

Section 2:

After the Diagnosis

How I am feeling after the diagnosis and who can I talk to?

Being given a diagnosis can be overwhelming for the individual and their family. It can cause many emotions to come to the surface immediately or can take time and slowly overwhelm you. It's important for you to process the information you have received and create a plan to move forward. Below are several steps you can take to help you through this new journey.

Step One - Take time to breathe and process through the information you have received. For some the diagnosis could be a shock and for others they may have questioned the possibility of a diagnosis for some time. Every individual and caregiver will handle the situation differently and it is recommended to implement self-care techniques to help navigate through the changes in your family. These techniques may feel new at the beginning but are easy additions to a regular routine moving forward.

Step Two - Knowing the disability is important, but it does not define your loved one. This step is incredibly important as you begin your journey. For many of us who have been a part of this community, we will say the person has been diagnosed with a disability and not that they are their disability (i.e., Tom has been diagnosed with autism, not Tom is autistic). You may hear people in the disability community refer to this as People First Language (PFL). This is a way for us to acknowledge the individual has a disability, but we never want it to be the sole attribute to define them. Your loved one is still your loved one and their value doesn't change with the diagnosis. Those diagnosed with the disability may choose to identify themselves as their diagnosis (i.e., I am autistic, I have down syndrome, I am deaf, etc.). This is a way for individuals to own their disability.

Step Three - Education is your greatest tool throughout your new journey. Take the time to learn everything you can about the diagnosis. Utilize the medical team who gave the initial diagnosis, your family physician, medical journals, books, websites affiliated with medical organizations, etc. Ensure you are using reputable sources when gathering information to help you through your new journey.

Step Four - Build your team of medical professionals, local providers, family, friends, educators, social media groups, local support groups. It takes a village and many people have been through the process before and want to provide you with support. Never hesitate to ask for assistance. It is not uncommon for caregivers to seek out support from a therapist to process through the diagnosis of their loved one. This is a valuable step in your journey and talking through your feelings can help create a solid plan to move forward.

Step Five - After you have taken the time to process through the diagnosis, gathered information, and start to build your team, now is the time to talk with family and friends. Some of these conversations can be the most difficult to have but are necessary. Having advocates and allies ensures you have people looking out for you on this journey.

Self-Care Techniques

De-clutter - Being surrounded by unnecessary clutter can increase feelings of being overwhelmed. Starting small will allow you to ease into de-cluttering while relieving additional stress. Choose a closet, a corner, or a room to start small and work at a pace you feel comfortable with.

Find a hobby - Find a hobby unrelated to your career. Drawing, painting, gardening, woodworking, etc. Allow yourself the opportunity to engage in something to allow your creativity to come out.

Fuel your body - Find ways to add fruits and vegetables into your diet, aim to have one healthy meal each day and increase to additional healthy options weekly.

Get outside - Walk, run, bike, garden, take your dog for a walk, etc. Find any reason to get outside to reset your mind.

Listen to music - Take 30 minutes each day and listen to your favorite music. This could be while you are getting ready for the day, your commute, while making supper, etc.

Massage - Set aside time once a month and get a massage. There are many options for massage therapists in our area. Some health savings plans will allow you to utilize your funds if a note is on file from your physician. Talk with your health savings account customer service for more information. If your plan does not cover massages, we have several massage schools in the area with students who offer training massages at discounted rates.

Meditate and Relaxation - Give yourself the gift of peaceful moments. Turn off your electronics, utilize aromatherapy through oils or candles, turn on calming music or sit in silence. Allow yourself time to rest.

Move - Get into an exercise routine before and after work by joining a class, going for a walk, lifting weights, dance, yoga, etc. If it helps, find a friend or neighbor who can join you.

Read a book - Find a cozy place inside or go find a great space outside with fresh air. Allow yourself a minimum of 15 minutes to read each day.

Relationships - Nurture current relationships and build new friendships. Surround yourself with positive people who support you and who you feel comfortable sharing how you are coping with the current demands of your life. Schedule time as a group or one on one.

