

After the Diagnosis of an Autism Spectrum Disorder: A Resource for Families Whose Child is Newly Diagnosed

Updated 12/8/21

Produced by: the Indiana Resource Center for Autism at Indiana Institute on Disability and Community, Indiana University – Bloomington

With support from: Easterseals Crossroads and Answers for Autism. This booklet is also made possible because of the kind donations received from family members, individuals, and organizations.

Publication done in collaboration with:

Arc of Indiana
Autism Society of Indiana
Family Voices Indiana
LOGAN Autism Learning Centers
Riley Child Development Center

Indiana Resource Center for Autism 2810 E Discovery Parkway Bloomington, IN 47408 https://www.iidc.indiana.edu/irca/

When your child is diagnosed with an autism spectrum disorder, your family begins an unexpected journey. The future may appear more uncertain and confusing. Filtering through the information and options can be overwhelming. There will be various professionals, complex terminology, and a vast amount of information and opinions from others. The intent of this booklet is to help families in Indiana begin their journey. Clearly, a booklet of this size cannot begin to present all the information families will need. Our hope is to merely provide a first step. It is our sincere desire that by taking the first step, you will experience some relief, and find hope and needed guidance for your family and your child.

This document assumes that your child has already received a diagnosis of an autism spectrum disorder. Your child may have only received an initial screening that shows ASD is suspected. This is an important first step; however, it will be important to obtain more thorough evaluations to assist in planning supports and programing for your child. A psychologist or physician who has training and experience in understanding autism spectrum disorders and other developmental disabilities can do comprehensive evaluations. A listing of those who can diagnose and assess in Indiana can be found at the following website: https://www.iidc.indiana.edu/irca/learn-about-autism/how-and-where-to-obtain-a-diagnosis-assessment-in-indiana.html. If it is suggested your child may be on the autism spectrum, DO NOT wait for a more comprehensive evaluation to occur before pursuing services. The earlier you intervene, the better.

Service/programming options will be explained below.

Before We Begin... Let's Get Organized

You are entering a new world and there is much to learn and do. It will be helpful to develop a system for organizing information. You and your child will be meeting with many professionals along the way, and you will be asked for and receive a lot of information. Think about how you will organize all this information. For example, some may find a binder or other filing system helpful, while others may use some type of notebook or electronic application. Do not trust your memory to be able to absorb all the information you will receive. Have a method for documenting milestones, doctor and other professional recommendations, appointments, concerns, celebrations and for storing important documents. Keep a record of treatment options you try and how your child responds to each one.

Some find it helpful to maintain a log of all those you have called/emailed/texted along the way. In all likelihood, you and your child will be visiting various professionals and have numerous meetings to attend. Identify a scheduling or calendar system to help you keep track of all these meetings, and to serve as a reference. Maintaining all this information will help as you involve new people and as you continue to problem solve on behalf of your child. Remember that you will serve as your child's primary case manager and lifelong advocate. Keeping organized from the start will help.

What Are Autism Spectrum Disorders

Your son or daughter has received a diagnosis of an Autism Spectrum Disorder (ASD), but what does that mean? First of all, it is important to understand that it is called a spectrum disorder because each child is different; no two are the same. This means that what works for one child may not work for another.

Learning about ASD will help you interpret your child's frustrations and behaviors. It will also help you recognize skill deficits that you might need to help your child work on. As you learn more about the characteristics of ASD and what they look like, some of your child's challenges and behaviors will make more sense.

There are two main categories that characteristics of ASD fall into. These are articulated and described thru the Diagnostic and Statistical Manual, fifth edition (DSM-5). The entire diagnostic criteria can be found at: https://www.iidc.indiana.edu/irca/learn-about-autism/diagnostic-criteria-for-autism-spectrum-disorder.html.

The first category addresses deficits in social communication and social interactions. This means that children with ASD often struggle with the normal give-and-take of everyday interactions. Some parents describe their children as being "in their own world" or unresponsive to things like hearing their name called or being asked questions. Your child may not be able to have a back-and-forth conversation, especially about a topic that does not interest them. He or she may have a voice that "sounds different" (e.g., robot-like or very high pitched). Your child may not show you objects that they enjoy.

