After You Receive the Diagnosis of an Autism Spectrum Disorder: A Resource for Adolescents and Adults Who are Newly Diagnosed

Produced by the Indiana Resource Center for Autism
Indiana Institute on Disability and Community, Indiana University.
February 2017

This booklet is made possible because of the kind donations received from family members, individuals and organizations.

With Special Thanks to the members of the Students on the Spectrum Club at Indiana University – Bloomington for sharing their insights as they navigate college and work settings as well as community and home life.

Indiana Resource Center for Autism at Indiana Institute on Disability and Community, Indiana University
2810 E. Discovery Parkway
Bloomington, IN 47408
https://www.iidc.indiana.edu/irca

Introduction

As a teen or adult who has recently been diagnosed with an autism spectrum disorder you will likely need more information about autism, how it affects you, and also where to find appropriate resources, services, and supports for yourself. The information you will need to know will be different depending on whether you are a teen or an adult. What you do, after you are diagnosed, will also depend on your needs, interests, and goals. This booklet was written to provide some information and important resources as you begin to take steps to live your life with your new diagnosis.

This booklet assumes that you have already received a diagnosis of an autism spectrum disorder (ASD). You may have only received an initial screening that shows that ASD is suspected. This is an important first step; however, it may be valuable and necessary to obtain a more thorough evaluation to get a diagnosis. If someone has suggested that you may be on the autism spectrum, you will likely want to explore this possibility and what it means to you.

A diagnosis is important because it can lead you to knowledgeable professionals, supports, and programs. Without a diagnosis, you may not qualify for some programs, services, and supports that could assist you in school, on the job, or in other areas of your life. A psychologist or physician who has training and experience in ASD and other developmental disabilities can do more comprehensive evaluations. A listing of Indiana professionals who can diagnose and assess in Indiana, can be found at the following website: https://www.iidc.indiana.edu/pages/how-and-where-to-obtain-a-diagnosis-assessment-in-indiana. Professionals on the list who see adults for diagnosis are noted at the end of the entry.

A diagnosis of an autism spectrum disorder is made based on an evaluation of behavioral characteristics that meet the criteria in the current edition of the Diagnostic and Statistical Manual of the American Psychiatric association (DSM). See a link to the current diagnostic criteria in the next section of this booklet.

What is an Autism Spectrum Disorder?

General information

It is important to remember that ASD is a neurological disorder. This means how you interpret and understand the world may be different from other people your age. An autism spectrum disorder is not an emotional or behavioral disorder. It is a developmental disability that is the result of a neurological difference that affects brain development. You were born with an autism spectrum disorder.

There is no single known cause for autism spectrum disorders. As research continues, it appears there are multiple factors. It is also important to know ASD is not caused by something your parents did or did not do. It is not from a lack of discipline as a child or a result of “cold” parenting or trauma you have experienced.

Though ASD is a life-long disorder, your symptoms may change throughout your life. Some accommodations and strategies you have found on your own or with the support of others may have helped you to overcome some of your challenges. A focus on your strengths and interests may have helped you to do very well, in some areas of your life, but not others. A diagnosis will not lead you to a “cure” for ASD because no cure exists. It will help you recognize areas in which you may need additional support. As you learn more about the characteristics of ASD and what they look like, your habits and challenges may make more sense.

Characteristics: Social Interaction and Communication Descriptions

An autism spectrum disorder is referred to as a spectrum because ASD manifests and presents in different ways among different people. That means that you may not have the same needs as another person on the autism spectrum. Though the list might look negative to some, it is a brief summary of common ASD characteristics, stated simply, with no judgements intended.

Overall, characteristics of ASD fall into two main categories. These are described in the current edition of the Diagnostic and Statistical Manual. 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 encompasses significant difficulty with social communication, interactions, and relationships. This means you may have difficulty understanding or dealing with the give-and-take of everyday interactions. You may also find it hard to sustain conversations with other people that require a back-and-forth exchange, especially if the topic is "small talk" or not especially interesting to you. Descriptions you may have heard about your social and communication skills might include:

- Someone who is "in their own world"
- Someone who is very blunt
- Someone who speaks with an unusual tone and/or speaks too loud or not loud enough
- Someone who needs more time to process verbal messages
- Someone who takes information very literally
- Someone who uses "unique" phrases
- Someone who has difficulty understanding non-verbal communication skills (i.e., facial expressions and body language)
- Someone who has difficulty with eye contact
- Someone who talks excessively about their special interests

As a teen or adult, you may have difficulty establishing and/or maintaining relationships either socially or romantically. Another common problem for individuals on the autism spectrum is knowing whom to trust or how to tell whether someone is really a friend. It may feel hard to sustain friendships for you, and/or you may find that you need substantially more alone time than other people may need.

