10 Top Resources when you have an Autism Diagnosis for your child

The wind just got knocked out of your sails. The fear you have harbored regarding your child's behavior has now been confirmed with an autism diagnosis. Once you get your breath back, take another deep breath and set your mind on what can be done to help you and your child forge the difficult path ahead. This isn't cancer, but if it was, you would do whatever you could to help your child recover. The same goes for autism. It is not the end of the world. It will be a hard journey, but one in which you will be blessed along the way. So many families have gone ahead on this journey and have made countless discoveries along the way, with the help of researchers committed to discovering what helps your child's body as well as their behavior. You will see hard days ahead as well as days that will give you much joy and hope. Kids do get better but it takes a lot of hard work and a change in perspective as well as a LOT of patience with a positive outlook. You need to be willing to change the way you do things, but it will end up for the better.

You got this!

Are you ready? Let's go!

1. Sign up your child with the **Department of Developmental Disabilities** in your state. In some cases, that includes signing up for **Social Security Benefits for the Disabled**. This can be the gateway for getting your child on **Medicaid**, which will help pay for the services your child will need. Some states have allowances for your child to be put on Medicaid based on their disability and although they look at your income, your child can still get covered if you make over the amount for the cut off. In Idaho that involves applying for the Katie Beckett Waiver when you make too much money to qualify for SSDI or Medicaid for your child. Some states you have to rely on what your private insurance covers and more and more reforms are being pursued to help you get the coverage you need, but it is slow in coming. If you have limited coverage, there are grants out there on the Internet that can help you get the therapy you need for your child.

2. Depending upon the age of your child, next, sign up with the local school district for **Special Education Services.** There is Birth to Three services and then Developmental Preschool. Ask for assessments in every area available: Speech, Occupational Therapy, Physical Therapy, etc. You will get an IEP (Individualized Education Plan) which is golden. You need to remember that YOU are key to your child's success and their strongest advocate to get them what they need to be successful. With that in mind, it is imperative to have good communication with the school district and be an active participant. The schools are mandated by federal law to provide the most appropriate education. If you feel more is needed for your child, don't settle, but also be as reasonable as you can. Find out what the laws are and simply make it known you are going to ensure that your child is going to be well cared for. There is help out there, too, if you get any trouble along the way. See below for additional resources related to this vital part of your child's development.

3. Due to the limitations that the school districts have, it is important, vitally important, to get assessments from **outside service providers**. These include:

    a. **Speech Therapy**: Whether or not the child is verbal, children still need speech services when they are on the autism spectrum. There is so much involved in speech: Speech/Articulation and Language Development; Expressive-Receptive Language Development; Social Language Skills; Literacy development and much more!

    b. **Occupational Therapy**: Sensory Integration/Processing, Listening Therapies, Gross Motor and Coordination Skills Development, Myofascial Release, Fine Motor/Visual Motor Skill Development, Oral Motor/Oral Sensory Development, Play Skills, Craniosacral Therapy, Visual Perception/Visual Processing, and Lymphatic Drainage Therapy. (I can't emphasize these two therapies enough. For a description of these therapies please look at the website www.synergyidaho.com)

    c. **Physical Therapy**: Pediatric physical therapy addresses the following: Balance; Cardiopulmonary Endurance; Caregiver Assistance and Routines; Coordination; Developmental Activities; Joint Range of Motion and Function; Motor Planning New Activities; Movement & Mobility; Muscle Tone and Spasticity Management; Posture and Skeletal Alignment; Recreation, Play & Leisure; Safety and Prevention Programs; Sensory and Neuromotor Development; Strength for Age-Appropriate Activities; Use of Adaptive Equipment or Assistive Technology. (Some of these apply to our kids and some don't but getting a full evaluation is worth it.)

    d. **Vision Therapy**: Vision Therapy is an individualized, supervised, treatment program designed to correct visual-motor and/or perceptual-cognitive deficiencies. Vision Therapy sessions include procedures designed to enhance the brain's ability to control: Eye alignment; Eye tracking and eye teaming; Eye focusing abilities; Eye movements; and Visual processing. (To learn more about Vision Therapy check out http://alderwoodvisiontherapy.com/services/vision-therapy/.)

    e. **ABA (Behavioral) Therapy**: Applied Behavior Analysis is the process of systematically applying interventions based upon the principles of learning theory to improve socially significant behaviors to a meaningful degree, and to demonstrate that the interventions employed are responsible for the improvement in behavior. (Baer, Wolf & Risley, 1968; Sulzer-Azaroff & Mayer, 1991). Some states have Developmental Disabilities Agencies that you can get a list of from the Department of Developmental Disabilities. States like Idaho have ABA administered in utilizing Habilitative Intervention or Habilitative Supports.