Also included in this characteristic is a lack of nonverbal communication skills. Perhaps your child doesn't point at objects in an attempt to get you to see them or make eye contact with you when they are talking or listening. Your child may not pick up on subtle cues like when you make a face or put your hands on your hips for emphasis. Your child may have limited facial expressions, including a lack of a "social" smile in response to your smile.

Children with ASD also have trouble with relationships. Your child with ASD may appear uninterested in peers/siblings, have a hard time with pretend play, and may prefer to play alone.

Your child may be interested in having friends but may not know how to interact with them. Your child may not seem to understand the unwritten rules of friendship and how to "fit in." There are likely significant problems understanding the thoughts and feelings of others and regulating social interactions and emotions.

The second main category of ASD characteristics is restricted, repetitive patterns of behavior, interests, or activities. For instance, you might see your child repeat physical movements, such as flapping their hands or

rocking back and forth. Parents often report that children with ASD line up their toys rather than "play" with them. Repetitive speech is also included in this category. Perhaps your child repeats words or phrases back to you at times that don't seem to make sense. Your child may even repeat entire scenes from their favorite movie. This is referred to as echolalia.

Children with ASD often prefer things to be the same. You may find your child prefers eating the same foods, wants to follow specific routines, or becomes upset by changes in their daily schedule. Play "routines" may be repeated over and over with little variation, or they may prefer only a few certain toys.

Some children with ASD are extremely interested in one particular topic. Your child may learn a great deal about a subject, such as trains or dinosaurs, and spend hours engaged in playing and/or talking about that topic. Their interest in a toy may be limited. For example, your child might play with the wheels on a toy car rather than "driving" it on the ground.

Individuals with autism frequently perceive sensory information such as sounds, smells, textures, tastes, and sights differently.

Your child may show an over (hyper) reaction or under (hypo) reaction to various sensory input. For example, certain sounds (e.g., fire alarms, vacuums, sirens) may be painful for them or particular smells (e.g., perfumes, candles, foods) may be overly distracting. Various types of lighting (e.g., fluorescent) may be upsetting, making it hard for them to focus on the task at hand. Some may only eat certain foods because of the texture or taste. Some children will wear only one type of clothing or to the extreme only one item of clothing repeatedly because of how it feels on their body. Your child may not be able to tolerate tags or seams in their clothing. And on the other hand, your child may show no reaction to painful circumstances such as ear infections, headaches, burns or broken bones. This is especially scary for some families, as you must try to guess if your child is not feeling well or if something is hurting. Or your child may seek out sensations like the feel of a certain blanket, deep pressure or spinning on the swing set.

Autism Spectrum Disorder (ASD) often occurs along with difficulties in expressive communication (how they deliver information) and receptive communication (how they take in information). In many cases, there is a language delay or a total lack of spoken language. Higher functioning children on the autism spectrum may develop elaborate language, but still have difficulty explaining what they want or what they feel. Your child may talk about the same topic or item repeatedly. Children with impairments in language may struggle with starting and sustaining a conversation. Regardless of the degree of communication impairment, all children must have a way to communicate early on. Communication systems can include sign language, an augmentative alternative communication device, a picture book or choice card, or the use of PECS (Picture Exchange Communication System). The need for an alternative communication system may be true whether they have spoken language or not. These systems will help to minimize frustration that can lead to behavioral outbursts. Giving your child an alternative way of speaking will not hinder language development; it may help it.

In terms of receptive communication, know that even though your child may not speak they are still processing information. Be careful what is said in front of them or what they are allowed to watch on TV, they are taking everything in. Some children may be slow to process language and others will not understand instructions given in a group setting. For some children, bombarding them with too much language can be overwhelming. In that case, minimize your verbal instructions to only the essential message (e.g., "sit down here", rather than "I think you should sit down and relax for a bit,"). Still others will benefit from the use of visual supports. A full catalogue of visual supports can be found on the Indiana Resource Center for Autism website at https://www.iidc.indiana.edu/irca/resources/visual-supports/index.html.