Characteristics: Behavioral Descriptions

The second category of characteristics from which an autism spectrum diagnosis is made includes very narrow and/or repetitive patterns of behavior, interests. or activities either currently or when younger. Again, though the list might look negative to some, it is a brief summary of common ASD characteristics, stated simply, with no judgements intended. These may include some descriptions you may have heard about your behaviors, either currently or in the past:

- Someone who insists on keeping routines
- Someone who is very anxious with small changes

- Someone who has difficulty with transitions
- Someone with rigid thinking patterns
- Someone who has repetitive motor movements
- Someone with extremely focused interests or preoccupations that are intense
- Someone with high pain tolerance

You may experience an over (hyper) or under (hypo) reaction to different sensory input. This can include the way that you experience sounds, smells, textures, tastes, and sights. For some it may be painful to hear certain sounds. Others may find it difficult to eat certain types of foods due to the texture or the smell of the food. It's also possible that you may prefer to wear only certain clothes because some types of clothes and different fabrics may cause you extreme uncomfortable feelings.

Resources for Materials on ASD

You may still have questions about what ASD is and would like to learn more. It will take time to understand how being on the autism spectrum affects you. There are, no doubt, positive qualities that you possess that have not been mentioned. Your many strengths are very important to keep in mind and celebrate as well. For example, your talent may be your ability to think critically, analyze and memorize specific information of interest, and/or your creativity.

A workbook written by Catherine Faherty about self-awareness and life lessons may be of interest to you. The workbook is called, "*Autism….What Does it Mean To Me?*" The revised and expanded 2nd edition includes sections for older readers. Ms. Faherty is a professional who had several individuals on the autism spectrum contribute to her workbook. Books written by other professionals as well as books written by teens and adults on the autism spectrum might be very helpful. "*The Aspie Teens Survival Guide*" by J.D. Kraus is one such book for teens.

These books and others may be borrowed free of charge from the Library at the Indiana Institute on Disability and Community by anyone in Indiana. See the listing at the end of this booklet. The Library at the Indiana Institute on Disability and Community is a full service lending library for the state of Indiana. A wide variety of books, DVD's, and other materials about disabilities, including ASD, are available online and for checkout. Materials are mailed FREE across Indiana. (The only cost is to mail back or return them to ANY IU affiliated campus library across Indiana.) A full catalog through IU Libraries is available at https://www.iucat.iu.edu/.

Secondary Diagnoses

ASD may occur on its own as a single diagnosis, or may be diagnosed along with other conditions. Anxiety disorders are very common secondary diagnoses in individuals with an autism spectrum disorder. This may appear as debilitating worries or fears. There is an article on the Indiana Resource Center for Autism website that can give you more information on anxiety and ASD's at https://www.iidc.indiana.edu/pages/anxiety-and-autism-spectrum-disorders.

It may be that previously you have received a diagnosis of an anxiety disorder and been treated for anxiety years before the diagnosis of an autism spectrum disorder. The diagnosis of anxiety might only explain a part of your challenges. With the additional diagnosis of ASD, a better understanding of all your challenges can now be addressed.

Many individuals who are diagnosed later in life with ASD have received other previous diagnosis that may explain some of their challenges but not all. Other common initial and/or co-occurring diagnosis include ADHD, OCD, and bipolar disorder.

An additional diagnosis will influence the particular characteristics or behaviors that are present. Due to the range of symptoms in people with ASD, intervention and supports will vary for different individuals across different environments. Because ASD is so different for each individual, regardless of the additional diagnoses you have received, it is important to get supports that are specific to your needs.

Disclosure: Communicating Your Diagnosis to Others

Disclosure, telling someone about your ASD diagnosis, is necessary if you want to apply for support from a variety of educational, employment, or social security programs which are described later on in this booklet. It can be necessary, and very important to disclose, especially when you need accommodations at school or work.