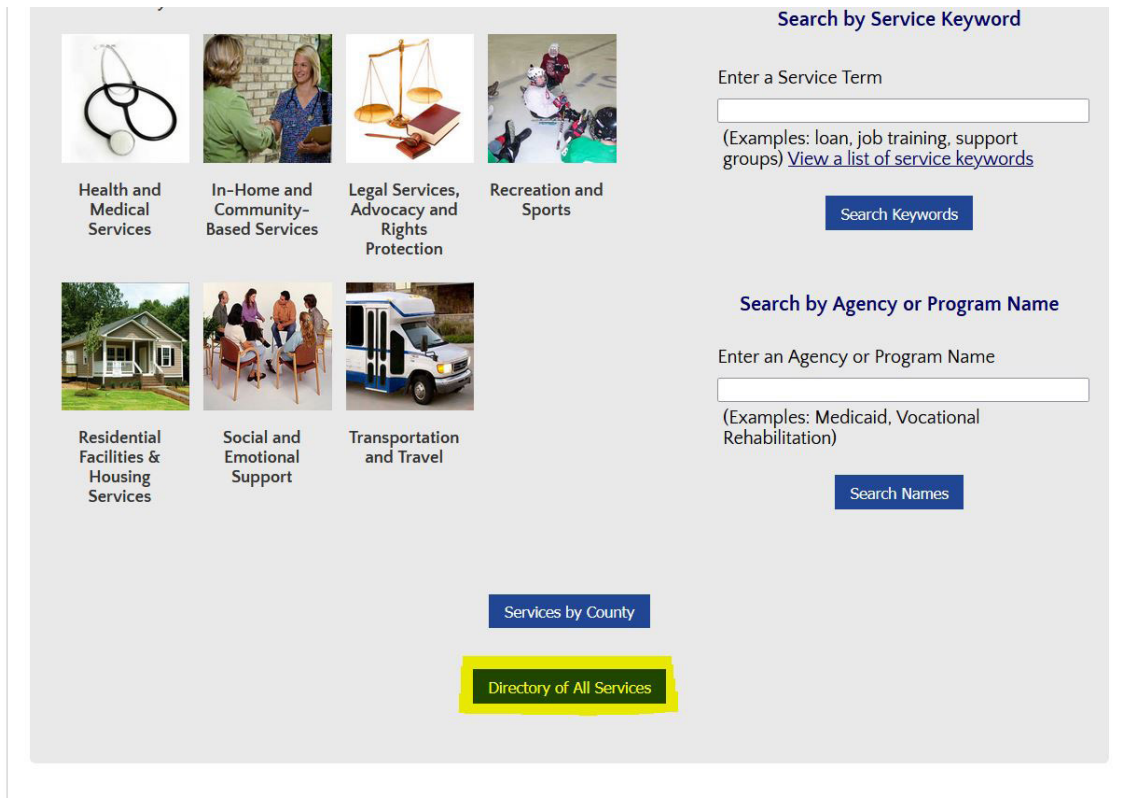
Sleep - Develop and implement a regular sleep routine. If the kids go to bed at 8 PM, there is no reason you can't be close behind. You will be your best self if you can get the rest you need.

Take breaks - This applies to both 15-minute breaks, walking breaks, and/or lunches. You can only run on fumes for so long before you need the time. Be aware of your start and stop times for work. It is easy to go in early or stay late, but self-care means you are making yourself a priority to be the best version for you and your family.

Vacation - Take time to get away. This could be a long weekend or a full week off. Allowing yourself to take time away to reset with your family. This will help you to re-energize and find balance.

Information Resources from Iowa Compass

Physicians, specialists, support groups and credible websites are all beneficial resources to gather information to help support you and your loved one. Below you will find instructions on how to find these supports in the Iowa Compass online resource database. To explore these condition-specific Information Resources [click this link](#) or navigate to search.iowacompass.org and click on the Directory of All Services button near the bottom of the page.