Remember that ASD is a neurological disorder. How your child interprets and understands the world will be quite different. Autism spectrum disorders can occur by themselves or in combination with other disabilities such as attention deficit hyperactivity disorder (ADHD), learning disabilities (LD), anxiety disorder, Down Syndrome, major depressive disorder, blindness, deafness, epilepsy, and/or cognitive/intellectual disability. An additional diagnosis will influence the particular characteristics or behaviors your child displays. Due to the

range of symptoms in children with ASD, intervention and supports will vary for different individuals across different environments.

Children with ASD can exhibit a wide range of challenging behaviors. These behaviors may include self-injurious behavior (SIB), aggression, self-stimulation, refusal to follow directions, withdrawal, and others. Many children on the autism spectrum have challenges with toilet training and sleeping. Realize that behaviors may be serving a real purpose for your son/daughter, or may be a reflection of other issues in your child's life. It will be important to involve professionals who understand how to assess behavior, and how to work collaboratively with others in establishing a behavioral intervention plan that is realistic in your home and other settings. Because behavior challenges are often a reflection of the skill deficits these children experience (lack of social and communication skills, self-management, impulse control), behavior change will best be achieved by teaching your son/daughter an alternative skill or replacement behavior. Behavior/punishment strategies that work with your other children may be less effective with your child on the autism spectrum.

There is no single known cause for autism spectrum disorders. As research continues, it appears there are multiple factors involved. Regardless of the cause, we know that autism spectrum disorders are neurologically based, and not emotional or behavioral disorders. Most importantly, parents do not cause their child(ren) to have an autism spectrum disorder; it is not from a lack of discipline or because of "cold" parenting.

Focus On YOUR Child

Depending on the type of evaluation/screening your child had, you may need to do some further testing to help determine appropriate next steps. Your doctor may have recommended assessments by a speech language pathologist (SLP), an occupational therapist (OT), or a pediatric specialist in Psychiatry, Neurology or Genetics. Depending on the age of your child and the type of program they attend (e.g., First Steps, School, Applied Behavior Analysis center, school), there will also be evaluations conducted to assist with programming. Completing these evaluations will help you identify more specific areas to work on.

Through this process of learning about your child's diagnosis, do not simply focus on deficits and challenges. Identify things your child does well and those things that motivate them. Ultimately, programming should capitalize on areas of strength and use areas of interest to motivate and reinforce.

Once you have a more complete picture of the impact of ASD on your child and the gifts they present, begin to set priorities, and make a plan. Identify the top issues and needs of your family and for your child. Start with those issues first and let other things wait. Once you have established priorities; develop a plan and enlist others in achieving these priorities.

Who Can Help? Assemble Your Team

Once a diagnosis is obtained, it is important to assemble your team by identifying needed services and resources. Each child with an autism spectrum diagnosis is different and each family and child will have different needs. Examples of services available in public school settings or through private pay for children and families may include: intensive early intervention programming, Applied Behavior Analysis (ABA), speech therapy, sensory integration therapy, physical and/or occupational therapy, medical services, financial assistance programs, advocacy, respite care, sibling support and education, and recreation. In some cases, families may need assistance in addressing the challenging behaviors of their son or daughter. Available services will differ from community to community.

Find those professionals who you can trust. Work on building partnerships with numerous people. These relationships may play a critical role at different points in your child's life. As you are choosing private providers, be an informed consumer. Ask other parents, visit programs or facilities yourself, and find out about the licensing of staff and their experience with children like yours. Find out how long the program or practitioner has been in business and ask for references. Ask for examples of plans and about programming provided. You are trusting this professional with your child; do not be afraid to ask any question that will make you feel more

comfortable. With the increasing incidence of autism spectrum disorders, many are getting into the business of ASD. The quality of services and expertise of staff vary greatly. If you begin working with a professional who does not seem to connect with your child or who is not able to provide some documented outcomes, they might not be the right professional. Ask trusted professionals and friends for recommendations for those who use evidence-based practices.

Once you have a team organized be sure to negotiate expectations and roles, be clear about goals, and identify how you will keep in contact and communicate about progress and concerns. Work on establishing positive relationships with professionals. You will need to work closely together to resolve difficult issues. Focus your efforts on attacking problems together and not each other.

