

# Next Steps...

What to do after your child receives an  
autism spectrum disorder diagnosis



**HANDS in Autism**

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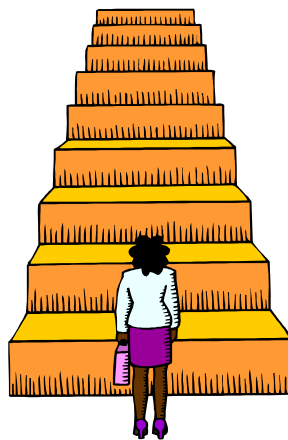


# What to do After the Diagnosis

This manual contains a wealth of information for caregivers of children with a Pervasive Developmental Disorder (PDD). Although the medical term for these disorders is Pervasive Developmental Disorders, many people call them Autism Spectrum Disorders (ASD). The terms ASD and PDD will both be used in this manual. The manual is divided into five major sections or chapters:

- Step 1: Information on Pervasive Developmental Disorders
- Step 2: Information on Family Life
- Step 3: Information on Available Support
- Step 4: Information on Rights and Regulations
- Step 5: Information on Education and Intervention Options

Each section is set up the same way. First is a cover page that gives a brief overview. Next are articles written for caregivers and information written for professionals but that may also be useful to caregivers. You'll find information about future steps you can take, including resources to seek out. Finally, each section has a summary that reviews the important points.



## My child was diagnosed with a Pervasive Developmental Disorder... now what?

Raising a child with a diagnosis on the autism spectrum is not the same today as it was 10 or 20 years ago. Then, there was relatively little known about these disorders. Today, there are many interventions and treatments available, there are many professionals who know how to work with children on the autism spectrum, and there is a lot that can be done to help your child reach his or her potential. Many specialized services and professionals are available to help your child, and often it is easier to obtain these services for your child once he or she has an autism spectrum diagnosis. So rather than focusing on all that you've lost since your child has been diagnosed, try to think of all you've gained. If you haven't already been receiving services through First Steps (if your child is under 3) or through the school system (if your child is over 3), you can now seek those services out. You can apply to receive services through the Medicaid Autism waiver. You can work with autism spectrum specialists to help your child be his or her best. Before you had the diagnosis for your child, your time was likely focused on getting answers about why your child behaved differently than you expected. Now that you've gotten the answer you needed, you can start the process of helping your child.

The information in this manual is designed to help you help your child. The manual is divided into 5 chapters or steps that you'll need to take, one at a time.

The first step you'll need to take is to learn all you can about your child's diagnosis. There is a wealth of information available about Autism Spectrum Disorders, and the more you know the more you can fight for all that your child will need. Learn the diagnostic criteria. Learn the facts about your child's diagnosis. Learn all you can about this new diagnosis that will likely become a large part of your everyday life.

Next, address how this diagnosis will affect everyone in your family. You and the other caregivers who care for your child may each react differently to this diagnosis. That's okay. Rely on one another, take turns being strong, and allow each other to adjust to the diagnosis however works best for each of you. Realize that this diagnosis will affect all of the children in the home. If you have other children, talk to them about the diagnosis and answer their questions as honestly as you can. Make sure that their needs are also being met. Keep in mind that your immediate family does not exist completely separately from the rest of the world. There are likely many family members who love your child and who will all need time to adjust to the diagnosis. Talk to your extended family and explain all the new information you learn about your child and his or her diagnosis.

**Introduction: What to do After the Diagnosis**

Third, realize that you cannot do it alone. Find sources of support. Seek out family and friends who can help you when you're having tough times. Find other parents of children with the same diagnosis. You are not the first one to walk this road; learn from the experiences of others and remember to ask for guidance and help when you need it.

Fourth, organize yourself so you can best help your child. Create a binder with all of your child's evaluations and information. Learn what is available for your child through insurance or Medicaid. Learn your rights and your child's rights. Be sure to start networking with area professionals, especially those at your child's school.

