

After Your Child Receives the Diagnosis of an Autism Spectrum Disorder

By Kelly A. Ernsperger, LCSW
Autism Counseling and Behavior Consultation, Inc

It's official. Your child has been diagnosed with an Autism Spectrum Disorder. Now what? For some this is a liberating and justifying confirmation that there is something going on with their child that supersedes all of the nasty stares, rude comments and well intended, yet misguided parenting advice from family, friends and strangers. For others it's a sock in the stomach, smashing all of the hopes and dreams that arrived in the first moments of even finding out that they were going to have a child. Whether your response to the official diagnosis was the first scenario, the second scenario or a mixture of both, most families feel little opportunity to sort through those feelings because everyone is chanting "early intervention".

I don't have time to think about me, I'm already behind! Can I make up for lost time? Is it too late? What does 'early intervention' even mean???

Early intervention begins with information. Your primary role in these first few months after receiving a diagnosis is to find out what are the current best practices in the treatment of Autism Spectrum Disorders and how to put these practices to work for your child, in your community and in consideration of your budget. This is obviously no small feat. The amount of information you are preparing to process is overwhelming at best. Here's the catch. Information has no value if it cannot be retained, organized and used at the appropriate time. It is no secret that cognitive functioning is compromised in times of emotional turmoil such as stress and grief. It only makes sense that attending to your own grief and the emotional needs of your family should be a priority. So if early intervention begins with information, it must start with your own emotional health and the emotional health of your family. Considerations at this stage should include:

- Grieving
- Taking care of yourself physically and emotionally
- Taking care of your adult relationships
- Taking care of the emotional needs of the siblings

Nonetheless, most of you need some concrete goals to pursue in order to feel in control. So *while* you attend to your own emotional needs, the following is a list I created a few years ago to help parents accomplish some beginning tasks.

10 Things to Do after Your Child Has Been Diagnosed With an Autism Spectrum Disorder

Once your child has been diagnosed with an Autism Spectrum Disorder, most parents feel the push for early intervention. Helping your child can often feel overwhelming and confusing. The following is a list of tasks you can employ to stay on track after the diagnosis. While you will receive advice to do many things, some on this list and others not, the following 10 items will keep you moving in the right direction for your child.

1. **Grieve.** This is a step that many families forget to address. Your child is still the beautiful young boy or girl that you've loved for years. This simple fact does not change the reality that some of your dreams for your child may be altered following the diagnosis. Grieving does not mean that you've given up on your child's potential to accomplish great things; it simply reflects that it is o.k. and natural to feel a sense of loss. Denying your own emotional reaction to what lies ahead is non-productive for you, your child and the rest of your family. The energy you are wasting on pushing your emotions aside could be better used in the journey ahead. Take the time to take care of yourself. Caring for yourself is often your last priority when you have a family, but it is most necessary. A strong home cannot be built on a faulty foundation. You are the foundation that your home (your children and spouse, in this case) is built upon. Seeking help is a prudent choice that demonstrates strength in character for recognizing and addressing your own needs. Individual, family and couples counseling is often a wise investment for a family with special needs. (*Sound familiar?*)
2. **Apply for the Medicaid Waiver.** Contact your Bureau of Developmental Disabilities Services and inquire about the Medicaid waivers. Your child most likely qualifies for one or several Medicaid waivers that can help him or her throughout the lifespan. Medicaid Waivers are available **regardless of family income** or the individual's age. Waivers can supply funding for therapy, environmental modification and many other necessities. Unfortunately, the wait lists for the Waivers can be quite lengthy, estimated by some sources to be as long as nine years. Therefore, it is important that you have your child's name added to the wait list immediately. You will be asked to provide demographic information when you make the first call. You will then be mailed a packet to fill out. It can look intimidating, but take a deep breath and dive in. If you fill something out incorrectly, the agency will contact you for clarification.
3. **Educate yourself.** Congratulations, you've just become an expert. Every professional you meet should look to you for guidance on what works best for your child. Your duties will include being your child's greatest advocate. Understanding your child's diagnosis will give you the tools to fight misinformation and the ability to do so with confidence.
4. **Create a binder.** Between doctors, therapists, school and community supports, you will be handling a great deal of paperwork. While your papers may soon grow in numbers significant enough to fill a filing cabinet, keep the most recent information handy in a binder you can take to meetings and appointments with you. Items such as recent reports from the professionals involved in your child's life, copies of the IEP (Individual Education Plan), notes to and from school, current medications and other pertinent information are good items to keep on hand. This will be especially helpful when meeting new members of your child's "team" or when having meetings with the existing team.
5. **Understand your rights.** Know the laws that pertain to your child both in your community as well as at school. Information on the "American's with Disabilities Act" as well as "Article 7" can be obtained on line or at your local library. "Article 7" is the document containing the rules and laws that dictate special education in Indiana. You do not know what to ask for if you do not know what your protected rights are. This is an important document to be familiar with as well as keep in your child's binder. A free copy of Article 7 can also be obtained by contacting the Department of Education. Additionally, the Department of Education can guide you to special education consultants who can answer questions regarding how certain laws pertain to your particular situation.
6. **Partner with your school.** One of the most studied and effective treatments for Autism are educational interventions. Recognizing the importance of such intervention, many parents find themselves in a battle with school personnel over what a free and appropriate public education is for their child. Remember, all of the individuals involved in your child's team want to help children. It is important that all involved respect each other for what one another can bring to the table as a valued part of the team. Respect the