A good working relationship is a productive one, and one in which your child is the winner.

Know that over time your team will evolve and grow as your child changes and learns. Organizations listed at the end of this booklet may be able to assist families in Indiana to locate critical agencies, supports and services.

We Have The Diagnosis: What's Next?

When you start looking into treatments and therapies for children with ASD, you will quickly become overloaded with information. Find people and organizations that can help guide you through this process. Through the Autism Society of Indiana, the Autism Resource Network of Indiana (ARNI) has a database of services and organizations throughout Indiana. You can find these resources by visiting their website at https://www.autismsocietyofindiana.org/. Again, look at the end of this booklet for organizations to contact for information and support.

It is also important to focus on the most current knowledge and research available, particularly about evidence-based practices. Use a variety of sources to collect the information you need. Read, attend conferences and other educational events, check helpful websites, get on mailing lists, and talk to other parents. The challenge will be weeding through all of the information reflecting varying philosophies and differing opinions about effective treatments, medical interventions, therapies and educational programs.

As you are weeding thru all the programs, opinions and information, remember that there is no magic cure or quick fix. Beware of professionals who make unrealistic promises. We want you to have hope and to investigate options, but we do not want you to be coerced by unrealistic promises. In all likelihood, your child may need a combination of therapies, including communication/speech therapy, educational programming, behavioral therapy (ABA), sensory programming and other intervention approaches.

Early Intervention

If your child is under 3 years of age, you should contact your local First Steps program for your county. A System Point of Entry Coordinator (SPOE) will coordinate an assessment to determine your child's eligibility for early intervention therapies. The phone number for your local First Steps Coordinator can be obtained by calling 317-233-6092 or 800-441-7837, and also by checking their website at https://www.in.gov/fssa/index.htm.

Educational Services

If your child is between 3-21 years of age, contact your local school district to find out about options in your area. Remember, you will need to request an evaluation to determine if your child is eligible for special education services. While a medical diagnosis can provide some insight and determine medical necessity, schools will need to conduct their own evaluations to determine educational eligibility and to plan services.

It will also be important to understand Indiana's rules and regulations guiding special education services (this is referred to as Article 7 in Indiana) and your parent rights. A guide to help you learn about this is called Navigating the Course – Finding Your Way Through Indiana's Special Education Rules: https://www.doe.in.gov/sites/default/files/specialed/navigating-course-art-7-revisions-2019.pdf. If you need

information on finding your special education planning district or assistance in obtaining a copy of Article 7, contact the Indiana Department of Education, Office of Special Education at 317-232-0570 or 877-851-4106, or visit their website at https://www.in.gov/doe/students/special-education/.

If your child is found eligible for special education services, an individualized education program (IEP) will be designed by the case conference committee. Family members, school staff and those invited by the family and/or school are equal members of this important committee. If your child is not found eligible for an IEP, they may still be eligible for a 504 plan. Under 504, the school is expected to make reasonable accommodations for your son or daughter. There are agencies with information about special education services, in Indiana, that you can contact. Some also provide advocacy support. See the resource list at the end of this booklet to request advocacy support from INSOURCE, Family Voices Indiana or the Autism Society of Indiana Allies.

Don't despair if your child is older when a diagnosis occurs; appropriate educational programs can still be implemented. You can request an evaluation at any point by simply contacting your building administrator and/or director of special education. Educational supports are available, when a student is eligible, through age 21. If your child is already in high school when the diagnosis occurs, you may feel relief to finally have an answer.

It may also be a shock and/or disappointment that your son or daughter has almost finished high school without the correct understanding and support. Even starting in high school your child may be eligible for special education, related services and transition to adulthood planning from the school.

How Do I Find Funding?

There are various funding mechanisms for families in Indiana. Medical insurance is one way to fund medical treatments. Indiana has an insurance mandate that funds services determined medically necessary. The rules around paying for health care are complicated and always changing. Learn about your insurance policy and what programs/services are covered. To make it easier, we often think of health insurance in 2 categories: private and public. You can find out more information about the insurance mandate at https://www.iidc.indiana.edu/irca/articles/indianas-health-insurance-mandate-for-autism-spectrum-disorders-and-pervasive-developmental-disorders-pdds.

