

After You Receive the Diagnosis of an Autism Spectrum Disorder



A Resource for Adolescents and Adults Who are Newly Diagnosed





Modified by the Regional Autism Advisory Council and the Transition Task Force. Spring 2021.



Regional Autism Advisory Council
3333 Burnet Ave. MLC 4002
Cincinnati, OH 45229
513-636-7616

www.raacsw.org

With special thanks to Indiana Resource Center for Autism for the original development and permission to use the content of this booklet. The original version can be viewed at:

<https://www.iidc.indiana.edu/irca>

Indiana
Resource
Center for

*A*utism


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



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 general 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. For assistance finding a trained professional please contact that Autism Society Greater Cincinnati at info@autismcincy.org.

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.

Please note that the neurodiversity movement intends to shift the language away from the use of deficits, disorders, and impairments. While recognizing there may be some who prefer to use other language besides disorder, the intention of this book is not to debate the language, but to provide resources for those who have recently received the diagnosis. Therefore, the use of the word disorder is used throughout this booklet as it is the current diagnostic label that most are likely to receive when diagnosed with ASD.



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/pages/Diagnostic-Criteria-for-Autism-Spectrum-Disorder>.

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 Ohio Center for Autism and Low Incidence (OCALI) Lending Library. The OCALI Lending Library is available to any person over the age of 18 residing or working in the state of Ohio. The application to access books is available at:


http://www.ocali.org/project/lending_library

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. Statistics range from 10% to 60% of people with autism also having a mental health diagnosis. The most common co-occurring mental health diagnoses include depression and anxiety. Anxiety 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 diagnoses that may explain some of their challenges, but not all. Other common initial and/or co-occurring diagnoses 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.


It is also important to consider work place accommodations that may help to support mental wellness on the job. A good resource to utilize in this area is the federal Job Accommodation Network at <https://askjan.org/media/psyc.htm>.

Future Planning: For All Ages

Regardless of your age and ability, everyone sets dreams and goals for the future. There are several tools that can help you determine what your short and long term goals are and assist you in identifying the people and supports that might help you to achieve them. Both of these tools described below can be done in a self-directed manner and with those who you consider part of your support network.

The Arc's Center for Future Planning is a resource network developed to help individuals with developmental and intellectual disabilities and their families with future planning. These resources can be found at: <https://futureplanning.thearc.org/>

The Charting the LifeCourse tools are another helpful resource for planning. The Charting the LifeCourse Framework was created by families to help people of all abilities and all ages develop a vision for a good life, think about what they need to know and do, identify how to find or develop supports, and discover what it takes to live the lives they want to live. Individuals and families may focus on their current situation and stage of life but may also find it helpful



to look ahead to think about life experiences that will help move them toward an inclusive, productive life in the future.

Even though it was originally created for people with disabilities, this universally-designed framework may be used by any person or family making a life plan, regardless of life circumstances.
<https://www.lifecoursetools.com/>




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 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.


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 14 years or older 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.

Educational Resources

State Support Teams

The state has been divided into 16 regions. Each region has a support team. The goal of the support team is improve school delivery, literacy, special education compliance and school readiness. There is a parent contact or representative at most teams who can talk with parents about school concerns related to special education. To find your local contact please visit <http://education.ohio.gov/Topics/School-Improvement/State-Support-Teams>



State Support Team 13 which serves Hamilton, Butler, Clermont and Warren Counties, has a parent contact at 513-674-4234.

Parent Mentors of Ohio

A parent mentor is a parent who has a child with a disability and is employed by the school system to help the school district and families communicate effectively. There is no charge when working with a parent mentor. They can provide guidance, support, information and resources to families. In addition, they often are willing to attend school meetings with families. Not all districts have a parent mentor, to find out whom your parent mentor is contact the Director of Special Education in your district and/or visit <http://www.ocecd.org/ContactaParentMentor.aspx> Spanish-speaking families: marbellac@ocecd.org or 844-382-5452

Ohio Coalition for the Education of Children with Disabilities (OCECD)



Ohio Coalition for the Education of Children with Disabilities

This is a statewide program that works with families to get education assistance. There are regional contacts that can provide support and assistance regarding special education.

