What to Do If You Suspect Your Son/Daughter Might Have an Autism Spectrum Disorder

Contributed by:

Dr. Cathy Pratt, BCBA: Indiana Resource Center for Autism
Dr. Angie Tomlin: Riley Child Development LEND Program
Dr. Noha Minshawi: Christian Sarkine Autism Treatment Center
Dana Renay: Autism Society of Indiana

During the last decade, there has been much attention on the increasing incidence of autism spectrum disorders (ASD). As a result, parents and professionals may be more likely to recognize developmental differences that could signal autism than in the past. Despite this increased awareness, knowing how to get an accurate diagnosis and what to do after a diagnosis is made, can be confusing and overwhelming. Our goal is to help clarify options, highlight characteristics, and suggest next steps.

Often times, primary care physicians such as family practice doctors and pediatricians are the first professionals that family members will ask for guidance. Doctors can ask parents or guardians specific questions about developmental milestones or behaviors, and may even screen your son or daughter for an autism spectrum diagnosis using a standardized tool. As a result of this process, your child may be given a diagnosis of autism. However, best practice guidelines require a more extensive assessment process that includes a combination of parent interview and direct observation completed by a multi-disciplinary team of professionals who are experienced in working with individuals with autism spectrum disorders.

If you wish to pursue a more thorough medical diagnosis, a list of professionals who can diagnose/assess is available on the website for the Indiana Resource Center for Autism at http://www.iidc.indiana.edu/index.php?pageId=269. This list includes individual providers, such as licensed psychologists, specialty physicians, and diagnostic teams including the Riley Child Development Center LEND Program. These organizations are able to conduct evaluations that may lead to medical diagnoses. When you contact these clinics, ask about waiting lists, whether you need a referral, and the types of payments/insurance they will accept.

While you are waiting for an assessment or diagnosis, DO NOT wait to pursue services. If your child is younger than age three, and you are concerned about behaviors or delays, contact Indiana's Early Intervention System, First Steps at http://www.in.gov/fssa/ddrs/2633.htm or by calling 1-800-441-7837. Your child can receive a professional assessment and if eligible, may receive early intervention services with providers such as a developmental therapist, physical therapist, speech clinician and/or occupational therapist in your home or other community settings. There is no charge to you for the evaluation although there may be some charge for services. The Autism Resource Network of Indiana (http://www.arnionline.org) can be used to locate First Steps therapists and providers in your area.

If your child is three years of age or older, contact your local special education planning district. They will probably need to evaluate your son/daughter using a team approach that includes a speech clinician, educators, occupational therapist, psychologist, and other professionals.
You will also have the chance to provide input. Even if your child has an autism spectrum disorder diagnosis provided by a physician or psychologist, he or she will still need to be evaluated by the school to show they meet educational eligibility to receive services. In other words, a medical diagnosis does not mean that a child is eligible for educational services.

Autism spectrum disorders are referred to as a ‘spectrum’ to demonstrate that while individuals share common characteristics, how these characteristics are manifested can be quite different. In other words, no two individuals are the same. The characteristics of autism spectrum disorders present themselves differently in each child. Some children with an autism spectrum disorder show hints of future problems within the first few months of life. In others, symptoms might not appear until 24 months or later. Some children with an ASD seem to develop normally until around 18 to 24 months of age and then they stop gaining new skills, or they lose the skills they once had. For example, a child with an ASD might:

- Not respond to their name by 12 months
- Not point at objects to show interest (example: point at an airplane flying over) by 14 months
- Not play “pretend” games (example: pretend to “feed” a doll) by 18 months
- Avoid eye contact and wants to be alone
- Have trouble understanding other people’s feelings or talking about their own feelings
- Have delayed speech and language skills
- Repeat words or phrases over and over
- Give unrelated answers to questions
- Get upset by minor changes
- Have obsessive interests (example: lining toys up repeatedly, talking in great depth about only one subject)
- Flap their hands, rock their body, or spin in circles
- Have unusual reactions to the way things sound, smell, taste, look or feel

For more information about characteristics and normal developmental milestones, visit the website for the Centers for Disease Control at http://www.cdc.gov/ncbddd/autism/facts.html.

If your son or daughter is given an autism spectrum disorder diagnosis either by a medical provider or by the school, you will have many questions. There is much information on the web and via the media. Your challenge will be discerning what is useful and what strategies have a proven record. Each child on the autism spectrum will need a different intervention, and the decision about what is right for your child and family is a hard one. There are many services and options in Indiana. Contact one of the following organizations and they can help you navigate the service delivery system, as well as provide support, resources, and referrals within your area.

**Indiana Resource Center for Autism** at 1-812-855-6508, http://www.iidc.indiana.edu/irca or via email at prattc@indiana.edu


**Autism Society of Indiana** at 1-800-609-8449, http://www.inautism.org or via email at info@inautism.org