AutismHearts

Autism Resource Directory

New Autism Diagnosis Roadmap

7 Practical Steps for Parents & Caregivers

From AutismHearts – Autism Resource Directory

autismhearts.com

Welcome – A roadmap for the first months after diagnosis

When you first hear that your child is autistic, you are given important information—but often very quickly. There may be new terms, long reports, and multiple recommendations, all arriving at once. It is completely normal to feel overwhelmed, confused, relieved, worried, or all of these at the same time.

This roadmap is designed to help you move through the early months after a diagnosis in clear, practical steps. You do not need to follow every step in a perfect order, and you do not need to become an autism expert overnight. Instead, you can use these seven steps to decide what to focus on now, what can wait, and where to find support for your child and your family.

Each step is written in plain language and includes questions you can ask professionals, along with simple worksheets you can print or fill out. At the end of the guide, you will find ways to connect with autism services, support groups, and state-specific resources through AutismHearts, so you can move from information to action.

How to use this guide

- Read one step at a time.
- Circle or highlight ideas that feel most relevant now.
- Use the worksheets to organize information and questions.
- Return to sections as your child's needs and supports evolve.

Step 1: Responding to the diagnosis

When you receive an autism diagnosis, you are not just hearing a label—you are being given a framework for understanding how your child experiences the world. That can be both helpful and emotionally heavy.

Many parents feel a mix of emotions: shock, worry, relief, sadness, guilt, or even validation if they have suspected autism for some time. None of these feelings mean you are a bad parent. They are simply understandable reactions to important news.

It is also common to look back and wonder if you missed signs or could have done something differently. It can help to remember that you did not cause your child's autism. Autism is a neurodevelopmental difference, not the result of something you said, did, or didn't do.

In the first days and weeks, give yourself permission to slow down. You do not have to solve everything right away. Start by identifying one or two trusted people you can talk to openly—such as a partner, close friend, or family member—who can listen without judgment. Sharing your feelings in a safe space can make it easier to move from shock and worry toward practical action.

You may also find it helpful to write down what you are feeling. Putting thoughts into words, even briefly, can make them more manageable and gives you something concrete to bring to appointments or support groups. At the same time, it can be grounding to list your child's strengths and interests: what they enjoy, what they are good at, and what makes them unique. These reminders show that the diagnosis adds information; it does not replace who your child is.

Right now, I feel...

My child's strengths and interests...

Step 2: Understanding evaluations and reports

An autism diagnosis usually follows careful evaluations rather than a single quick test. These evaluations are designed to build a detailed picture of your child's development.

Depending on your child's age and location, different professionals may be involved: developmental pediatricians, child psychologists, neurologists, speech-language pathologists, occupational therapists, or other specialists. They may gather information from:

- Your child's developmental and medical history
- Observations during play and interaction
- Questionnaires and checklists you complete
- Standardized assessments of communication, social skills, and behavior
- Input from teachers or other caregivers, when available

After the evaluations, you typically receive a written report. These reports can be long and technical, and it is very common for parents to feel intimidated when they first read them. Most reports, however, follow a similar structure:

- Background and history
- Observations and behavioral descriptions
- Test or checklist results
- Diagnostic impressions
- Recommendations for supports and services

When you first read the report, it may help to focus on a few key areas rather than trying to absorb every detail at once. Many parents begin with the sections that describe strengths and interests, because they show what is going well and what can be built on. Next, you can look at the sections describing specific challenges, such as communication differences, social interaction, repetitive behaviors, or sensory sensitivities. Finally, pay close attention to the recommendations—they explain what kinds of support the professionals believe will help your child most at this stage.

You do not need to understand every technical term. It is perfectly okay to underline or highlight words and phrases that are unclear and bring them to your next appointment. Consider writing down questions such as: *"Can you explain this result in everyday language?"*, *"What do you see as our top three priorities over the next six months?"*, or *"Which recommendations should we start with, given our child's age and our family situation?"*

Evaluation and report summary

My child's strengths

Main challenges described in the report

Recommended supports and services

- **Therapy or programs:** _____
- **School supports:** _____
- **Other recommendations:** _____

Questions I still have for providers

Note: You can share this page with school staff, therapists, or other caregivers so everyone is working from the same understanding.