800-374-2806 ext. 20 <http://ocecd.org>

Disclosure: For Employment Accommodations

If you need accommodations to obtain or keep a job, then disclosure of your diagnosis to your employer is necessary. "Disability Disclosure 101", is a free workbook for youth to help discuss disclosure with an employer and is accessible online at <http://www.ncwd-youth.info/411-on-disability-disclosure>

Opportunities for Ohioans with Disabilities 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 Vocational Rehabilitation 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 in Ohio 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. One place to look for social skills support is on the Office of Disability Employment Policy Website at

<https://www.dol.gov/odep/topics/youth/softskills/>. This curriculum was developed for 14 to 21 year olds to teach work place readiness skills to enhance communication, enthusiasm and attitude, teamwork, networking, problem solving and critical thinking, and professionalism.

The University of Kansas Research and Training Center on Independent Living has developed a series of Fact Sheets that you may find helpful including one on Social Support and Networking. These are titled, Out and About: Laws that Protect People with Disabilities and can be found at, <https://rtcil.drupal.ku.edu/resources/factsheets#out>.



The Autism Society of Ohio and the local chapters such as the Autism Society of Greater Cincinnati maintain online databases of services and organizations throughout Ohio. You can find these resources by visiting their website <https://autismohio.org/> or <http://www.autismcincy.org/>. Also look at the end of this booklet for information to contact the Autism Society of Ohio 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/pages/Supporting-Youth-with-Autism-Spectrum-Disorders-Through-Postsecondary-Transition>.

In Ohio, 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 high schools hold an annual Transition Fair where many local organizations and programs come for an evening to talk with students and parents, answer questions and distribute information.



A helpful transition resource is available through the Opportunities for Ohioans with Disabilities (OOD). The website offers resources and information about the services provided. <http://www.ood.ohio.gov/Transition-Students>

The Ohio Employment First website also offers resources and forms to help in the transition planning process. You can visit their website at www.OhioEmploymentFirst.com or call 614-466-6612.

In addition, the Transition Bootcamp occurs annually and may be helpful resource for caregivers to connect with the resources to help plan for the transition process. Transition Bootcamp is a one-day, intensive training seminar that provides information about the components of a successful transition for children with disabilities to adult life. Breakout sessions are offered on topics such as financial strategies, Employment First, education options after high school, SSI, SSDI, the Medicaid application process, transitioning to adult healthcare and guardianship. A vendor fair with over 50 state and local organizations are available throughout the day. Attendees leave with a binder of useful tools and resources. Because a person can't go to all sessions in one day, booster sessions are offered throughout the year for continued support. For information on upcoming Transition Bootcamp, Booster sessions, and other training events please visit https://www.ucucedd.org/?page_id=129.

Consider utilizing Career Connections which provides a framework to help Ohio students develop a vision and a realistic plan for their future by recommending coursework related to career interests.

<http://education.ohio.gov/Topics/Career-Tech/Career-Connections>.

The Ohio Age-Appropriate Transition Assessment Library (OHIO AATA) has multiple free assessments that may be helpful to identify interests, needs, and strengths as part of the career interest exploration. www.ohioAATAlibrary.org


Ohio Means Jobs offers Career Cluster Inventory and Strengths Skills Inventory which can suggest career pathways that may be of interest. When you create an account all search results are saved in a “virtual back-pack” for future reference. While this website is not specifically designed for students with disabilities, it is an important resource as it is used by all state-regulated employment support and placement agencies in Ohio. www.ohiomeansjobs.com

A number of providers are available to help navigate the transition process and offer a variety of career planning resources. Utilize the Department of Developmental Disability Provider Search tool for the most up to date list of provider options. http://providersearch.dodd.ohio.gov/pui_results.aspx?es=e9d4c0a1d8e94c3c81486e99098eae9



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.



