

What to Do After Diagnosis

Introduction

Having a child diagnosed with autism can be a very emotional and difficult time for a family. The autism spectrum includes a range of different symptoms, skills and levels of disability, and at first, understanding what this means for you and your child can be very confusing. If your child's doctor or teacher suspects that your child may have autism, they are likely to send your child for further evaluation to a developmental pediatrician or clinical psychologist, who will confirm the diagnosis. Once you have a confirmed diagnosis, you will probably receive a lot of information from them about autism.

But where do you go from there? How do you begin to gather all the information you need, and who do you turn to for advice? This module will give you some ideas on how you can embark on this journey.

Taking Care of Yourself

One of the first things you may want to do is to gather your thoughts, and allow yourself some time to go through the many emotions you may be feeling at this time. You may feel depressed, anxious or angry, and many parents go through a grieving process, knowing that this could be a life-altering diagnosis for their child. It is important to take the time you need to come to terms with this. If you share caregiving responsibilities with a spouse or partner, you may both be going through different emotions and may need time to talk about your feelings.

You may also have extended family who interact frequently with your child, such as grand-parents or aunts and uncles, and you should consider how and when you want to talk to them about your child's diagnosis. Your extended family and close friends may be a source of comfort and support for you in the coming months and years. Some families may choose to be open and transparent with extended family, while others may not be ready to share their child's diagnosis. It is entirely your choice, but it is a good idea to discuss this with your partner so that you are on the same page.

Some employers and medical insurance companies offer free or low cost counselling sessions, and this might be an option to exercise if you need some support to cope with your feelings. You can also look for local support groups as they can be a great source of solace and information for you. Some may be state funded and others may be managed by other parents of children with autism. Over time, this new community may become an important part of your daily life. Your pediatrician or Department of Development Services can give you a list of local support groups. You may also find other support groups on social media sites.

Getting the Right Assessments

Now let's take a look at how you can get your child the help they need. Please remember that early intervention is critical for the best possible outcome for your child. Early intervention includes getting your child the right assessments and appropriate therapies to help them develop areas where they may have deficits.

Finding the right kind of care provider and scheduling assessments and follow-up services can be overwhelming at first. **The Individuals with Disabilities Education Act (IDEA) states that all children with disabilities who are three or older, are entitled to receive Free and Appropriate Public Education (FAPE) through the school district.** For children who are younger than 3, IDEA allows children to receive early intervention through state and federal grants.

A good place to start is your state's Department of Developmental Services or your state's Department of Health. Some states have Regional Centers that support people with disabilities. Here, you can request an evaluation for your child and in many cases, they will assign you a case manager to assist you with the process. These assessments are needed to determine what kind of interventions your child will need. Bear in mind that the wait times between requesting an evaluation and receiving services can be long.

Your child may need several types of assessments to determine treatment and services they will require. Here is a partial list of specialists who

provide services for children with autism. It may be useful to review this list with your child's doctor or case manager to ascertain what types of assessments your child needs. This list is not exhaustive and children may need additional assessments depending on their unique needs.

- 1) *Developmental Pediatrician or Clinical Psychologist* - If you haven't already done so, you should have your child see a developmental pediatrician or a clinical psychologist, who can give you a confirmed diagnosis for your child. A confirmed detailed diagnosis is a must for educational purposes as well and to determine insurance coverage and governmental support.
- 2) *Speech and Language Therapist* - Because autism affects many aspects of communication, you will also want to have your child's speech development assessed by a Speech and Language Therapist.
- 3) *Occupational Therapist* - Occupational therapists help individuals develop the skills they need to participate in daily activities. Occupational therapists can work with children throughout their life to develop important life skills and to regulate their sensory responses to the environment.
- 4) *Neurologist* - A neurologist can assess an individual's attention, memory, auditory and visual processing, motor development, behavioral functioning and more. You may want to consider seeing a neurologist if you would like to address specific neurological issues.
- 5) *Applied Behavior Analysis Therapist* – Applied behavior therapy (ABA) is a type of therapy used to bring about positive changes in behavior. It is AN EVIDENCED BASED METHODOLOGY that has been proven to be an effective treatment option for children with autism, and you will need to have your child assessed by a Board Certified Behavior Analyst to begin ABA therapy. You can refer for our module on ABA for more information.
- 6) *School District* – If your child is 3 or older, the school district will also need to conduct an assessment of your child to create an

individualized education plan for them. Please refer to our module on Individualized Education Plans for more information on this process.

- 7) *Hearing and Visual Assessment* – These types of assessments can rule out other contributing factors that may affect a child's development.

Once your child has been assessed, two documents will become extremely important for your child. The first is the Individual Family Service Plan (IFSP) FOR CHILDREN UNDER THE AGE OF 3, and the second is for children 3 or older and is called an Individualized Education Plan (IEP). An IFSP contains a thorough assessment of your child's current level of functioning, and outlines the types of interventions required to improve this level of functioning. This is typically administered through the Department of Developmental Services or a similar agency. An Individualized Education Plan is a legal written document created by your school district for a specific student with special needs, and outlines the education services that the individual should receive in order to meet specific educational goals. For more information about IEPs, please refer to our module in IEPs. These two documents together will determine all the services your child is eligible for.

Funding

Once you have a clearly defined intervention and treatment plan, you will need to figure out how to pay for the services you need. Some of the services that your family will be entitled to will be provided free of cost. Other services will require you to pay a partial amount to supplement state and federal funding, and some services may not be covered, and require you to pay for them. If you have private health insurance, you will need to contact your insurance carrier to determine what they will cover and what you may have to pay for out of pocket but be mindful of co-pays, CO-INSURANCE, and deductibles.

Finding the money to pay for services can be tricky, because each state has different rules on how funds are distributed to people with disabilities. Insurance plans also vary greatly and it may be helpful to meet with a financial planner who is

familiar with special needs to work out a long term strategy for managing your child's financial future.

Conclusion

While the road ahead may seem long, it can help to take it one step at a time. You will need to organize all the information you receive from various care providers chronologically, so that you will be able to access older information easily, and as needed. Using a large binder with tabs can make it easy to store documents. It is important to keep all documentation in one place, as you will need it for insurance as well as for the school district. Another thing to be aware of is that there can be a lot of misinformation available on the internet regarding autism. Unfortunately, some individuals or organizations tout bogus therapies that guarantee that your child will recover from autism. Before you begin any type of intervention, please speak with your child's doctor to discuss whether the treatment is evidence-based and has been proven to work for autism. Also, it is a good idea to check your therapist's credentials and qualifications before starting any type of therapy.

We hope you have found this information useful. We have many other modules with a great deal of information for you, including modules on Treatment Options, Caring for Yourself, Individualized Education Plans, ABA and more. Thank you for taking the time to review this module today.

Suggested Resources:

https://www.autismspeaks.org/docs/family_services_docs/100_day_kit.pdf

<http://www.dds.ca.gov/>

<http://idea.ed.gov/explore>

<https://www2.ed.gov/about/offices/list/ocr/docs/edlitle-FAPE504.html>

We hope that you have found these ideas useful. Remember, creating a special needs trust requires working with a professional who can guide your through the process. You can find additional resources on our website:
www.porchlighteducation.org.