Step 3: Building your child's support team

No parent is expected to do everything alone. Over time, most families build a team around their child, with different professionals and supports each playing a role.

Common members of a support team include:

- **Healthcare providers** such as pediatricians, developmental pediatricians, neurologists, or other specialists.
- **Therapists** such as speech-language pathologists, occupational therapists, behavioral specialists or ABA providers, and leaders of social skills groups.
- **School staff** such as classroom teachers, special education teachers, school psychologists, and counselors.
- **Family and community supports** such as extended family, parent support groups, respite care providers, and local autism organizations.

It can be helpful to start by listing the people who are already involved and then identify gaps where you may want to seek additional support. You might find that you have strong healthcare connections but need more school support, or that you have a helpful school team but want to add therapy or community resources.

A simple visual—your child's name in the center, with circles around them for "Healthcare," "Therapies," "School," and "Family & Community"—can help you see where support is strong and where it can grow.

AutismHearts can help you identify and connect with new members of your team. You can search for diagnostic centers, therapists, schools, and support groups in your area, and then use the contact information to reach out and learn more about how each provider works.

My child's support team

Use this table to track your providers and contacts as your team grows:

Role	Name	Organization	Phone / Email	Notes
Pediatrician				
Speech Therapist				
Occupational Therapist				
Teacher / School Contact				
Support Group / Community				
Other				

Step 4: Therapies and services overview

Many families hear about several therapy options at once, which can feel confusing. Understanding the basics can help you decide what to explore first based on your child's needs.

Here is a brief overview of common supports:

Speech-language therapy

- Focuses on communication, including understanding language, using words or alternative communication methods, and social communication.
- Often helpful when a child struggles to understand what is said to them, has limited speech, or finds back-and-forth conversations difficult.

Occupational therapy (OT)

- Focuses on daily living skills and sensory processing, such as fine motor skills, handwriting, dressing, eating, and coping with sensory input like sounds, textures, or movement.
- Often helpful when a child has difficulty with clothing, food textures, motor tasks, or becomes easily overwhelmed by sensory experiences.

Behavioral support / ABA

- Focuses on teaching new skills and building more useful patterns of behavior through structured support and reinforcement.
- Practices vary widely; families can look for approaches that prioritize the child's comfort, consent, communication, and wellbeing, and that involve parents in planning.

Social skills groups and developmental programs

- Focus on practicing interaction, play, flexibility, and understanding social cues, often in small groups of peers.
- Often helpful when a child wants friends but struggles to connect, or finds group settings challenging.

Choosing where to start

You do not need to choose all therapies at once. You can start by asking:

- Where does my child seem to struggle most right now—communication, sensory experiences, daily tasks, behavior and routines, or social connection?
- What does our current evaluation report recommend as priority supports?
- What is realistic for our family in terms of time, travel, and cost?

Quick Guidance

- If **communication** is the biggest concern, consider beginning with speech-language therapy.
- If **sensory and daily living issues** are central, consider occupational therapy.
- If **safety, aggressive behaviors, or very rigid routines** are central, consider behavioral support.
- If **social connection and peer interaction** are central, consider social skills groups.

To find providers offering these supports near you, use the AutismHearts directory to search by service type and location at `autismhearts.com`.

Step 5: School support, IEP/504, and rights

School is an important part of your child's life, and autism can affect how they learn, participate in class, and interact with peers. Many autistic students qualify for additional support through an Individualized Education Program (IEP) or a 504 Plan.

In simple terms:

- An **IEP** is a legal document that outlines special education services, specific learning goals, and related services for students who meet certain criteria.
- A **504 Plan** is a document that provides accommodations and supports to ensure equal access, without special education goals.

