

Family Resource Guide



The Arc of East Cental Iowa

Family Resource Guide

The Arc of East Central Iowa is a local chapter of The Arc of the United States, a national nonprofit organization headquartered in Washington D.C. We are one of 16 Iowa chapters advocating for people diagnosed with disabilities. Our chapter was started in 1953 by a group of parents who wanted to raise their children in their homes and communities and not in institutions. Our administrative office is located in Cedar Rapids, Linn County, Iowa, and we provide services to 5 additional surrounding counties.

This guide is a breakdown of information, resources, and tools to support individuals diagnosed with a disability, their caregivers, guardians, families, friends, and community members. This guide is intended for general information only and is not intended, nor should it be construed or relied on as legal or medical advice. You should seek the appropriate counsel prior to making any decision on services or resources. This guide will be reviewed and updated to reflect changes to policies, procedures, and additional resources.

A special thank you to lowa Compass for their support and contribution to this guide. Iowa Compass connects people with disabilities and complex health-related needs to services and supports in communities throughout lowa.

This guide is available to be printed in sections or in its entirety. For questions on the guide, please contact:

Kristen Krambeer
Advocacy Program Coordinator
The Arc of East Central Iowa
kkrambeer@arceci.org
319-365-0487 ext. 1028

Achieve with us.

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Section 1:

The Start of Your Journey

What is a disability?

An individual with a disability is defined by the Americans with Disabilities Act (ADA) as a person who has a physical or mental impairment that substantially limits one or more major life activities, a person who has a history or record of such an impairment, or a person who is perceived by others as having such an impairment. An impairment is a physical or mental anatomical, physiological, or psychological abnormality. A qualified diagnosis must come from clinical or diagnostic techniques or testing completed by a physician or specialist in the field. For more information on what qualifies as a disability visit www.ada.gov.

I am concerned my loved one has a disability. What do I do?

Meet with your family physician and share your concerns with them on the possibility of a disability. Often families will utilize the internet to complete research and to self-diagnose. It is important to seek confirmation from a physician who will direct you to the appropriate specialist. When you apply for services, you will have to provide documentation confirming the diagnosis from a physician or specialist. A specialist's documentation can carry more weight in the decision-making process for services or during the application process for government programs. When applying for government programs, you must provide medical evidence of the impairment.

How do I get a diagnosis for a disability?

During your visit with a specialist, they will complete a series of tests to diagnose the disability. It is not uncommon for other underlying diagnoses to show up during the testing process and the first specialist may direct you to another specialist for further testing.

Some clinical and diagnostic techniques and testing may include behavioral observation, blood test, genetic testing, newborn screening, prenatal (i.e., Amniocentesis or Chorionic Villus Sampling), ultrasound, etc.

A common test given to individuals is the Intelligence Quotient (IQ). IQ testing evaluates abstract thinking, academic learning, experimental learning, judgment, problem solving, and reasoning. Initial testing and recertification requirements for the state of lowa vary by the diagnosis and Home and Community Based Services (HCBS) waiver requirements. For more information on IQ testing requirements speak with your physician, specialist, or case manager.

Is my loved one protected with their disability?

Individuals diagnosed with a disability are protected under federal law. The Americans with Disabilities Act (ADA) was signed into law by President George H. W. Bush in 1990. This major civil rights bill prohibits discrimination based on disability in the private and government sectors. ADA enacted a comprehensive set of national goals to ensure individuals with disabilities enjoy equality of opportunity, full community participation, independent living, and economic self-sufficiency.

In 2008 President George W. Bush signed a revision expanding the term of disability to broaden the definition resulting in protection for more Americans under the ADA and other federal disability nondiscrimination laws.

More information on ADA and other protections against discrimination are provided in the K-12 Education and Post-Secondary Alternatives sections of this guide.



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.