Now that you have a diagnosis you may want others to know about why you think and behave the way that you do. However, you may want to take some time to think and plan before fully disclosing to others. You can think about whom it would be appropriate to tell, what you would gain from telling that person, and how to advocate for yourself.

By disclosing your diagnosis, you may increase some empathy and understanding among your peers, your family, and others close to you. By disclosing that you are diagnosed with ASD, it may help people understand why you have different or unique behaviors. It will also help to explain why you are not always sure when things are appropriate to say which others describe as having issues with a social filter. You may also have an unusual repetitive behavior, and with proper information, people will know that this is just a part of your symptoms of ASD, rather than an intellectual or emotional disability.

You should also know there may be risks that come with disclosing your diagnosis of ASD. Some people may have a negative view of ASD. This may lead to a negative reaction to the news that you are diagnosed on the autism spectrum. Some, because of their limited knowledge of ASD, may not believe you and may question the diagnosis. It is also possible that some people will not respect your confidentiality when you disclose to them. If you ask someone not to tell another person about your diagnosis, it may happen anyway. It is important to understand the risks, as well as the benefits, when you are thinking about disclosing to another person.

As an adult, it is your choice to disclose. If you are still a minor, your parent(s) may feel it is important to tell others in your life. Hopefully you can have a discussion with your parent(s) and decide together who will be told and even how they will be told of your diagnosis. Consider your friends, people at work or school, in the professional community, and other groups to which you belong such as your faith community. Consider what is important to share and why.

A unique book about self-advocacy and self-disclosure that may be of interest to you is "*Ask and Tell: Self-Advocacy and Disclosure for People on the Autism Spectrum.*" The book is edited by a man with ASD, Stephen M. Shore, and all contributors are adults on the autism spectrum. The six adults on the autism spectrum provide very specific details and step-by-step information about how they have gone about disclosing their diagnosis and advocating for themselves. This book is also available to borrow from the Library at the Indiana Institute on Disability and Community.

In the next section are some ideas and resources to help you when you are thinking about disclosure.

Disclosure: For Supports at School

If you are in middle school or high school when you get an autism spectrum diagnosis from a medical professional, you will need to also get a diagnosis through the public school if you want to receive accommodations at school. An educational evaluation can be requested at any time by having your parent or guardian contact your school principal or the director of special education. If you are already 18 years old and a legal adult, you may request these evaluations yourself. It is often a good idea for you and/or your parent/guardian to make the request in writing for an educational evaluation for an autism spectrum disorder. You should mention that you recently received a medical diagnosis of an autism spectrum disorder.

After the school completes their evaluation (usually within 60 school days) you will be notified if the school finds you eligible for services as a student with an autism spectrum disorder. The school staff schedules a case conference meeting and, if eligible for educational services, the members of the case conference committee will develop an individualized education program (IEP) or 504 Plan. If you are a junior or senior in high school when you receive an educational diagnosis of ASD, a transition plan will be developed as part of this process. The transition plan will include information and steps in the process to move on to life after high school. The transition plan is individualized to your needs and interests and should address your plans after leaving high school such as further education and/or training programs, employment, and life as an adult in your community.

You may talk to your parents about attending these meetings and/or in some other manner providing input into the IEP, 504, or transition plan that is developed to help support you in school. Attending these meetings and/or providing input concerning your education is a big step in advocating for yourself and your needs. Educational supports are available in the public school to eligible students through age 21.

Some possible accommodations a student with ASD might receive at school include: seating, lighting, or sound related accommodations, on-task reminders, reinforcement and/or positive behavior supports, extra time on tests, and/or changes in presentation format of written materials.

IN*SOURCE (Indiana Resource Center for Families with Special Needs) is a wonderful resource for families and students in Indiana who need information about the special education evaluation process, special education law, the IEP process, and/or 504 Plans. They also have information and resources for transitioning from school for students receiving special education services. Information on accessing IN*SOURCE is listed at the end of the booklet.

Disclosure: For Employment Accommodations

If you need accommodations to obtain or keep a job, then disclosure of your diagnosis to your employer is necessary. Indiana Vocational Rehabilitation Services (VR) is a state program that assists people with disabilities to obtain services that help them prepare to obtain and maintain employment. Please see the section in this booklet outlining information about VR services and how they can support your efforts to obtain a job and stay successfully employed.