teachers' and administrators' positions as the professionals, attending meetings with questions instead of solutions. As your child's advocate and one and only expert, expect the same respect from these individuals. Use meetings as opportunities to share what your worries and dreams are for your child as well as a time to share what works for your child at home. Your reputation can precede your child, so make a positive impression. Stay in close contact with your child's teacher, asking for reports that provide measurable accounts of what is happening in the classroom. Don't accept "Tommy had a bad day" as a report. Ask the teachers and aids to describe the problems—and successes—with words that are specific, measurable events. Additionally, keep the school aware of any information that may affect your child's day in the classroom. Most importantly, if you feel your child's rights are being disregarded and you are not able to settle the situation personally, contact an advocacy agency that can help by providing a trained individual to attend meetings with you and guide you in your rights and the laws of special education.

7. **Seek out specialists.** Many of the therapists who will be working with your child will be generalists in their field. If you feel these individuals are doing a good job with your child and are happy with the services they are providing, there is no reason to switch therapists. Nonetheless, it would be wise to visit a specialist who is knowledgeable in the field of Autism and can provide recommendations as well as future consult to the professionals you are already seeing. These specialized individuals can offer insight and direction specific to the learning considerations and interventions relevant to their field of practice and Autism Spectrum Disorders.
8. **Join a support group.** This can be a daunting consideration, with visions of strangers sitting in a circle holding hands and crying. This is what support groups look like in the movies, not in real life. Attending a support group often places you at a local school or church where you have an opportunity to listen to a speaker on topics important to you and your child. It's a great opportunity to begin meeting people in your neighborhoods who are struggling with the same issues you are and to pick their brains for what has worked well in their experience. If you are interested in a more intimate experience, there are smaller "breakout" groups that exist. But again, these groups are not designed for you to take on the problems of others; they often meet at local restaurants or coffee shops and are intended for sharing joys, triumphs and knowledge.
9. **Invest your time wisely.** There are many alternative therapies for Autism. The Internet, newspapers and television newsmagazines abound with information of how one family cured their child of Autism. Be certain that any therapies you invest your time and money in are research based. Don't be drawn in by fancy advertising and pseudo-scientific citations. Know your choices, but be aware of how the effort impacts the entire family, weigh your options and proceed carefully. Be certain to speak to many individuals who have employed these approaches and to not abandon the time tested and literature supported therapies that are known to work for individuals with Autism.
10. **Enjoy your family.** With all you have to do, it's easy to forget the simple pleasures. Laugh and play with your children and find a way to go on a date with your spouse. Where there is a will, there is a way. If you have time to do any of the other items on this list, you have time to make this one work as well. We cannot survive life without joy. Our families are our joy; nurture this.