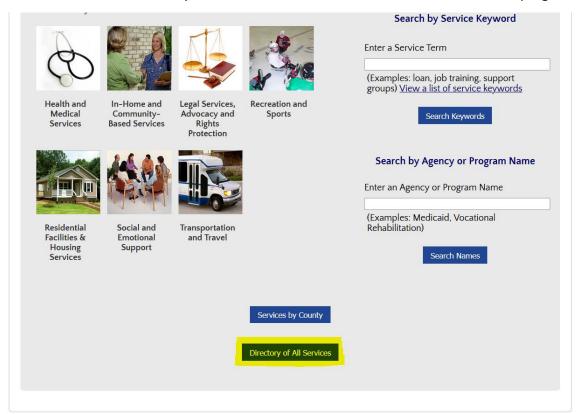
Sleep - Develop and implement a regular sleep routine. If the kids go to bed at 8 PM, there is no reason you can't be close behind. You will be your best self if you can get the rest you need.

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.

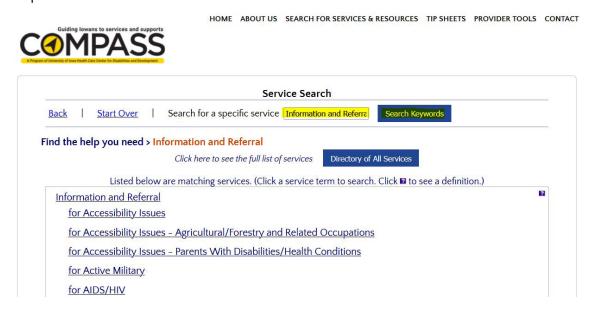
Vacation - Take time to get away. This could be a long weekend or a full week off. Allowing yourself to take time away to reset with your family. This will help you to re-energize and find balance.

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 lowa Compass online resource database. To explore these condition–specific Information Resources <u>click this link</u> or navigate to <u>search.iowacompass.org</u> and click on the Directory of All Services button near the bottom of the page.

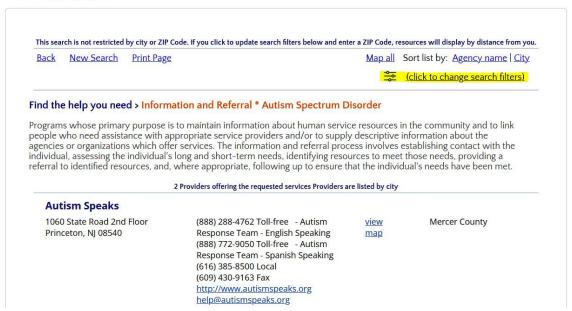


From the directory, type in "Information and Referral" into the "Search for a Specific Service" field and click "Search Keywords". While in the sub-directory you will find a wide variety of disability related conditions/populations to explore.



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



If you are a reader, spend time exploring the catalog of the <u>Disability Resource Library at the University of Iowa Center for Disabilities and Development</u> (319-356-1345). There you will find a <u>curated catalog</u> 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 lowa 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/fscommunicating-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.

Section 3:

Health Insurance

Who's going to pay for all the things we will need help with?

For many families and individuals with a disability, finding ways to pay for the care and support you need can be overwhelming. This section outlines the available options with resources to help answer questions.

I have insurance through my employer, how will it work?

In most scenarios individuals with disabilities who have employee sponsored health insurance through their employer or from a family member, can combine both insurance options. The employer insurance picks up the bill first and then any additional costs are covered by public insurance programs. This is where you will often hear the concept of "payer of last resort".

When you receive bills for services received, you will submit the bill to the employer's insurance first. The bill will be approved in full, partially covered or denied. Regardless of the amount paid on the bill, you will receive a formal decision, referred to as a Notice of Decision letter. If a full or partial payment is still required after the formal decision from the employer's insurance, the provider or individual submitting the bill balance will send it to the public insurance program payer "payer of last resort". This is done under the assumption the bill is for a covered service.