The screenshot displays the Iowa Compass search interface. On the left, there are seven service categories, each with a representative image and a text label: Health and Medical Services (stethoscope), In-Home and Community-Based Services (two women talking), Legal Services, Advocacy and Rights Protection (scales of justice), Recreation and Sports (people playing), Residential Facilities & Housing Services (a house), Social and Emotional Support (a group of people sitting), and Transportation and Travel (a bus). On the right, there are two search sections: 'Search by Service Keyword' with a text input field and a 'Search Keywords' button, and 'Search by Agency or Program Name' with a text input field and a 'Search Names' button. At the bottom center, there are two buttons: 'Services by County' and 'Directory of All Services', with the latter highlighted in yellow.

From the directory, type in “Information and Referral” into the “Search for a Specific Service” field and click “Search Keywords”. While in the sub-directory you will find a wide variety of disability related conditions/populations to explore.



Service Search

[Back](#) | [Start Over](#) | Search for a specific service **Information and Referral** [Search Keywords](#)

Find the help you need > **Information and Referral**

[Click here to see the full list of services](#) [Directory of All Services](#)

Listed below are matching services. (Click a service term to search. Click to see a definition.)

[Information and Referral](#)

- [for Accessibility Issues](#)
- [for Accessibility Issues - Agricultural/Forestry and Related Occupations](#)
- [for Accessibility Issues - Parents With Disabilities/Health Conditions](#)
- [for Active Military](#)
- [for AIDS/HIV](#)

By clicking on one of the terms, you can use the search filter to narrow the zip code/age/change conditions by clicking on the “Change Search Filters” link.

Search Results

This search is not restricted by city or ZIP Code. If you click to update search filters below and enter a ZIP Code, resources will display by distance from you.

[Back](#) [New Search](#) [Print Page](#) [Map all](#) Sort list by: [Agency name](#) | [City](#)

[\(click to change search filters\)](#)

Find the help you need > **Information and Referral * Autism Spectrum Disorder**

Programs whose primary purpose is to maintain information about human service resources in the community and to link people who need assistance with appropriate service providers and/or to supply descriptive information about the agencies or organizations which offer services. The information and referral process involves establishing contact with the individual, assessing the individual's long and short-term needs, identifying resources to meet those needs, providing a referral to identified resources, and, where appropriate, following up to ensure that the individual's needs have been met.

2 Providers offering the requested services Providers are listed by city

<p>Autism Speaks</p> <p>1060 State Road 2nd Floor Princeton, NJ 08540</p>	<p>(888) 288-4762 Toll-free - Autism Response Team - English Speaking (888) 772-9050 Toll-free - Autism Response Team - Spanish Speaking (616) 385-8500 Local (609) 430-9163 Fax http://www.autismspeaks.org help@autismspeaks.org</p>	<p>view map</p> <p>Mercer County</p>
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If you are a reader, spend time exploring the catalog of the [Disability Resource Library at the University of Iowa Center for Disabilities and Development](#) (319-356-1345). There you will find a [curated catalog](#) of books written by and/or for individuals diagnosed with a disability. Many books are available online for all age ranges, diagnosis, and relatable content. In addition to printing, adapted toys can be mailed for free to any Iowan.

Building a Team

When building a support team, the team will generally start small and increase in size as you learn more about the diagnosis or are referred to additional physicians and specialists. Here are some possible members of your team:

Developmental and Behavioral Pediatrician - a physician specially trained to address behavioral, developmental, and/or learning needs of children. They will provide diagnosis, referrals, and assist in locating community resources.

Local Service Provider - an organization supporting individuals with a development, intellectual, or mental health diagnosis (i.e., The Arc of East Central Iowa, Abbe Center, etc.). The staff can help provide resources, education, and support throughout all stages of an individual's journey.

Medical Specialist - a medical professional focused on certain areas of the body (i.e., audiologist, cardiologist, genetics, immunologist, internal, neurologist, podiatry, etc.).