Also be aware of the Americans with Disabilities Act (ADA). The ADA is legislation with specific laws mandating that employers provide reasonable accommodations in the work environment to enable a qualified applicant or employee with a disability to participate in the application process or to perform essential job functions. The Job Accommodation Network (JAN) is major source of free, expert, and confidential guidance on workplace accommodations and disability related employment issues. The JAN is provided by the U.S. Department of Labor's Office of Disability Employment Policy (ODEP). For more information call Job Accommodations Network: (JAN): 800-526-7234 or see https://askjan.org/.

Helpful Hints and Important Programs to Access for Support and Services

Self-Advocacy

Self-advocacy is an important life-long skill. It can be learned and may take practice and confidence for you to do it well. It is important to know when to advocate and how to do it appropriately. You can also get help from a family member, friend, or professional. If you are still in middle or high school, your parent(s) will likely take the lead in advocating for you. It will be very beneficial, though, to talk with your parent(s) and ask them for support in becoming your own self-advocate.

When advocating for yourself, explain to others what they need to know and do when they communicate with you. If you have trouble communicating and understanding what you are told, you can always ask the other person to slow down and be specific and concrete in their conversations. If needed, you can ask others to stay with one topic at a time when they have several different things to tell you. If it is helpful, you may also ask them if they can provide information to you in written form.

If you are better at writing your own thoughts than you are at speaking, you might want to write or type out information. Once written/typed, you can share this information and/or practice saying the information out loud before you share with others.

Advocating for yourself also includes communicating to others about your differences. An example might be to explain you are still interested in what a person is saying, even if you cannot maintain eye contact throughout the conversation.

You may need to advocate for accommodations to support your sensory needs. The accommodations you need will vary by the environment as well as your specific sensitivities. For example, if you are sensitive to various sounds, and you are a student, an appropriate accommodation might be to ask for a quiet place to take tests. This should be an accommodation on your IEP (Individualized Education Program) or 504 Plan, or on your list of approved accommodations through the Student Disability Office if you are in a post-secondary program.

If you are employed, you could ask for a work space that is quieter and away from the specific sounds that are distracting or overwhelming for you. It will be important to explain your specific sensory challenges and why they are a problem for you as well as how they impact your work.

Actively Seek Social Groups and Social Skills Programs

You may find that you avoid social contact more often compared to your friends and family who are not diagnosed with ASD. While it may feel comfortable and familiar to be by yourself, spending time alone is not what most people want all of the time. Feeling content being alone may make it harder to seek out situations where you are socially engaged with others. It can also feel exhausting to interact with others. However, it is important to not isolate yourself from the world. You can prevent becoming isolated in a variety of ways.

Some of these ways may include finding a group of people for teens and/or adults on the autism spectrum. There are a few social groups around Indiana for teens and/or adults on the autism spectrum where you can get to know other people who have been through similar experiences. You could also seek out a group related to a special interest of yours such as Harry Potter, automobiles, martial arts, anime, or many other topics. You may find it more enjoyable to be around other people by joining a group with people that have similar interests to yours. This will give you a topic or focus in which to engage with other people that will feel more natural and enjoyable.

You may also wish to work with a therapist, counselor, life coach, mentor, or other individual who can actively work with you to learn and practice new social skills. There will likely be a cost for these social skill development activities. If you have health insurance, these services may be covered.

There are a few places to start looking for someone or some place that can provide assistance with social skills training. The same listing of those who can diagnose and assess in Indiana is also a place to check for professionals who work on social skills development with teens and adults on the autism spectrum at https://www.iidc.indiana.edu/pages/how-and-where-to-obtain-a-diagnosis-assessment-in-indiana. Remember, those on the list who see adults, are noted at the end of the entry.

The Autism Society of Indiana offers an online database of services and organizations throughout Indiana, Autism Resource Network of Indiana (ARNI). You can find these resources by visiting their website at https://www.autismsocietyofindiana.org/. And again, look at the end of this booklet for information to contact the Autism Society of Indiana directly as well as other organizations to contact for information and support.