For more information on navigating public health insurance programs contact <u>your local SHIIP counselor here</u> or connect with your case manager (see Section 6 to find out who your case manager is and where to contact).

Health Insurance Marketplace

If you are employed but do not have insurance through your employer and are not eligible for Medicaid or Medicare, you will need to utilize the Health Insurance Marketplace to find private Individual Health Insurance programs. Use HealthCare.Gov to help identify plans covering the ten Essential Health Benefits in compliance with the Affordable Care Act. In Iowa benchmark plan is offered through Wellmark and can be used to explore what is minimally available on the marketplace.

Medicaid

In Iowa, SSI recipients automatically qualify for and are enrolled in Medicaid. There are three main types of Medicaid in Iowa; Iowa Health Link, Medicaid Fee-for-Service and Hawki (further defined below). In each program, eligibility is based on income. To qualify for Medicaid the applicant needs to be a resident of lowg and a U.S. citizen.

lowa Medicaid covers a wide range of health care services for lowans including physical health care, prescription costs, durable medical equipment, behavioral care, transportation, home and community-based services (HCBS) and nursing facility services. https://hhs.iowa.gov/ime/members/what-services-are-available

For dental care, lowa Medicaid members have the option of choosing Delta Dental or MCNA Dental through the Dental Wellness Plan https://hhs.iowa.gov/dental-wellness-plan

You can apply for <u>lowa Medicaid online</u> or by visiting your county's DHS office <u>https://hhs.iowa.gov/dhs_office_locator</u>.

Medicare

Medicare is a federal government health insurance program for individuals 65 years of age and older and for those living with a disability or other illness under the age of 65. Before choosing a plan, take the time to review each plan in its entirety. Medicare is broken down into four parts based on coverage:

- Part A: Covers hospital care and services related to hospital care. This does not include custodial or long-term care.
- Part B: Covers outpatient medical care and doctor's appointments.
 This includes ambulance services, mental health coverage, durable medical equipment, and some prescription drugs.
- Part C: Covers the benefits in Parts A and B but is offered through a private insurer. This plan is commonly referred to as Medicare Advantage and in some cases covers Part D's prescription drug coverage. This plan may include vision, hearing, and dental care.
- Part D: Covers Prescription Medication (generic and brand name).
 A monthly premium is required for the program and is offered through a private insurer.

For more information see https://shiip.iowa.gov/medicare-basics-a-b-c-d

Medicare Supplement Insurance (Medigap)

A health insurance policy from a private insurer to help offset the costs not covered by Part A and Part B. Items may include deductibles and coinsurance when outside of the United States. In Iowa, Supplemental plans range in cost from \$65 to \$342 each month based on coverage. For more information see https://shiip.iowa.gov/medicare-supplement-insurance

Dual Enrolled Medicare-Medicaid

Individuals who are eligible for Medicare and Medicaid are referred to as "Dually Eligible". This is where "Payer of Last Resort" is often used with medical bills being submitted to Medicare first. Medicare may pay some of the cost. If the bill is not covered in full or denied with a formal decision letter, the bill is sent to Medicaid to cover the remaining cost. Please note, due to the size of both programs, interaction between Medicare (federal program) and Medicaid (state program) can result in issues with getting health care bills paid.

https://www.medicare.gov/sites/default/files/2021-10/02179-Medicare-and-other-health-benefits-your-guide-to-who-pays-first.pdf

Dual Eligible Special Needs Plans (D-SNP)

D-SNP plans are a subset of Medicare Advantage Plans for those receiving Medicare and Medicaid benefits and/or those who reside in a nursing home or skilled facility. D-SNPs are designed to work together with Iowa Medicaid and offer benefits and resources often not available in Original Medicare or other Medicare Advantage Plans. On D-SNP's you have a care coordinator who will help you navigate doctors and specialists. The SHIIP program in Iowa has a breakdown of available D-SNP's to explore in their Medicare Advantage & Other Plans In Iowa 2023 guide.

https://shiip.iowa.gov/medicare-basics-a-b-c-d/medicare-advantage-part-c

TRICARE

Uniformed service members, veterans and their families may be eligible for health benefits through the government. TRICARE provides comprehensive health care as well as many <u>Special Programs</u> individuals and family members with disabilities can access. Connect with your <u>county Veterans</u> <u>Affairs Clinic</u> or our two Health Care Systems in Iowa City and Des Moines to explore these public insurance benefits.