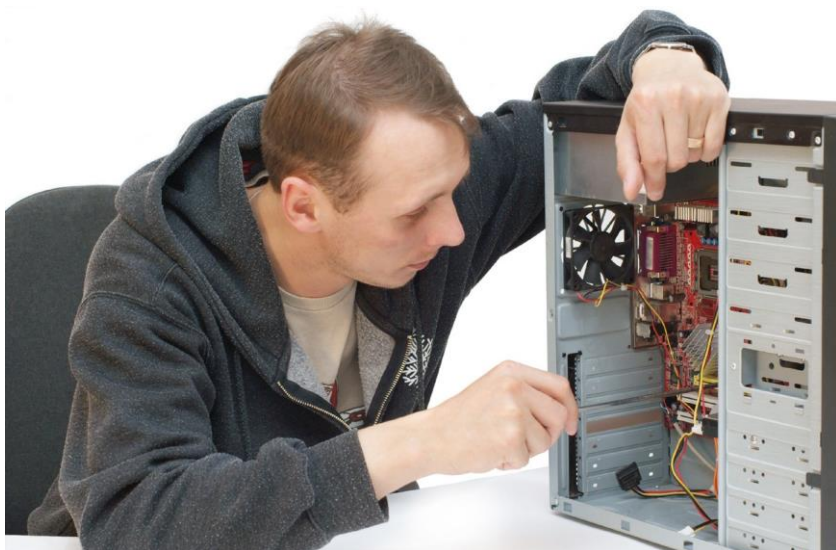
An important piece of advocating for yourself is to apply for services from the Disabilities Student Services (DSS) office on campus.

If you have decided to attend college or are already in college and need support, the article, *Making my Way Through College: A guide for students with disabilities*, is a helpful resource and available at http://www.ohioemploymentfirst.org/up_doc/Making-My-Way-through-College_FINAL.pdf

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 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 contact 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 those services.

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.

An additional resource in this area is Think College at www.ThinkCollege.net. Think College is a national organization dedicated to developing, expanding, and improving inclusive higher education options for people with intellectual disability.




Actively Seek Support for Employment Needs

Getting a job and keeping it can be difficult for many on the autism spectrum. Being an exceptional high school student does not automatically lead to success in college or in 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 the Bureau of Vocational Rehabilitation (BVR) 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

The Bureau of Vocational Rehabilitation (BVR) provides individuals with disabilities services and supports necessary to help them attain and maintain employment. The Ohio Bureau of Vocational Rehabilitation Services, is operated through the Opportunities for Ohioans with Disabilities (OOD). OOD is a state program for adults and high school students (usually starting at age 14) with any disability. Disabilities may include physical, intellectual, mental health, or sensory disabilities. Vocational Rehabilitation (VR) services are customized for each individual through assessments and one-on-one meetings with professional VR Counselors. VR services are available in all 88 counties and include:

- Evaluation and treatment of an individual's disability;
- Information and referral services;
- Vocational counseling and training;
- Job search and job placement assistance;
- Educational guidance (tuition resources and other support);
- Transportation services;
- Occupational tools and equipment;
- Personal attendant services (reader, interpreter, etc.).

Vocational Rehabilitation Counselors are available at OOD offices located throughout the state of Ohio to assist individuals with disabilities. Counselors at these local offices can assist individuals with disabilities determine if they qualify to receive services from OOD.



Eligibility for vocational rehabilitation services is based on four factors:

1. You have a physical, cognitive, or mental impairment documented by the appropriate qualified professional (doctor, psychologist or other).
2. Your documented impairment causes a substantial impediment (barrier) to employment.
3. You can benefit from vocational rehabilitation services that lead to an employment outcome.
4. You require vocational rehabilitation to prepare for, secure, retain or regain employment.