Actively Plan for Transition from High School: Teens and Young Adults

If you are a teen or young adult still in high school, you have decisions to make about what you plan to do when you graduate. Do you want to go to college and pursue studies in an area of interest or do you want to find a job? It may be that you have been so busy, and at times overwhelmed, that you have not had much opportunity to think clearly about your choices after you graduate. An article on the Indiana Resource Center for Autism website, "*Supporting Youth with Autism Spectrum Disorders through Postsecondary Transition,*" might be very helpful, to you and your parents, in planning your transition from high school. Here is the link for the article: https://www.iidc.indiana.edu/irca/articles/supporting-youth-with-autism-spectrum-disorders-through-postsecondary-transition.html.

In Indiana, public school students age 14 and above (often the freshman year of high school) must have a Transition IEP (Individualized Education Program). As mentioned previously, as a teen with a diagnosis you, will be a member of the case conference team writing measurable goals that facilitate your progress from school to post-school activities. Your local high school likely has a variety of resources to help you and your parents plan for the future. Most high schools have a transition coordinator and offer a variety of written materials to families. Many have a yearly Transition Fair where many local organizations and programs come for an evening to talk with students and parents, answer questions and distribute information.

Another helpful resource for transition information is the Center on Community Living and Careers (CCLC) at the Indiana Institute on Disability and Community (IIDC). Contact CCLC at 812-855-6508 or visit their website at https://www.iidc.indiana.edu/pages/cclc. While CCLC does not provide direct services to individuals and families, they work to train teachers and other professionals throughout Indiana. CCLC has a lot of information on their website about career development, secondary education, and transition to adult life and services.

For more information about transition in Indiana, IN*SOURCE offers a publication, *"Transition to Adult Life"* available at this link on their website: http://insource.org/files/pages/0090-Transition%20Guide-Rev%2010-28-14.pdf. Some other articles you may find helpful about planning for life after high school can be found on the IN*SOURCE website at http://insource.org/resources/transition-to-adult-life/.

Actively Plan for Supports at College

Ideally, preparing for the demands of college started years earlier. As a college student with an autism spectrum diagnosis you should be experienced in advocating for yourself. An important piece of advocating for yourself is to apply for services from the Disabilities Student Services (DSS) office on campus. If you have decided to attend college or are already in college and need support, the article, "*Academic Supports for College Students with an Autism Spectrum Disorder: An Overview"* could be very helpful to you at https://www.iidc.indiana.edu/irca/articles/academic-supports-for-college-students-with-an-autism-spectrum-disorder.html.

The demands at college are far different than in high school. If you have been supported by an IEP in high school, you will likely benefit from services from the DSS office. Some student disability services offices do offer peer programs that can help with meeting others and learning more about social opportunities and other resources on campus. Students in post-secondary education should make contact with the disability services office on campus as soon as they are accepted into a college program or even in considering whether to apply. It will likely take at least one visit to learn about the services offered and how to sign up and feel comfortable accessing services from this office.

Sometimes you can apply online for services for students with disabilities, at the website of the college you will be attending. If you apply online, you may have the application completed and your eligibility determined before you visit their office. You can visit their office at any time in the process. Visiting the disability services office before you start classes is important so that you can be prepared in advance to access their services.

Two other post-secondary resources for students with disabilities and their families planning for further education after high school are Think College Indiana, a website with information and resources focused on postsecondary education at http://www.thinkcollegeindiana.org/index.php and PACER's National Parent Center on Transition and Employment at https://www.pacer.org/transition/.

Actively Seek Support for Employment Needs

Getting a job and keeping it can be difficult for many on the autism spectrum. Being an exceptional student in school does not automatically lead to success as a college student or to successful employment. If you are an adult, you may have been successful in finding employment in a field where you excel. More likely, though you have a job you are not happy with, had a series of jobs that have ended or have yet to find your first job after graduation.

The extent that ASD affects your pursuit of a job differs from person to person. Some individuals may find a job where they are appreciated for their expertise in their area of special interest and/or for their excellent work ethic. For others, it may be more difficult because they need to first overcome the challenges of the interview process. You may need further resources and support to help you get and stay employed in a job that is a good fit for you.

Seek out services from Indiana VR if you need support to obtain or maintain employment. See the information below about VR services and how to apply. As mentioned previously, the Job Accommodations Network (JAN) is very helpful if you have questions about workplace accommodations or questions about the Americans with Disabilities Act (ADA) and how it relates to support for employment.