If your child is between 3-21 years of age, contact your local school district to find out about options in your area.

If you have private health insurance through employment, the Healthcare Marketplace, or another individual plan, there are some key things you need know:

- Learn your plan's limits and coverage levels for different types of services.
- Check for specific therapies/ services and see if the providers you prefer are in-network.
- Learn the steps needed for getting pre-certifications, filing claims, and appealing coverage decisions.

You are likely to find this information on the plan's website or in the booklet you received when you signed up for the plan. If you have insurance through work, your Human Resources (HR) department may have the basic plan information. You may also need to call your insurance provider's customer service line to ask specific questions.

There are several forms of public insurance that may be available to you, depending on your family's situation. Medicaid, Medicaid Disability and Children's Special Health Care Services are all programs to check into for possible coverage of medical expenses.

There are multiple types of Medicaid; a state and federally funded health insurance.

• There are two Medicaid programs for children based on your family's income: Package A and Package C. The two plans differ in how much income the family is allowed in order to be eligible.

 There are also some Medicaid programs that are based on the child's disability: mainly traditional Medicaid Disability and Hoosier Care Connect. Hoosier Care Connect provides additional care management services.

As with private insurance, you should learn your plan's limits, processes and, most importantly, providers.

More information about Medicaid, including how to apply, is available in this factsheet: https://www.fvindiana.org/wp-content/uploads/2020/09/FS Medicaid-9.2020.pdf.

More information about Medicaid Disability is available in this fact-sheet: https://www.fvindiana.org/wp-content/uploads/2020/09/FS MedicaidDisability-9.2020.pdf.

Medicaid Waivers can provide Medicaid funds to children with disabilities regardless of family income, if the child needs significant support. In Indiana, there are multiple waivers, and you can get one based on the type of disability (medical or developmental) and level of care your child needs. Most families of children with ASD apply for the Family Supports Waiver. Waiver services can cover some services and supports, notably respite care that are not available under traditional Medicaid. Be aware that there are currently waiting lists to get the waivers, and they are processed by the application date. More information can be found at https://www.iidc.indiana.edu/irca/articles/medicaid-waiver-programs-home-and-community-based-services-for-adults-and-children.html.

Indiana has a state funded program called Children's Special Health Care Services (CSHCS). Eligibility for diagnosis and treatment payments through this program is based on both medical and financial criteria. Autism is one of the disabilities that can be considered for this program. Children ages birth to 21 who are covered by CSHCS can receive coverage for services related to their disability, as well as primary care services. Of note, it is possible to receive a small amount of ABA services through this program. More information can be found at <a href="https://www.iidc.indiana.edu/irca/articles/childrens-special-health-care-services-program-of-indiana.edu/irca/articles/childrens-special-health-care-services-program-of-indiana.edu/irca/articles/childrens-special-health-care-services-program-of-indiana.edu/irca/articles/childrens-special-health-care-services-program-of-indiana.edu/irca/articles/childrens-special-health-care-services-program-of-indiana.edu/irca/articles/childrens-special-health-care-services-program-of-indiana.edu/irca/articles/childrens-special-health-care-services-program-of-indiana.edu/irca/articles/childrens-special-health-care-services-program-of-indiana.edu/irca/articles/childrens-special-health-care-services-program-of-indiana.edu/irca/articles/childrens-special-health-care-services-program-of-indiana.edu/irca/articles/childrens-special-health-care-services-program-of-indiana.edu/irca/articles/childrens-special-health-care-services-program-of-indiana.edu/irca/articles/childrens-special-health-care-services-program-of-indiana.edu/irca/articles/childrens-special-health-care-services-program-of-indiana.edu/irca/articles/childrens-special-health-care-services-program-of-indiana.edu/irca/articles/childrens-special-health-care-services-program-of-indiana.edu/irca/articles/childrens-special-health-care-services-program-of-indiana.edu/irca/articles/childrens-special-health-care-services-program-of-indiana-articles/childrens-special-health-care-services-program-of-indiana-articles/childrens-spec

Social Security Income (SSI) is a federal program that makes monthly payments to people with low income who are disabled. A child may qualify if they meet Social Security's definition of disability for children, and your family has limited income and resources. While this is not a health insurance program, the income may be useful for some families. More important, Indiana now automatically enrolls individuals deemed eligible for SSI into Indiana Medicaid Disability. More information can be found on this fact sheet: https://www.fvindiana.org/wp-content/uploads/2020/09/FS_MedicaidDisability-9.2020.pdf.