To Apply for VR Services:


The first step in securing services from Opportunities for Ohioans with Disabilities is to complete an application for services. An application can be submitted by telephone, electronic mail, facsimile, or by visiting the nearest OOD office. Visit <http://www.ood.ohio.gov/Core-Services/BVR/Application-for-Services> or <http://www.ood.ohio.gov/Core-Services/BVR/Regional-Offices> to find information for local offices.

After the application is completed, an interview will follow to help determine eligibility. A friend or family member may accompany you to the interview. A counselor will discuss career goals, work history, educational background, disability and the services necessary to reach an employment goal.

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.

If the applicant is receiving Social Security benefits, please bring the letter that you received from the Social Security Administration.



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 timeframes 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.

Ohio 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 through the Ohio Autism Insurance Coalition at <https://asdohio.com/>. The Ohio Autism Insurance Coalition provides helpful guides and FAQs to help navigate insurance coverage.

Heath Care: Public Insurance

There are several forms of public insurance that may be available to you, depending on your situation. Medicaid, Medicaid Disability, Medicare, and Children with Multiple Handicap Program (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. The Ohio Department of Medicaid provides a variety of programs to assist people with disabilities in health care coverage and supports to be integrated into the community. Visit <http://medicaid.ohio.gov/> for information about Ohio Medicaid programs and eligibility. 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.

The Children's Health Insurance Program (CHIP) serves uninsured children up to age 19 in families with incomes too high to qualify them for Medicaid. States have broad discretion in setting their income eligibility standards, and eligibility varies across states. To check CHIP eligibility call 1-800-318-2596 (TTY: 1-855-889-4325) or fill out an application through the Health Insurance Marketplace at <https://www.healthcare.gov/>.

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. You automatically get Part A and Part B after you get disability benefits from Social Security or certain disability benefits from the RRB for 24 months.



For specific Medicare billing questions and questions about your claims, medical records, or expenses, log into www.MyMedicare.gov or call 1-800-MEDICARE (1-800-633-2273) or TTY users call 1-877-486-2048.

The Ohio Department of Health administers a Children with Multiple Handicaps Program (BCMh). BCMh links families of children with special health care needs to a network of quality providers and helps families obtain payment for the services their children need.

BCMh provides assistance to children with special health care needs and their families who meet the medical and financial eligibility criteria. Assistance is provided to children under the age of 21 who have special health care needs and are residents of the State of Ohio. Spina Bifida is a covered diagnosis.

Although BCMh covers a wide range of services, it is important to know BCMh does not cover all the services a child with special health care needs may require, nor are all services available for every diagnosis. Services must be related to the child's BCMh-eligible condition. For more information please contact 1-800-755-4769 (families only) or (614) 466-1700 or BCMh@odh.ohio.gov.

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.



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 www.socialsecurity.gov/locator 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. For questions about work incentives and to find out more about the Ticket to Work Program, please call the Ticket to Work Help Line at 1-866-YOURTICKET (1-866-968-7842), visit www.chooseworkttw.net, or email support@chooseworkttw.net. A helpful resource for disability benefits is the Disability Benefits 101 <https://oh.db101.org/> which gives Ohioans tools and information on health coverage, benefits, and employment.

Medicaid Waivers


Medicaid Waivers can provide Medicaid funds to eligible children, teens, and adults with disabilities who meet Medicaid income eligibility requirements. Waivers are one way to pay for services that help people with developmental disabilities live their lives. If under 18 years old Medicaid income eligibility is determined by the income and assets of the child.

There are currently three waiver programs administered by the Ohio Department of Developmental Disabilities. The Individual Options, Level One, and Self-Empowered Life Funding (SELF) waivers each have different spending limits and offer some different services. The state of Ohio is in the process of making changes to the waiver system so please visit www.fixthelist.info for up to date information about waivers.

By braiding together multiple funding sources, such as local county board of developmental disability levy funds and Ohio Medicaid benefits, a person with developmental disabilities may be able to have their service needs met without a waiver.