Nurse Practitioners (NP), Advanced Registered Nurse Practitioner (ARNP) or Advanced Practice Registered Nurse (APRN) - a nurse who has graduated with an advanced nursing degree. They can complete a wide range of tasks.

Parent Partner Support - a fellow parent or caregiver of an individual diagnosed with a disability who can lend a listening ear, share their experiences, and offer advice as you go through your journey. If you are needing additional support contact Kristen Krambeer at The Arc of East Central Iowa at kkrambeer@arceci.org to be connected to a parent partner.

Physicians - a medical professional with a medical doctorate degree who can provide an individual with a diagnosis, care, treatment, and prescribe medication.

Physician's Assistant - a medical professional licensed to provide services under supervision of a physician.

Psychologist - a person who studies the mind and brain. A psychologist will help an individual utilize psychotherapy to adjust changes in the individual's behavior.

Psychiatrist - a person who diagnoses and helps to prevent and treat behavioral, emotional, and mental health.

School Staff - a member of a school who provides support to students and their families (i.e., teacher, school counselor, principal, etc.).

Spiritual Advisor - is anyone in your faith you acknowledge as a leader to help guide you through your journey (i.e., bishop, elder, guru, lama, imam, minister, pastor, priest, rabbi, reverend, etc.).

Therapist - a specialist who works to support an individual through the process of handling multiple emotions through a diagnosis and medical process (i.e., Occupational, Play, Physical, Respiratory, Speech, Musical).

Talking with others about the diagnosis

It can be easy to feel like it is your job to explain the diagnosis everywhere you go. Luckily, there are many wonderful resources online, books, public speakers, podcasts, etc. that anyone can access to learn more about a particular diagnosis. Never feel you are alone or must educate everyone in every circumstance. Sometimes the best thing you can do is direct them to places where they can learn more and make yourself an open resource if they have follow-up questions.

Helpful tips when sharing a diagnosis with another person:

Make sure the information you share is accurate. With all the resources online, you want to direct people to appropriate and useful information.

Be aware of the audience you are speaking to and how much information you share. For a friend or family member, you may be okay sharing every detail, but with a stranger, you may say, “they/I have been diagnosed with a disability” and choose to share nothing else.

If you go into further detail, it is best to provide the information in a private location to help maintain your privacy but allow time for the individual to process the information. They may begin to ask questions during the initial conversation or ask to speak to you in the future if you are open to further discussion.

It is important to remember disclosing is always a choice. You should never feel pressured to disclose a diagnosis and you are not required to disclose. This includes disclosures to current or future employers.

Additional resources for sharing someone’s disability diagnosis or how to interact with individuals diagnosed with a disability:

Center For Disease Control and Prevention: Communicating with People with Disabilities

<https://www.cdc.gov/ncbddd/disabilityandhealth/materials/factsheets/fs-communicating-with-people.html>

Cincinnati Children’s Hospital Medical Center: How to Talk to Kids About People with Disabilities

<https://blog.cincinnatichildrens.org/86/how-talk-kids-people-disabilities>

Raising Children: Talking About Your Child's Disability

<https://raisingchildren.net.au/disability/family-life/communicating-relationships/talking-about-child-disability>

Respectability: Etiquette: Interacting with People with Disabilities

<https://www.respectability.org/inclusion-toolkits/etiquette-interacting-with-people-with-disabilities/>

After a Conversation: What are things, someone can do to help end the stigma around disabilities?

Ask questions. It is always better to ask in an open honest way about someone's disability. Taking the time to hear people's stories may help you understand who they are as a person, their experiences, and some of the struggles they face each day.

Never joke about having a disability and if you hear something, saysomething.

Using the phrase of "Everyone's a little on the spectrum", "I'm a little slow too", "I couldn't even tell", or "I'd like to cruise around on two wheels all day too" can be extremely hurtful for those who are experiencing the real challenges of being diagnosed with a disability.