And finally, take all of the information you've gathered and begin making treatment choices for your child. Carefully determine your child's needs, consider the various treatments available, and evaluate which will work best for your child and your family.

Immediately after you receive the diagnosis for your child you may feel overwhelmed. You may feel lost and not know what to do next. This manual will help you figure out what steps to take next and where to go after an autism spectrum diagnosis.

*Helping my Child after the Diagnosis*

There are many steps to take after your child has been diagnosed. This chart can help you to track the steps you take for you and your child. Keep in mind that your needs and your child's needs will change over time. Revisit this document frequently to assess how thoroughly needs are being met.

**Resources for Information – Step 1**

There is a great deal of useful information about Autism Spectrum Disorders available. This attached chart lists some good starting places. Be sure to add others as you learn about them, through this manual or other sources.

Autism Society of America	<b>Contact:</b> www.autism-society.org 1.800.3AUTISM	<b>My Contact:</b>
	<b>Additional Information:</b> Information and local chapters/support groups	<b>Notes:</b>
Autism Society of North Carolina Bookstore	<b>Contact:</b> www.autismsociety-nc.org 919.743.0204	<b>My Contact:</b>
	<b>Additional Information:</b> Books about ASDs for parents, children and professionals	<b>Notes:</b>
Indiana Resource Center for Autism (IRCA)	<b>Contact:</b> www.iidc.indiana.edu/irca 812.855.6508	<b>My Contact:</b>
	<b>Additional Information:</b> Informational support	<b>Notes:</b>
Autism Society of Indiana	<b>Contact:</b> www.inautism.org/ 317.695.0252	<b>My Contact:</b>
	<b>Additional Information:</b> Support and advocacy	<b>Notes:</b>
HANDS in Autism	<b>Contact:</b> www.handsinautism.org 317.274.8162	<b>My Contact:</b>
	<b>Additional Information:</b> Information and events	<b>Notes:</b>
	<b>Contact:</b>	<b>My Contact:</b>
	<b>Additional Information:</b>	<b>Notes:</b>

**Family Life – Step 2**

Keep in mind that your family and friends will need time to react to your child's diagnosis as well. They will also be able to help you as part of your support system.

Ask friends and family how each one thinks he/she can best help so you know who to go to for each need.

	<b>Contact:</b>	<b>Relationship:</b>
	<b>Helps With:</b>	<b>Notes:</b>
	<b>Contact:</b>	<b>Relationship:</b>
	<b>Helps With:</b>	<b>Notes:</b>
	<b>Contact:</b>	<b>Relationship:</b>
	<b>Helps With:</b>	<b>Notes:</b>
	<b>Contact:</b>	<b>Relationship:</b>
	<b>Helps With:</b>	<b>Notes:</b>
	<b>Contact:</b>	<b>Relationship:</b>
	<b>Helps With:</b>	<b>Notes:</b>

**Create a Support Network – Step 3**

Having a child with autism can be overwhelming. It is important to take time for yourself and to be sure you have the supports you need. Some ways to ensure you do that are included on the chart.

IRCA Respite Provider List	<b>Contact:</b> <a href="http://www.iidc.indiana.edu/irca/ServArticles/respitedir.html">http://www.iidc.indiana.edu/irca/ServArticles/respitedir.html</a>	<b>My Contact:</b>
	<b>Additional Information:</b> Listing of respite care providers, who allow parents a break from childcare.	<b>Notes:</b>
Autism Society of America; Local ASA Chapter	<b>Contact:</b> <a href="http://www.autism-society.org">www.autism-society.org</a> 1.800.3AUTISM	<b>My Contact:</b>
	<b>Additional Information:</b> Support and information	<b>Notes:</b>
Autism Society of Indiana	<b>Contact:</b> <a href="http://www.inautism.org/">http://www.inautism.org/</a> 317.815.0859	<b>My Contact:</b>
	<b>Additional Information:</b> Support and information	<b>Notes:</b>
Safety Store	<b>Contact:</b> <a href="http://www.preventinjury.org">www.preventinjury.org</a> ; Safety Store at Riley: 1.888.365.2022	<b>My Contact:</b>
	<b>Additional Information:</b> Car safety; supplies for child-proofing homes	<b>Notes:</b>
About Special Kids (ASK)	<b>Contact:</b> <a href="http://www.aboutspecialkids.org">www.aboutspecialkids.org</a> 317.257.8683	<b>My Contact:</b>
	<b>Additional Information:</b> Advocacy	<b>Notes:</b>
IN*Source	<b>Contact:</b> <a href="http://www.insource.org">www.insource.org</a> 1.800.332.4433	<b>My Contact:</b>
	<b>Additional Information:</b> Advocacy	<b>Notes:</b>