Vocational Rehabilitation Services

Indiana Vocational Rehabilitation Services, sometimes referred to as VR Services, is a state program for adults and high school students (usually starting in their junior year) with any disability. VR assists people to access services that help with employment. Once found eligible, VR Services can provide a variety of services to support you to get and keep a job. There is no charge for these services.

An individual is eligible for VR services if:

1. S/he has a physical or mental impairment that substantially interferes with the ability to prepare for, enter, engage, or retain employment; and,
2. Vocational Rehabilitation services are required for the individual to become employable.

Services provided if determined appropriate can include, but are not limited to:

- Testing and assessment to determine needs
- Vocational counseling and guidance
- Job related services including job search and placement assistance
- Job related training including vocational, college or university, on the job, and other training services
- Treatment for physical, mental, and emotional impairments which are considered a substantial impediment to employment
- Transition services for students to help make the transition from school to work
- Rehabilitation technology including telecommunications, sensory, and other assistive devices and aids
- Placement assistance and follow-up
- Limited post-employment services may be provided.

To apply for VR services:

- Locate the local VR service office for your county.

  Here is the Indiana state website for VR services https://www.in.gov/fssa/ddrs/2636.htm where you can find contact information for all the local offices around Indiana..

At the VR appointment:

- Bring your social security number, copies of any diagnostic reports, as well as informational reports about treatments you receive.

- Bring a copy of your IEP or 504 Plan from school.
- Sign permission for VR to obtain any medical or educational records needed to help verify eligibility and/or service needs.
- If diagnostic and/or treatment information is not available and/or does not reflect your current condition, the VR counselor will ask for a combination of diagnostic tests and evaluations to be done at no cost to you.
- Complete the VR Application.

After a VR Application is completed, a determination of eligibility should be made within 60 days. The VR counselor must explain how you can appeal if you are found ineligible for VR services.

Once found eligible for the VR program, you and the VR counselor develop an Individualized Plan for Employment (IPE). The IPE contains employment outcome goals based on your unique abilities, interests, strengths, priorities, and concerns. The IPE will also list the services to be provided and who will provide the services along with times frames and methods used to evaluate progress.

You and the VR counselor sign the IPE indicating there is agreement. The IPE is reviewed at least once a year, or more if needed. When reviewing the IPE, changes may be made if necessary and put in writing.

Actively Seek Possible Financial Resources

Heath Care: Private insurance

There are various financial assistance programs for families and individuals in Indiana. Medical insurance is one way to fund medical treatments. Learn about your insurance policy and what programs/services are covered. Indiana has an insurance mandate that funds autism services determined medically necessary. You (or your parent(s) can find out more information about the insurance mandate at https://www.iidc.indiana.edu/pages/Indianas-Health-Insurance-Mandate-for-Autism-Spectrum-Disorders-and-Pervasive-Developmental-Disorders-PDDs.

Heath Care: Public Insurance

There are several forms of public insurance that may be available to you, depending on your

situation. Medicaid, Medicaid Disability, and Children’s Special Health Care Services (age’s birth-21) are all programs to check into for possible coverage of medical expenses. As with private insurance, there will be limits on what medical services are covered and a limited number of medical providers who accept certain public insurance.

Medicaid is a health insurance program for persons with limited income and resources. Several programs are part of Medicaid in Indiana. An application for Medicaid is completed through the Division of Family Resources (DFR). Applications may be completed at the county office, by mail, or online. Individuals applying for Supplemental Security Income (SSI) with the Social Security Administration are also considered, at the same time, for Medicaid. Individuals who are found eligible for SSI will automatically receive Medicaid Disability. Note that eligibility for SSI may take longer than the 90 days allowed for Medicaid eligibility determinations.

Healthy Indiana Plan (HIP 2.0), provides health coverage for adults ages 19-64 who meet specific income levels (as of February 2016: individuals with an annual income up to $16,436.81, couples with an annual income up to $22,246.25, and a family of four with an annual income of $33,865.13 may qualify) and who are not eligible for Medicare or another Indiana Medicaid category. There are two types of coverage. Both cover medical expenses such as doctor visits, hospital care, therapies, medications, prescriptions, and medical equipment. Some plans may cover vision and dental coverage as well. For more information check their website at https://www.in.gov/fssa/hip/.