Finally, know that there are also several other funding options available, including private grants and low-interest loans. A listing of private grants can be found on the IRCA website at https://www.iidc.indiana.edu/irca/articles/grant-funding-opportunities.html. Often families use (and must juggle) multiple sources of financing for their children's health care. You will be most successful with some knowledgeable people on your side helping to guide you through the maze of options and processes. Some helpful groups in Indiana are:

- The Autism Society of Indiana https://www.autismsocietyofindiana.org/ or 800-609-8449.
- The Arc of Indiana's Insurance Advocacy Resource Center https://www.arcind.org/our-programs/insurance-advocacy-resource-center/ or 317-977-2375.
- Covering Kids and Families, for assistance in enrolling in Medicaid Package A and C https://www.ckfindiana.org/ or 574-968-1645.
- Family Voices Indiana, for assistance navigating both private and public health care financing https://www.fvindiana.org/ or 317-944-8982.

What Else Can I Do For My Child?

As parents, you play a critical role in supporting and teaching your child. Below are a few suggestions:

In addition to pursuing structured programming/educational options, realize that your child is learning continually. Be prepared to continually teach, coach, and guide your child in simple and complex learning and

social situations. Find out what your child is learning during therapy or in school and help them practice it at home.

Learn ways to simplify your life and the life of your child. Establish routines and structure (being careful not to make your child too rigid). Be consistent. Use visual supports in your home to clarify expectations and routines. Visual supports for home, school and work can be found on the IRCA website at: https://www.iidc.indiana.edu/irca/resources/visual-supports/index.html.

Work with and build upon your child's interests. Be creative. Realize that these interests and strengths may logically lead to a career in adulthood. Celebrate these strengths, interests, and accomplishments.

Learn to be consistent with praise and positive information. Minimize negative comments and punishment. Your child will learn best by being told what to do, rather then what not to do. Provide continual and direct guidance on expected behavior. And most important, stay as calm as possible as this will help to minimize your child's anxiety and help them maintain calm.

Find leisure and recreational activities that all family members can enjoy together. Work with the school to teach skills that will facilitate your child's involvement in these activities. Don't forget to play! Join in on those activities that bring your child pleasure, laugh together, and enjoy the fun.

Regardless of the young age of your child, they will grow up and become an adult. Encourage and enhance behaviors that will help your child become more successful as an adult. Overly accommodating your son's or daughter's behaviors and other challenges may set unwanted expectations for the future. Discourage and do not reward behaviors that will minimize future opportunities.

Be proud of the accomplishments of your child and yourself whether they are small or large. Small steps may be major accomplishments for your child. Engage, acknowledge, and celebrate!

How Do I Do Everything?

Supporting and educating your child may seem overwhelming at times. Take care of yourself and your health. You need exercise, rest, laughter, and time spent doing other things with friends and others. Spend quality time with others including your spouse, your other children, other family members and friends. It may feel like you do not have time to take care of yourself, however, it is vital for you to maintain your stamina and perspective. You owe this to yourself and to your family. Practice staying calm and finding humor each day.

Find respite care, even though you may not currently see the need. Respite services provide options for supervision for your child on a limited basis, so you and other family members have some time for other activities. Good respite care is a valuable resource for both you and your child to take a break from each other. All parents need opportunities for time away from their child whether or not their child has a disability. There is a cost for respite care, but often agencies have options for financial assistance.