Family Resource Center (Riley)	<b>Contact:</b> 317.274.1149 317.278.1645	<b>My Contact:</b>
	<b>Additional Information:</b> Information resources, computer programs	<b>Notes:</b>
ISTAR and PATINS	<b>Contact:</b> Department of Education (DOE)	<b>My Contact:</b>
	<b>Additional Information:</b> Specific program for technology assistance	<b>Notes:</b>
HANDS in Autism	<b>Contact:</b> www.handsinautism.org 317.278.7839	<b>My Contact:</b>
	<b>Additional Information:</b> Free workshops, and seminars	<b>Notes:</b>
Arc of Indiana	<b>Contact:</b> <a href="http://www.arcind.org/">http://www.arcind.org/</a> 800.382.9100	<b>My Contact:</b>
	<b>Additional Information:</b> Advocacy and support for families	<b>Notes:</b>
Place of Worship	<b>Contact:</b>	<b>My Contact:</b>
	<b>Additional Information:</b>	<b>Notes:</b>
	<b>Contact:</b>	<b>My Contact:</b>
	<b>Additional Information:</b>	<b>Notes:</b>
	<b>Contact:</b>	<b>My Contact:</b>
	<b>Additional Information:</b>	<b>Notes:</b>

**Useful Resources on Rights/Regulations – Step 4**

It is important that you be fully informed about your rights and your child's rights. There are many resources that can provide support or recommendations. Some places to start learning this information are included in the chart.

Americans with Disabilities Act (ADA)	<b>Contact:</b> www.ericec.org/digests/e606.html	<b>My Contact:</b>
	<b>Additional Information:</b> Educational rights	<b>Notes:</b>
Individuals with Disabilities Education Act (IDEA)	<b>Contact:</b> www.ericec.org/digests/e606.html	<b>My Contact:</b>
	<b>Additional Information:</b> Educational rights	<b>Notes:</b>
Section 504, Rehabilitation Act	<b>Contact:</b> www.ericec.org/digests/e606.html	<b>My Contact:</b>
	<b>Additional Information:</b> Educational rights	<b>Notes:</b>
Article 7	<b>Contact:</b> www.doe.state.in.us/exceptional/speced	<b>My Contact:</b>
	<b>Additional Information:</b> Educational rights, Indiana	<b>Notes:</b>
Article 7 Companion Guide	<b>Contact:</b> www.doe.state.in.us/exceptional/speced/pub_LLWP.html	<b>My Contact:</b>
	<b>Additional Information:</b> Educational rights, Indiana	<b>Notes:</b>
Family and Social Services Administration (FSSA)	<b>Contact:</b> www.in.gov/fssa 317.233.9525	<b>My Contact:</b>
	<b>Additional Information:</b> Autism waiver information	<b>Notes:</b>
Wright's Law	<b>Contact:</b> www.wrightslaw.com	<b>My Contact:</b>
	<b>Additional Information:</b> General Understanding of Laws	<b>Notes:</b>

	<b>Contact:</b>	<b>My Contact:</b>
		<b>Notes:</b>
	<b>Additional Information:</b>	
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	<b>Contact:</b>	<b>My Contact:</b>
		<b>Notes:</b>
	<b>Additional Information:</b>	

**Assessments and Interventions – Step 5**

Children with autism may have skills at various levels, so it is important to carefully assess each skill or type of skill separately. There are many types of assessments and evaluations available. Once you have a good picture of your child’s specific strengths and weaknesses, you will be able to determine which specific services your child may need. You may need to involve a wide range of specialists and professionals to best meet your child’s needs. Some assessments and interventions that you may want to consider are included in the chart, but feel free to add other types of assessments and interventions beyond what is included here.