These plans may include:

- Instructional goals based on your child's needs
- Accommodations such as extra time, sensory breaks, visual supports, or seating changes
- Related services such as speech therapy, occupational therapy, or counseling provided at school

Preparing for school meetings

To prepare for school meetings:

- Bring copies of evaluation reports and any medical or therapy information that helps explain your child's needs.
- Write down your child's strengths so they are clearly recognized during the meeting.
- List your main concerns and questions, such as *"What supports will help my child stay in class and learn?"* or *"How will we communicate regularly about my child's progress?"*

School meeting prep checklist

- ☐ I have gathered reports and notes.
- ☐ I have listed my child's strengths.
- ☐ I have listed my concerns and questions.
- ☐ I know who will be at the meeting.
- ☐ I have a place to write notes during and after the meeting.

Notes and Action Items

Step 6: Everyday life – sensory needs, meltdowns, and routines

Daily life continues after a diagnosis; what changes is your understanding of why certain situations are hard. Many autistic children experience sensory differences—being more sensitive or less sensitive than other children to sounds, lights, textures, movement, or touch.

You can begin by noticing:

- What seems to trigger discomfort or distress (e.g., loud stores, crowded events, certain fabrics, bright lights).
- What seems to help your child feel calmer or safer (e.g., favorite objects, quiet spaces, headphones, weighted blankets, predictable routines).

It can also help to think about the difference between a meltdown and a tantrum. A meltdown is usually a loss of control due to sensory overload, stress, or frustration, while a tantrum is more often a way to try to get a specific outcome. Understanding this difference helps you respond with safety, comfort, and support rather than punishment when your child is overwhelmed.

Routines and sensory planning

Routines can make daily life more predictable and less stressful. You do not need complicated systems—simple, consistent patterns can make a big difference. For example:

- **A morning routine** with clear steps: get dressed, eat breakfast, brush teeth, put on shoes.
- **A bedtime routine** with the same sequence of quiet activities each night.
- **Transition routines** for leaving the house or moving between activities.

Visual supports, such as picture schedules or simple charts, may help your child understand and follow routines.

Things that upset or overwhelm my child

Things that help my child feel calmer

Our morning routine

Our bedtime routine

Step 7: Caring for yourself and finding support

You are an essential part of your child's support system, and your wellbeing matters. Caring for an autistic child can be deeply rewarding, and it can also be emotionally and physically demanding over time.

It is common for parents to feel exhausted, isolated, or worried about the future. Taking care of yourself does not mean ignoring your child's needs. It means recognizing that you are more able to support your child when your own needs are at least partly considered.

Realistic self-care might include:

- Short breaks when another adult can step in, even briefly
- Regular check-ins with a friend, family member, or support group
- Attending a parent support group (in person or online) where others understand your experience
- Speaking with a counselor or therapist if you feel persistently overwhelmed, anxious, or depressed

Needing support is not a sign of failure—it is a normal response to ongoing demands.

Caregiver support planner

You may find it helpful to:

- Write down a few small things that help you feel more settled (e.g., a walk, reading, a quiet cup of tea, talking to someone who listens).
- Identify at least one parent support group or online community that feels respectful and helpful.
- Consider reaching out to professionals who specialize in supporting caregivers.

You can use AutismHearts to search for:

- Parent and caregiver support groups
- Counseling and mental health services
- Respite care and other family support services

Ways I can take small breaks

People I can talk to when I feel overwhelmed

Support groups or communities I want to explore

Toolkit: Feelings & strengths review

My feelings reflection

My child's unique strengths and passions

Toolkit: Daily routine planner

Morning Flow

Afternoon / Transition Flow

Evening & Bedtime Flow

Toolkit: Sensory triggers & calming strategies

Sensory Triggers (Sounds, lights, textures, crowds)

Calming Strategies & Safe Spaces

Taking next steps with AutismHearts

As you move through these seven steps, you will likely reach points where you are ready to connect with specific services and supports. AutismHearts exists to help you find trustworthy autism resources more easily.

On AutismHearts, you can:

- Search autism services near you, including diagnostic providers, therapists, schools, adult services, and support groups
- Browse resources and services by state
- Discover support groups and parent resources
- Learn about screening tools and other helpful information

You can visit `autismhearts.com` to begin searching for services and supports that fit your child and family.

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