    f. **DIR/Floortime Therapy:** DIR® has a deep foundation in the science of human development and can sound very technical at times. However, it is also very simple. It is a way to understand our children and each other that builds connections, understanding, love, communication, and engagement. Through this approach, the true potential of each person can be discovered. DIR is the Developmental, Individual-differences, & Relationship-based model that has become the foundation for understanding child development and providing support and intervention that helps children reach their fullest potential. The DIR® model is also a framework that helps clinicians, parents and educators conduct comprehensive assessments and develop educational and/or intervention programs tailored to the unique challenges and strengths of each child. DIR/Floortime® is the application of the DIR model into practice. (http://www.icdl.com/DIR)

g. **RDI Therapy:** Relationship Development Intervention (RDI®) offers treatment programs for individuals and families that face Autism Spectrum Disorders and other developmental difficulties. It is often described as “the missing piece of the puzzle” in the treatment of ASD because instead of focusing on symptoms, our program works to activate the grow-seeking drive essential to remediating the universal impairments associated with ASD. RDI® programs teach parents how to guide their child to seek out and succeed in truly reciprocal relationships, while addressing key core issues such as motivation, communication, emotional regulation, episodic memory, rapid attention-shifting, self awareness, appraisal, executive functioning, flexible thinking and creative problem solving. (http://www.rdiconnect.com/about-rdi/)

That is a lot of therapy! Yes, it sure is! However, early intervention helps so much. Some therapy will take precedence and some will be incorporated into their behavioral therapy. The wait lists for therapy can be long, so the sooner you can get in for an evaluation, the better. You will find the time to work it all in and it will be all worth it. You will be able to work in breaks here and there when it makes sense but if your child was in a wheel chair and needed therapy to be able to walk on their own, you would do it. You will have a new normal but it will be okay. You also will learn so much so you can carry the skills home and incorporate them into your daily life. It will be a gradual process, just like when kids learn to walk, they first need to learn how to roll over, sit up, pull up to standing and then take those first, tentative steps before running all over. The different stages they go through will take longer to go through but they will improve, just at a different pace.

What other resources are there to help?

4. **Personal Care Services**: Depending upon the age and severity of the child’s autism, you may be able to make use of Personal Care Services once your child is deemed eligible for Disability Services. It is a valuable, in home care program that can help care for your child’s personal care needs: bathing, feeding, laundry, dishes, food preparation. Some agencies will hire someone you designate, which can make it a little easier getting used to another person in the home. The amount of hours your child receives depends upon their age, and level of need, ranging from anywhere from 10 hours a week up to 20 or more. Parents who are needing eyes in back of their heads can finally get some extra help!

5. **Biomedical/Integrative Medicine** or finding a naturopathic doctor or a doctor who does environmental or functional medicine including a chiropractor. You may have noticed that your child has medical issues such as GI problems. If you are able to, find a MAPS (Medical Association of Pediatrics for Special Needs) or DAN (Defeat Autism 'Now) doctor http://www.tacanow.org/blog/treating-autism-maps-doctors-dan-doctors/. Having a biomedical doctor who is knowledgeable about the medical issues with autism can help your child's body heal and improve their symptoms. This usually goes hand in hand with the next one:

6. **Changing the Diet**. One thing you CAN control is what goes into your child's body especially the food. Hippocrates claimed all disease starts in the gut. Science is showing this to indeed, be the case. Now, it is important to realize that there is not any particular diet that is "the autism diet" but there are a lot of ones that do help with autism symptoms. The Autism Research Institute has some good advice in this area:
   https://www.autism.com/treating_diets#sthash.4B1XW4Ot.dpbs

   It's going to take some time to discover what you child is struggling with and begin to make the changes. Going from the Standard American Diet will be a process, but you will discover that cooking and making things from scratch isn't as hard as it seems. Buying GMO free and organic can be a bit more costly but worth it. Our environment is full of toxins, including the food we eat. There are various diets to explore, **GAPS, SCD, The Fiengold Diet, and The Body Ecology Diet**, to name a few. Working with a nutritionist would be helpful if you are able to. Usually a nutritionist is covered under one's insurance plan. The earlier a diet is introduced, the better, too. What you will find out that it will end up helping the entire family eat more healthy. You can go from having a child with picky eating habits to a child who has a healthy, with a wide range diet. Having a naturopath or functional medicine/environmental medicine doctor will also help, especially when sorting out what supplements may be helpful. Someone who looks at your child in a biomedical framework, helping to discover what is not working right and help the body to heal. A lot of kids on the spectrum are picky eaters or may have stomach aces or even head aches. Reducing the toxic load while helping the body repair itself is essential. The autism symptoms and more, can relate to one's gut health, which is the body's "second brain". You will learn about such things as Probiotics, cultured foods, gluten free, casein free, etc. It may be a gradual process to completely get on the diet, but it will be worth it.