Contact your local county board of developmental disabilities if you need additional supports to see if they can be provided through a waiver or other resources.
<http://dodd.ohio.gov/CountyBoards/CNT/Pages/default.aspx>.

Each of Ohio's county boards of developmental disabilities maintains the requests of people seeking Individual Options, Level One, or Self-Empowered Life Funding waivers.



This Waiting List is prioritized first for [emergency needs](#), then by [priority categories](#). All other requests are organized by the [date of the request](#) when there is no emergency need or priority category.

Level 1: allows for minimal paid support and relies heavily on natural supports assisting individuals to live in community settings of their choice with supports instead of living in an institution.

Eligibility: Individuals must meet be Medicaid-eligible and have an ICF level of care – there are no age requirements.

Services provided by the Level 1 Waiver include:


Homemaker/personal care; community respite; personal emergency response systems, environmental accessibility adaptations, supported employment, residential and information respite, transportation, specialized medical equipment, emergency assistant, day habilitation

SELF: Ohio's first participant-directed waiver. It lets people direct where and how they receive services, this is known as self-direction.

Eligibility: Individuals must be willing and able to self-direct at least one waiver service, be able to have their health and welfare needs met through the SELF waiver, need of at least one SELF waiver service, be Medicaid eligible, and have an ICF level of care. There are no age requirements for eligibility.

Services provided by the SELF waiver include:

Support brokerage, community inclusion (personal assistance/transportation), residential respite, community respite, adult day supports, vocational habilitation, supported employment-enclave, remote monitoring and equipment, integrate employment, functional behavioral assessment, clinical/therapeutic intervention, participant-directed goods and services, participant/family stability assistance.



Individual Options (IO): more comprehensive waiver which allows individuals to live in community settings of their choice with supports instead of living in an institution. The IO waiver has a higher funding limit and waiver services are developed in order to meet a person's individualized needs.

Eligibility: Individuals must meet Medicaid eligibility criteria and have an ICF level of care – there are no age requirements.

Services provided by the IO waiver include:

Homemaker/personal care; residential and informal respite, personal emergency response systems, environmental accessibility adaptations, supported employment, community respite, Ohio Shared Living, transportation, specialized medical equipment, day habilitation, career planning, group employment support, vocational habilitation, nutrition, waiver nursing, money management, home delivered meals, and interpreter services.

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.

Helpful groups in Ohio who can answer questions and help you understand current healthcare coverage, are listed below.

- The Arc of Ohio: 614-487-4720 or 800-875-2723 or <https://www.thearcofohio.org/>
- Local board of Developmental Disability Services <http://dodd.ohio.gov/CountyBoards/CNT/Pages/default.aspx>
- Ohio Autism Insurance Coalition <https://asdohio.com/>



ABLE/STABLE

In 2014, federal legislation was passed leading to the creation of the Achieving a Better Life Experience (ABLE) Act. ABLE allows for individuals with disabilities to accumulate and save wealth without risking the loss of Social Security or other government benefits, including Medicaid. Ohio's ABLE program, known as STABLE, allows participants to contribute to a tax-free savings plan for disability related expenses. For more information contact team@stableaccount.com or 1-800-439-1653 or visit the website at www.stableaccount.com.


Guardianship and Alternatives

After a person turns 18, you become your own guardian. While everyone needs some help to make decisions, many people with disabilities do not have or need guardians. Many alternatives to guardianship such as Supported Decision Making offer necessary support with less intrusion. Guardianship and alternatives are based on the person's competence and capacity to make decisions. Before choosing guardianship or alternatives assess the areas in which the person needs support to make decisions. The law requires considering the least restrictive options first. Guardianship is the most restrictive option and is difficult to terminate once awarded. Alternatives to Guardianship support may include releases of information, supported decision making, trusts, authorized representation, protective orders, Powers of Attorney, Conservatorship, representative payee, and/or limited guardianship.

Assistance to Consider Guardianship and Alternatives

It is encouraged to explore options and seek external legal advice when considering options for guardianship or alternatives. Resources are listed below to help in the decision making process.