Additional Medicaid Programs

Early and Periodic Screening, Diagnostic, and Treatment (EPSDT)

lowa EPSDT Care for Kids is the state's federally mandated Medicaid program for children. The Early and Periodic Screening, Diagnosis and Treatment (EPSDT) program was first created by Congress in 1967.

Any person under the age of 21 enrolled in Medicaid through a state plan is eligible for EPSDT.

If an individual has nursing services, EPSDT should be discussed with the care team for consideration of extra support in the school system.

https://www.iowaepsdt.org/iowa-epsdt/

Habilitation Services

Provide services funding and individualized support to maintain eligible persons in their own homes or communities who would otherwise require care in a medical institution. Provision of these services must be cost effective. This is also called the Habilitation waiver.

Target Population: Iowans diagnosed with a functional impairment typically associated with chronic mental illness.

Ages: 18 and up

Hawki (Healthy and Well Kids in Iowa)

Healthy and Well Kids in Iowa (Hawki) provides health care coverage for children of working families. No family pays more than \$40 per month and some families pay no premiums. Dental-only coverage is also available under Hawki for children whose families have health insurance but not dental insurance.

https://hhs.iowa.gov/hawki

Health Insurance Premium Payment Program (HIPP)

HIPP is for people who are eligible for Medicaid if they or a family member have a disability and pay for private insurance through an employer. If the state determines the employer's health insurance is more cost effective over enrollment in Iowa Health Link enrollees, their premiums will be paid by the state and the individual will utilize the Medicaid Fee for Service structure.

https://hhs.iowa.gov/ime/members/medicaid-a-to-z/hipp

lowa Health Link

IA Health Link brings together physical, behavioral, and long-term care into one program across Iowa. Most Iowa Medicaid members are enrolled in the IA Health Link managed care program, with coverage provided by a Managed Care Organization (MCO) you get to choose. These organizations receive a fixed dollar amount per member per month from the state to ensure members receive essential health care services and support.

https://hhs.iowa.gov/iahealthlink/choosing-a-health-plan

lowa Health and Wellness Plan

The lowa Health and Wellness Plan provides limited health coverage at low or no cost to lowans. Eligibility is based on household income. Iowa's version of Medicaid expansion covers health care costs for low-income households, but not those low enough to be eligible for Medicaid and often do not require a high level of medical care. Most members on the lowa Health and Wellness Plan will be on the lowa Health Link Program and receive managed care support through our state's designated MCO's. It is important to explore available benefits through the Health and Wellness plan, as many services covered through traditional Medicaid are not covered through the Health and Wellness plan.

https://hhs.iowa.gov/ihawp

Medicaid Fee for Service

Medicaid members who receive their services through Fee-for-service allows providers to directly bill the state for Medicaid covered services and bypassing Managed Care Organizations (MCOs). Most common uses of Medicaid Fee for Service are parents of children with disabilities who access the HIPP program.

https://hhs.iowa.gov/ime/members/FFS

Medicaid for Employed Persons with Disabilities (MEPD)

MEPD is a program for lowans with disabilities under the age of 65 to access Medicaid when your income or countable resources are above the imposed limits. Iowans utilizing MEPD may have seen their SSDI benefits stop because of an increase in income but may still be eligible to continue to receive Medicaid through MEPD. Another scenario could be those who require access to Medicaid but do not meet the health care spending threshold through Medically Needy.