7. ***Read, read and read some more!*** One of the best resources you want for some practical help to start with your child is the two book series: **The Autism Discussion Pages on the Core Challenges of Autism and The Autism Discussion Page on anxiety, behavior, school, and parenting strategies: A toolbox for helping children with autism feel safe, accepted, and competent,** by Bill Nason. Both books provide concise, accessible information and simple tools for supporting children with these vulnerabilities. Another valuable book is **Healing the New Childhood Epidemics: Autism, ADHD, Asthma and Allergies** by Dr. Kenneth Bock. Do some research, watch YouTube videos, and learn all you can.

8. **Look for resources and foundations in your area to help get the resources you need for your child.** Some of these provide grants for therapies not covered by insurance or for items you may need for your child. **Thinking Mom's Revolution** and **TACA (Talk About Curing Autism)** provide grants for biomed treatments http://teamtmr.org/grant/, http://www.tacanow.org/ , for example. There are local ones such as the ones in the area of Northern Idaho: **The Isaac Foundation** http://theisaacfoundation.org/, **The Panhandle Autism Society** https://panhandleautismsociety.org/, **Team Autism 24/7**, http://teamautism247.com/, for example. Additionally, there are also resources to help with getting what your child needs for an IEP for school, such as **Idaho Parents Unlimited** https://www.ipulidaho.org/ IPUL helps in other ways too, so check out their website for more information. There are similar resources in most states, you just have to look and be persistent…just like your child is, to get what they need! Two websites that have connections for other states is **Family to Family Health Information Center**, http://www.fv-ncfpp.org/ and another similar one is, **Parent Center Hub**, http://www.parentcenterhub.org/find-your-center/.

   When you have the time, look into conferences that can be helpful: **Autism One** http://www.autismone.org/ offers one every year at a reasonable price, as well as TACA and others. There is a lot to learn and you will have time to take it all in when the time is right. **Autism Speaks** is a predominate resource that provides information and links to more local help https://www.autismspeaks.org/family-services/resource-guide. They are a wealth of information even have a free 100 Day Kit for families of newly diagnosed kids and much more: https://www.autismspeaks.org/family-services/tool-kits

9. **Online support groups, including Facebook groups**: There is a lot of information out there and you can get easily overwhelmed by it all. It can be confusing and there are various opinions but through it all, you will need support. You will need to vent and having a community of other moms who understand makes it all a little easier to bare. You will get a lot of advice and just like when you are at a party and someone offers you an appetizer, take what you need at the time and leave the rest.

10. **Self care:** The list of things to help your child is extensive and goes beyond this list here. What is of primary importance is taking care of yourself as you are key to your child's recovery. You are often sleep deprived, overwhelmed, at wits end but some way, some how, you need to carve out a way to take care of yourself in this journey. Your child needs you to be on top of your game as much as possible. You need to have a sense of humor and a lot of patience while also the determination to help your child learn the skills he/she needs to be successful and fulfilled in life. You need to take care of your body, eat healthy, and just like your child, make adjustments to your lifestyle and perhaps perspective so your child can get all the encouragement they need to do the hard work ahead. Reach out. It's okay to be vulnerable. There are going to be people who simply don't understand but there are going to be a lot more who do. When people ask what they can do to help, tell them. Even if it's a little thing, it helps. Perhaps someone can help with buying the supplements you want for your child. Perhaps someone else could come over to watch your child while you get a nap. Others could help with food prep, doing laundry or cleaning the house, or even grocery shopping. If you decide to join your child with a diet change, take it slow and steady. You will start feeling better after your body starts detoxing (just like your child will). Don't give up. YOU CAN DO THIS! You have the support.

How do you juggle all of this? Baby steps. If you are in need of help as you go along this journey, especially in the realm of balancing your child's care as well as your own, contact me and we can figure out what works best for you considering your unique circumstances. I can be reached by email: sheilamh67@gmail.com or by phone: 208-449-9019. Let me walk with you along this journey as your Life Coach.