-6751K, \(PDF\)](#) outlines resources available to young adults and adults as they transition into independent living and the work world.

Call on your natural networks for support

Caring for a child with special needs demands a lot of your time and energy. There are resources in your own community to assist your child and family. This might include advocacy organizations, your local county or tribal office.

In addition, it is critical to include supportive family members, friends, support groups, community organizations and faith-based organizations if you would like. Joining support groups may connect you to other parents and caregivers who have been through similar experiences as you and who may be feeling similar emotions. They can offer advice and be a shoulder to lean on for support. These people may also be able to provide you with respite support to allow you the opportunity to take a break or a few hours or days when needed. You may want to explore online support groups or in person [support groups](#) to help you learn from other parents on a similar journey. There are also a variety of online groups through social media platforms such as Facebook.

Remember to take time for yourself. You can't and shouldn't do everything on your own. Don't be afraid to ask for help. If the stress is becoming overwhelming and you are feeling anxious or depressed, seek out individual, marital or family counseling to help work through some of the challenges.

For more information and other resources, see the [Minnesota Autism Resource Portal website](#). For questions, email ASD.DHS@state.mn.us.