First Steps	<b>Contact:</b> http://www.in.gov/fssa/ddrs/4964.htm1.800.441.STEP	<b>My Contact:</b>
	<b>Additional Information:</b> Therapy/services to children under 3 years old	<b>Notes:</b>
School System	<b>Contact:</b> www.doe.state.in.us Local school	<b>My Contact:</b>
	<b>Additional Information:</b> Education and therapy to children 3-21	<b>Notes:</b>
Department of Education	<b>Contact:</b> www.doe.state.in.us 317.232.6610	<b>My Contact:</b>
	<b>Additional Information:</b>	<b>Notes:</b>
Psychologist	<b>Contact:</b> School psychologist, clinical psychologist	<b>My Contact:</b>
	<b>Additional Information:</b> IQ and adaptive testing	<b>Notes:</b>
Geneticist	<b>Contact:</b> Geneticist, Referral from Primary Care Physician	<b>My Contact:</b>
	<b>Additional Information:</b> Information regarding genetic abnormalities	<b>Notes:</b>
Occupational Therapist	<b>Contact:</b> Occupational therapist, behavior therapist, school	<b>My Contact:</b>
	<b>Additional Information:</b> Therapy for sensory and fine motor concerns	<b>Notes:</b>

Physical Therapist	<b>Contact:</b> Physical therapist	<b>My Contact:</b>
	<b>Additional Information:</b> Therapy for gross motor concerns	<b>Notes:</b>
Speech/ Language Therapist	<b>Contact:</b> Speech Language Pathologist, psychologist	<b>My Contact:</b>
	<b>Additional Information:</b> Therapy for pragmatics, social/functional language	<b>Notes:</b>
Educator	<b>Contact:</b> Special educator, school psychologist	<b>My Contact:</b>
	<b>Additional Information:</b> Focus on school-based skills, setting/ measuring IEP goals	<b>Notes:</b>
Medical Doctor	<b>Contact:</b> Psychiatrist, neurologist, pediatrician	<b>My Contact:</b>
	<b>Additional Information:</b> Medication management for behavior concerns	<b>Notes:</b>
Medical Specialist	<b>Contact:</b> Varies by specialty, contact primary care physician	<b>My Contact:</b>
	<b>Additional Information:</b> Assessment to rule out additional physical and/or adaptive challenges	<b>Notes:</b>
Dietician	<b>Contact:</b> Dietician	<b>My Contact:</b>
	<b>Additional Information:</b> Identification of food allergies, and development of special diets and healthy eating habits	<b>Notes:</b>

Behavioral Support Specialist	<b>Contact:</b> Autism/behavior consultant: school, mental health center, Christian Sarkine Autism Treatment Center	<b>My Contact:</b>
	<b>Additional Information:</b> Therapy to teach skills, adapt environment, behavior intervention	<b>Notes:</b>
Social Skills Therapist	<b>Contact:</b> Psychologist, behavior specialist, special educator, Christian Sarkine Autism Treatment Center	<b>My Contact:</b>
	<b>Additional Information:</b> Therapy to teach skills for appropriate interaction	<b>Notes:</b>
	<b>Contact:</b>	<b>My Contact:</b>
	<b>Additional Information:</b>	<b>Notes:</b>
	<b>Contact:</b>	<b>My Contact:</b>
	<b>Additional Information:</b>	<b>Notes:</b>
	<b>Contact:</b>	<b>My Contact:</b>
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	<b>Contact:</b>	<b>My Contact:</b>
	<b>Additional Information:</b>	<b>Notes:</b>