Do not hesitate to look for outside guidance or support. Lean on your family and faith community, if appropriate. Seek a counselor or therapist, if needed. Access parent groups either online or in person. Choose those that will not drag you down into negativity, but rather those who will help you celebrate the positive and assist you and your child in making progress. Find the leading support organizations both nationally and in Indiana. Seek out parents who have "walked the walk" and can provide truly positive support and guidance.

Listen to and read about people on the spectrum that may provide insight into your son's or daughter's disability. Remember that your child is unique. An approach that has been effective for one child may be ineffective for your son or daughter.

Don't do it alone, you can't. Learn how to ask for and accept help from others. Asking for help is difficult, but necessary if you are parenting a child on the autism spectrum. However, you will need to be able to identify specifically what type of help you need (e.g., an hour to take a walk, an evening to reconnect with other family members, help taking your child to an appointment). There are family members, friends and professionals who

want to help, but you need to be specific and then you must be willing to take their help. To ensure it is a successful experience for all involved, it may be helpful to write down information about your child, including how they communicate, what strategies work best with them, any feeding or toileting issues, and other important information. Most important, don't feel guilty asking for help.

As such, family members and friends may need support and information in understanding your son/daughter's diagnosis. There are numerous publications available, which provide a wealth of information on a wide range of topics. Various books and videos are available free for loan to Indiana citizens. Contact the Library at IIDC and/or access their library collection online at https://www.iidc.indiana.edu/library/. Many of the organizations listed at the end of this booklet also have websites that may contain valuable information.

And Finally...

Receiving a diagnosis may alter your dreams for your son or daughter. Remember to maintain your determination and to not lose hope. There are few guidelines for predicting outcomes for children within the autism spectrum. Research into causes and interventions continues to grow at an amazing rate. More adults on the autism spectrum are describing their experiences and providing us with incredible insight. Clearly, there are successes that have been accomplished with hard work, creativity and perseverance from individuals themselves, their family members, and the professional and community members who are involved. Raising a child with an autism spectrum diagnosis is not what you planned. Most likely you will continue to experience a rollercoaster of emotions: anger, frustration, joy, relief, pride, grief, burn-out and confusion along the way. Remember that while you are your child's best advocate, you are not alone.

Agencies In Indiana

- Arc of Indiana: 800-382-9100 and https://www.arcind.org/
- ASK: About Special Kids, Inc.: 317-257-8683 and https://www.aboutspecialkids.org/
- Autism Society: 800-328-8476 and https://www.autism-society.org/
- Autism Society of Indiana (ASI): 800-609-8449 and https://www.autismsocietyofindiana.org/
- Autism Speaks: 888-288-4762 and https://www.autismspeaks.org/
- Bureau of Developmental Disabilities Services (BDDS): 800-545-7763, and https://www.in.gov/fssa/ddrs/developmental-disability-services/
- The Library at the Indiana Institute on Disability and Community: 812-855-9396 and https://www.iidc.indiana.edu/library/index.html
- Children's Special Health Care Services (CSHCS): 800-475-1355 or 317-233-1351 and https://www.in.gov/isdh/19613.htm
- Indiana Department of Education: Office of Special Education: 877-851-4106 or 317-232-0570 and https://www.in.gov/doe/
- Easterseals Crossroads: 317-466-1000 and https://www.eastersealscrossroads.org/
- Family Voices Indiana: 844-232-4636 and https://www.fvindiana.org/
- First Steps: 800-545-7763 and https://www.in.gov/fssa/firststeps/
- Hoosier Healthwise: 800-889-9949 and https://www.in.gov/medicaid/members/174.htm
- Indiana Governor's Council for People with Disabilities: 317-232-7770 and https://www.in.gov/gpcpd/
- Indiana Resource Center for Autism (IRCA): Access through the Indiana Institute on Disability and Community (IIDC): 812-855-6508 and https://www.iidc.indiana.edu/irca/
- Indiana Resource Center for Families with Special Needs (INSOURCE): 800-332-4433 or 574-234-7101 and https://insource.org/
- Riley Child Development Center: 317-944-4846 and https://www.rileychildrens.org/departments/child-development
- Social Security Administration: 800-772-1213 and https://www.ssa.gov/

<u>/ .</u>	v/fssa/ddrs/rehabilitatior
_	