https://dhs.iowa.gov/ime/members/medicaid-a-to-z/mepd

Medically Needy

"Medically Needy" is a program designed to provide medical coverage if you have limited income or high medical expenses resulting in the use of most of your income. It's another avenue into Medicaid when your income is not low enough to qualify but you will have ongoing high medical costs.

https://hhs.iowa.gov/ime/members/medicaid-a-to-z/medically-needy

Money Follows the Person

Money Follows the Person (MFP) Partnership for Community Integration Project is a grant funding program which allows individuals to move out of Intermediate Care Facilities for Persons with Disabilities (ICF/ID) into a home of their choice in the community. Nursing Facilities, Psychiatric Mental Institutes for Children (PMIC), and inpatient hospitals may qualify for MFP. The program provides funding for one year of support for individuals in their new independent living setting which can also include living setting costs.

Target Population: Individuals must be Medicaid eligible, diagnosed with an intellectual disability or brain injury, live in a qualifying facility for 60 consecutive days, and must express an interest in moving into the community.

Ages: All Ages

https://hhs.iowa.gov/ime/members/medicaid-a-to-z/mfp

Other Medicaid Programs

The Medicaid programs listed in this guide are a small snapshot of the most accessed public insurance programs for lowans with disabilities. For more details about other publicly available Medicaid programs see https://hhs.iowa.gov/ime/members/medicaid-a-to-z

Section 4:

Medicaid Waiver Services

What are waiver services?

Home and Community Based Services (HCBS) are a Medicaid entitlement program providing medical care and services for individuals diagnosed with a disability or for older lowans needing additional support. HCBS is designed to allow individuals to remain in their home and community, rather than medical institutions.

What does it mean to have services?

Having services means you can utilize the services based on what waiver you have been approved for. For example, if you qualify and are placed on the Health & Disability waiver, you can access the services provided on that specific waiver. If you need services provided by a different waiver, you will want to look at applying to the waiver that best fits your needs.

Who qualifies for waiver services?

Waiver qualifications are based on the disability or chronic health condition of the individual. You must be an lowa resident to qualify for lowa Waiver Services. Financial eligibility is based on the income of the individual, not the household income. To learn more about the HCBS Waiver Program, please read the HCBS Waiver Program brochure, "Are Home- and Community-Based Services Right for You?"

What waivers are available?

lowa currently supports eight HCBS waivers. Please note not all Medicaid service providers will support all the waivers listed.

AIDS/HIV Waiver (AH)

Acquired Immunodeficiency Syndrome/Human Immunodeficiency Virus Waiver (HCBS AIDS/HIV) provides service funding and individualized supports to maintain eligible members in their own homes or communities who would otherwise require care in a medical institution.

Target Population: Children and adults diagnosed with AIDS or HIV.

Ages: All

View the link for a list of available services AIDS/HIV Waiver information packet.

Brain Injury Waiver (BI)

Provides service funding and individualized support to maintain eligible members in their own homes or communities who would otherwise require care in a medical institution. Provision of these services must be cost effective.

Target Population: Children and adults diagnosed with a brain injury by accident or illness.

Ages: One month or older

View the link for a list of available services BI Waiver information packet.

Children's Mental Health Waiver (CMH)

Identify and provide services and supports that are not available through other mental health programs and services that can be used in conjunction with traditional services to develop a comprehensive support system for children with serious emotional disturbance. These services will allow children in this targeted population to remain in their own homes and communities.

Provision of these services must be cost effective.

Target Population: Children diagnosed with serious emotional disturbance.

Ages: 0-17

View the link for a list of available services <u>CMH Waiver information packet</u>.

Elderly Waiver (E)

Provides service funding and individualized support to maintain eligible members in their own homes or communities who would otherwise require care in a medical institution. Provision of these services must be cost effective.

Target Population: Adult 65 years of age or older.

Ages: 65 and up

View the link for a list of available services **Elderly Waiver information packet**.

