



**BBB AUTISM SUPPORT NETWORK**

[www.bbbautism.com](http://www.bbbautism.com)

## **When Your Child is Diagnosed with an Autism Spectrum Disorder**

*(BBB Autism: printable article #29)*

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<http://www.iidc.indiana.edu/~irca/fttrainpapers.html>

*Note: some information contained herein may be specific to Indiana; however, the content of the article is of interest to all of us.*

When a child receives a diagnosis of autism, Asperger syndrome, or other pervasive developmental disorder parents and family members may experience a range of feelings. These feelings can include grief, denial, anger, fear, and confusion. If you are a parent, you may feel or have felt these emotions. It is important to know that you are not alone, and that many parents experience these same emotions. It is also important to recognize and work through these feelings as you begin to search for understanding, services, and support for your family and for your son or daughter with an autism spectrum disorder.

One of the first steps is to learn as much as you can about the diagnosis and how it affects your son or daughter. Unfortunately, there are still no clear answers about the cause of an autism spectrum disorder. The Indiana Resource Center for Autism (IRCA) at the Indiana Institute on Disability and Community has prepared a bibliography of books that are current and relevant for families. Videos and print materials are available to help members of your immediate or extended family who are struggling to understand. As you learn more about autism spectrum disorders, you will see that there are characteristics common across all individuals. Being aware of the characteristics that apply to your child will enable you to begin seeking supports, and appropriate programs and treatment approaches.

Throughout your child's life, you are going to be expected to make decisions for which most of us are not immediately prepared. These decisions are further complicated when faced with laws with numbers, therapies with abbreviations, government service agencies with acronyms, medical jargon, and an array of educational approaches. Making sense of the information can be overwhelming! It is nice to know that there are others who have been down this road and who can be of assistance in helping to untangle the web of agencies, services, and resources. There are national organizations such as the Autism Society of America (ASA), that exist as support and advocacy groups for persons with autism spectrum disorders and their families. State and local ASA chapters exist in most states. The IRCA can provide residents of Indiana with the current contact person for the state organization and the chapter closest to your area. You may also find a support group in your area for families of children with other disabilities. These can assist in identifying the availability and type of local services. Support groups can help families find comfort, acceptance, and understanding of issues as the individual with an autism spectrum disorder goes through each stage of life. Whether or not you currently feel a need to actively belong to a support group, making an initial contact can provide valuable information.

Whatever the age of your child, one of the most important choices is going to be an appropriate educational placement. Children with autism can and do learn! Children are now, in some cases, being identified under the age of three. Children under age 3 identified and/or suspected of an autism spectrum disorder, can be served by the local First Steps program **(In other areas, contact Early Intervention Services – L.C.)**. First Steps services are free and include supports and resources according to the child's and families needs. Children of school age (3 to 21) identified with autism spectrum disorders are served by the local educational agency. A good transdisciplinary educational evaluation is necessary to determine the type of services your child needs. The Individuals with Disabilities Education Act (IDEA) provides for families to be actively involved in making decisions that impact their child's education.

Learning your rights under this law will make it easier to participate in the important decisions surrounding your child's education. Information about accessing special education services can be obtained through your local school district. They can provide information as you begin to access your educational system.



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Record keeping is another strategy that can help in your efforts. As your child matures, numerous professionals will need to know specific information about your son/daughter. A developmental history provides important diagnostic, evaluation, and programming information even into adulthood. No doubt you will have volumes of information by that time. Keeping information in an organized and concise manner will not only help you remember the information, but will be easier for busy professionals to access and utilize.

Identification of your child and family's needs is very important. Each family is different and each child with an autism spectrum disorder is different. As a result, your needs will differ and shift as your son or daughter matures. Examples of services individuals with autism spectrum disorders and their families may require include physical, occupational and speech therapy, behavior assessment and support, residential programs, medical and dental care, financial assistance programs, advocacy, legal information, respite care, intensive early intervention, sibling support and education, socialization, recreation, and vocational training. Accessing services can differ from community to community. The IRCA may be able to assist families of persons with autism spectrum disorders, in Indiana to locate critical agencies, supports, and resources.

As a parent of a child with an autism spectrum disorder there are many new things to learn. At times it will be challenging to balance routines, schedules and plans so that all family members feel accepted, supported and valued. Establish time for all family members to revitalize and gain perspective. Maintain your sense of humor. Laugh together to relieve tension. You can and will have your ups and downs. Keeping things in perspective and taking time for yourself are vital in reducing the stress that is common when parenting any child, including your child with an autism spectrum disorder.

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