Medicare is a federal government health insurance program for people age 65 or older and people under age 65 with certain disabilities. It also covers people of all ages with permanent kidney failure requiring dialysis or a kidney transplant. A person under age 65 who is receiving Social Security Disability Insurance (SSDI) benefits for at least 24 months becomes eligible to enroll in Medicare. The 24-month period begins from the date that an individual is determined to be eligible for SSDI payments.

Indiana also 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 from birth to age 21 who are covered by CSHCS can receive coverage for services related to their disability, as well as primary care services. More information can be found at https://www.iidc.indiana.edu/pages/Childrens-Special-Health-Care-Services-Program-of-Indiana.

Other funding options may be 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/pages/grant-funding-opportunities. Often families and individuals must use multiple sources of financing for health care coverage.

Social Security Benefits: SSI and SSDI

Supplemental Security Income (SSI) is financial assistance provided by the federal government to eligible persons with disabilities who also have a limited income. It is money in the form of a monthly check that is directly deposited in your bank account. This financial assistance helps pay for basics such as food and shelter. It is available to people who are elderly, blind, or disabled (according to Social Security's Listing of Impairments), and who have little assets or income. Adults must document that the disability is expected to last 12 months (or result in death) and interferes with their capacity for "substantial" work. A child, before their 18th birthday may qualify if s/he meets the Social Security's definition of disability for children and the family has limited income and resources.

Indiana will automatically enroll individuals deemed eligible for SSI into Indiana Medicaid Disability. More information can be found on the latest Family Voices Indiana Medicaid Disability fact sheet found on their website at http://fvindiana.org/home.

Social Security Disability Insurance (SSDI) is a federal program that makes monthly payments to persons who are disabled and who qualify for 'Insured Status' through previous work contributions made to Federal Insurance Contribution Act (FICA). If you had a job for several years and are no longer able to work, you might be eligible for SSDI benefits if you qualify under the Social Security Administration as an individual with a disability.

Also, if you are under 18 years old you might you might qualify to draw benefits as a dependent from another individual who has contributed to the FICA fund. SSDI is also available based on a parent's contributions if the parent is retired and the disabled person became disabled before the age of 22.

You can apply for Social Security benefits at your local Social Security office. Some Social Security benefits applications are also available online at https://www.socialsecurity.gov/forms/apply-for-benefits.html. To locate your local Social Security office go to https://secure.ssa.gov/ICON/main.jsp and plug in your zip code. You can also call their toll free number to access the forms you need: 800-772-1213 (TTY 800-325-0778).

It is important to know that Social Security offers some work incentives in order to allow you to work and keep your benefits. A helpful resource for work incentives and benefits information is the Center on Community Living and Careers (CCLC) at the Indiana Institute on Disability and Community (IIDC). CCLC was mentioned previously and is one agency listed at the end of this booklet. Once on the CCLC website check under the employment heading for Benefits Information and Work Incentive Fact Sheets.

Medicaid Waivers

Medicaid Waivers can provide Medicaid funds to eligible children, teens, and adults with disabilities who meet Medicaid income eligibility requirements. Note: As a result of Senate Bill 30 passed in 1991, parental income and resources are disregarded for children under 18 years for all of Indiana's Medicaid Waivers; although assets and income in the child's name are counted. If under 18 years old the services are provided regardless of the family income. For individuals 18 years of age or over, both the individual's income and assets are taken into consideration.

The Family Supports Medicaid Waiver (FSW) is the basic entry point to receive waiver services for a child or adult with a developmental disability (which includes an autism spectrum disorder). Most individuals with ASD would apply for the Family Supports Waiver (FSW). Waiver services can cover some services and supports that are not available under traditional Medicaid as well as some that are covered under traditional Medicaid. Access an article with more information at https://www.iidc.indiana.edu/irca/articles/medicaid-waiver-programs-home-and-community-based-services-for-adults-and-children.html.

There are currently waiting lists to get the waivers which are processed by the application date. There are however priority slots for eligible individuals ages 18 through 24, who have aged out, graduated, or permanently exited from their school setting, to enter waiver services without waiting, if funded slots are available. The local Bureau of Developmental Disabilities Services (BDDS) office will determine who qualifies.

Contact your local BDDS office and request an Application Packet to apply for the FSW. To locate your local BDDS Office, visit their website at https://www.in.gov/fssa/ddrs/2639.htm.