- Advocacy and Protective Services, Inc. (APSI): <http://www.apsiohio.org/> or 1-800-282-9363
- Lifespan: <https://lifespanohio.org/guardianship/> or 513-785-2937

- 
- Disability Rights of Ohio: www.disabilityrightsohio.org
 - Ohio Attorney General's Guardianship Guide:
[http://www.ohioattorneygeneral.gov/Files/Publications-Files/Publications-for-Consumers/Ohio-Guardianship-Guide-\(PDF\)](http://www.ohioattorneygeneral.gov/Files/Publications-Files/Publications-for-Consumers/Ohio-Guardianship-Guide-(PDF))
 - Legal Services:
http://www.ohiolegalservices.org/publiclegal_problem/wills-and-probate
 - Pro Seniors: <http://www.proseniors.org/>
 - Ohio State Bar Association:
<https://www.ohiobar.org/ForPublic/Resources/Pages/PublicResources.aspx>
 - National Resource Center on Supported Decision-Making:
www.supporteddecisionmaking.org
 - Jenny Hatch Justice Project on Supported Decision-Making:
www.jennyhatchjusticeproject.org
 - American Bar Association PRACTICAL Tool:
http://www.americanbar.org/groups/law_aging/resources/guardianship_law_practice/practical_tool.html
 - Missouri Guide (Stoplight Tool):
<http://moguardianship.com/Alternatives%20to%20Guardianship%20Tool%20Revised%2011-2015.pdf>



Conclusion

Up until this point in your life, you have already 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 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 Ohio

- The Arc of Ohio: 614-487-4720 or 800-875-2723 or <https://www.thearcofohio.org/>
- Autism Society Greater Cincinnati: 513-561-2300 or www.autismcincy.org
- Autism Society Ohio: <https://www.autismohio.org/>
- Department of Developmental Disabilities: 800-617-6733 or <http://dodd.ohio.gov/Pages/default.aspx>
- Disability Rights of Ohio: 614-466-7264 or 1-800-282-9181 (Toll free in Ohio only) or www.disabilityrightsohio.org
- Ohio Center for Autism and Low Incidence: www.ocali.org
- Ohio Coalition for the Education of Children with Disabilities: <http://ocecd.org>
- Ohio Department of Health: <http://www.odh.ohio.gov/>
- Ohio State University Nisonger Center: <http://nisonger.osu.edu/>
- Opportunities for Ohioans with Disabilities: 1-800-282-4536 <http://www.ood.ohio.gov/>
- Regional Autism Advisory Council of Southwest Ohio: 513-636-7616 or <https://sites.google.com/site/sworaac/>
- University of Cincinnati Center for Excellence in Developmental Disabilities: 513-803-3627 or <https://www.uccedd.org/>

National Agencies

- Autism Society: 301-657-0881, toll free 800-328-8476 or <http://www.autism-society.org/>
- Autism Research Institute's Autistic Global Initiative (AGI) 720-524-7232, email agi@autism.com or http://www.autism.com/AGI_adults
- Autistic Self Advocacy Network (ASAN): info@autisticadvocacy.org or <http://autisticadvocacy.org/>
- Autism Speaks: Autism Response Team: 888-288-4762 or <https://www.autismspeaks.org/>
- Disability*gov: <https://www.disability.gov/>
- Global and Regional Asperger Syndrome Partnership (GRASP): 888-474- 7277 or visit: <https://grasp.org>
- 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/pages/irca>
- Job Accommodation Network (JAN): 800-526-7234 or see <https://ask-jan.org/>
- Social Security Administration: 800-325-0778 or <https://www.ssa.gov/>
- Think College: 617-287-4300 or visit www.ThinkCollege.net
- University of Kansas Research and Training Center on Independent Living Out and About: Laws that Protect People with Disabilities: <https://rtcil.drupal.ku.edu/resources/factsheets#out>