Assistance to Apply for Healthcare, Medicaid Waivers, and Social Security Benefits

You will be most successful with some knowledgeable people guiding you through the maze of insurance and healthcare options and processes. Applying for the Medicaid Waiver can also be confusing. It is also important to note that medical coverage for healthcare is constantly changing. Two helpful groups in Indiana who can answer questions and help you understand current healthcare coverage, are listed below. These agencies, Family Voices Indiana and the Arc of Indiana, also have staff that can help explain and help you apply for other benefit programs such as Indiana's Medicaid Waivers and Social Security benefits.

- Family Voices Indiana: http://fvindiana.org or 317-944-8982;
- The Arc of Indiana's Insurance Advocacy Resource Center: https://www.arcind.org/our-programs/insurance-advocacy-resource-center/ or 317-977-2375;
- The Arc of Indiana's Advocacy Network: https://www.arcind.org/our-programs/the-arc-advocacy-network/ or 317-977-2375 or toll free at 800-382-9100.

Conclusion

Up until his point in your life you have already, no doubt, figured out many things about yourself and your needs. Now you have a diagnosis. You can now seek out more information and resources available for those on the autism spectrum. There is still work ahead but with information about your diagnosis, the important people in your life can learn more about how you process and interact with the world. Better understanding along with the proper support and commitment can go a long way to strengthen and enhance your relationships and your life!

Always remember you have strengths, interests, and abilities as well as challenges. After a diagnosis of an autism spectrum disorder, it is important to find the additional information and support you need. A diagnosis alone will not fix problems. You still have work to be done to understand ASD and how it impacts you and to find resources for support. It might still be hard to find support from programs and professionals who can help, but with a diagnosis, you can seek out professionals, services, and programs that are appropriate and better equipped to assist you. Listed below are key agencies that can provide further information, answer your questions and, in some cases, provide assistance and programs for further support.

Agencies in Indiana:

- Indiana Resource Center for Autism (IRCA): Access through the Indiana Institute on Disability and Community (IIDC): 812-855-6508 or https://www.iidc.indiana.edu/irca.
- Center on Community Living and Careers (CCLC): Access through the Indiana Institute on Disability and Community (IIDC): 812-855-6508 or https://www.iidc.indiana.edu/cclc.
- The Library at the Indiana Institute on Disability and Community: 800-437-7924 or https://www.iidc.indiana.edu/library.
- Bureau of Developmental Disabilities Services (BDDS): 800-545-7763 or https://www.in.gov/fssa/ddrs/2639.htm.
- Autism Society of Indiana (ASI): 800-609-8449 or https://www.autismsocietyofindiana.org/.
- LOGAN: 574-289-4831 or https://www.logancenter.org/.
- Easter Seals Crossroads: 317-466-1000 or https://www.easterseals.com/our-programs/autism-services/.
- Arc of Indiana: 800-382-9100 or https://www.arcind.org/.
- Family Voices Indiana: 317-944-8982 or http://fvindiana.org/home.
- IN*SOURCE (Indiana's Resource Center for Families with Special Needs):

  800-332- 4433 or 574-234-7101 or http://insource.org/.
- Indiana Department of Education: Office of Special Education: 877-851-4106 or 317-232-0570 or https://www.doe.in.gov/specialed. .
- Think College Indiana: http://www.thinkcollegeindiana.org/index.php.
- Vocational Rehabilitation Services: 800- 545-7763 or https://www.in.gov/fssa/ddrs/2636.htm.

National Agencies:

- Autism Society: 301-657-0881, toll free 800-328-8476 or https://www.autism-society.org/.
- Autism Research Institute's Autistic Global Initiative (AGI): 720-524-7232, email agi@autism.com or https://www.autism.com/AGI_adults.
- Autistic Self Advocacy Network (ASAN): info@autisticadvocacy.org or https://autisticadvocacy.org/.
- Autism Speaks: Autism response Team- 888-288-4762 or https://www.autismspeaks.org/.
- PACER National Parent Center on Transition and Employment: 888-248-0822, email transition@pacer.org or https://www.pacer.org/transition/.
- Global and Regional Asperger Syndrome Partnership (GRASP): 888-474-7277 or check: https://grasp.org.
- Job Accommodation Network (JAN): 800-526-7234 or see https://askjan.org/.
- Social Security Administration: 800-772- 1213 or https://www.ssa.gov/.