Health & Disability Waiver (HD)

Provides service funding and individualized support to maintain eligible persons in their own homes or communities who would otherwise require care in a medical institution. Provision of these services must be cost effective.

Target Population: Children and adults diagnosed with a physical or other medical disability.

Ages: 0-64

View the link for a list of available services <u>HD waiver information packet</u>.

Intellectual Disability Waiver (ID)

Provides service funding and individualized support to maintain eligible members in their own homes or communities who would otherwise require care in a medical institution. Provision of these services must be cost effective.

Target Population: Children and adults diagnosed with an intellectual disability.

Ages: All Ages

View the link for a list of available services **ID** waiver information packet.

Physical Disability Waiver (PD)

Provides service funding and individualized support to maintain eligible persons in their own homes or communities who would otherwise require care in a medical institution. Provision of these services must be cost effective.

Target Population: Adults diagnosed with a physical disability.

Age: 18 to 64

View the link for a list of available services PD waiver information packet.

Medicaid Home and Community Based Services (HCBS) Comparison Chart:

https://hhs.iowa.gov/sites/default/files/MHDS_Medicaid_HCBS_Program_Comparison_Chart.pdf?11112021144

Section 5:

Applying for Waiver Services

Apply for Waiver Services

Online on the Iowa Department of Human Resources website: https://dhsservices.iowa.gov/apspssp/ssp.portal

By US Postal Service by downloading: https://dhs.iowa.gov/sites/default/files/470-5170.pdf?040720211544

In person by visiting your local lowa Department of Human Services office and complete an application for Medicaid (Title XIX) services with an Income Management (IM) worker.

By phone contact the Department of Human Services for assistance in completing an application or for questions with your submitted application 1-855-889-7985 (Toll Free).

Waitlist

It is of important note some waivers currently have extensive waitlists. This applies to those who are new to waiver services and those who are transitioning from one waiver to another waiver. The process of getting onto a waiver can take several years. It is best to apply as quickly as possible to ensure you are not extending your start date of receiving services. When applying, remember your application date.

To check the status of each waivers waitlist, follow these steps:

- 1. Visit https://dhs.iowa.gov/ime/members/medicaid-a-to-z/hcbs/waivers
- 2. Scroll down to HCBS Waiver Program Resources
- 3. Click on the link HCBS Waiver Waiting List Information

Scroll until you find the waiver you have applied for. Locate the current month and read the line title "Next application date for slot". This date is the current date names are being removed from the waitlist. If you see a date of 12/3/2017, it means those who applied for the waiver on or before December 3rd, 2017, are being removed from the waitlist and placed on the waiver.

Section 6:

Case Management Options

Medicaid Managed Care Organization

Managed Care Organizations (MCO) coordinate care for lowa Medicaid members. Medicaid members can choose the MCO they feel will best support them in addressing their health care needs. Open enrollment timeframes are available twice per year to allow an individual to transition to a different MCO of their choice. An individual may choose to transition for various reasons (i.e., your doctor's contract ended with your current MCO, and you wish to stay with your doctor. The option in this case would be to move to the MCO the doctor is contracted with).

Amerigroup Iowa, Inc. (Anthem)

- Member Services Number: 1-800-600-4441
- Member Services Email: MPSWeb@amerigroup.com
- Website: www.myamerigroup.com/IA

Iowa Total Care (Centene)

- Member Services Number: 1-833-404-1061
- Website: http://www.iowatotalcare.com

Molina Healthcare of Iowa

- Member Services Number: 1-800-338-8366
- Website: https://www.welcometomolina.com/ia

Alternative to MCO

Integrated Health Home

Integrated Health Home (IHH) is a team of professionals, including family and peer support services, working together to provide whole-person, patient-centered, coordinated care for adults with a serious mental illness (SMI) and children with a serious emotional disturbance (SED). This includes individuals currently receiving Targeted Case Management (TCM) and Case Management through Medicaid funded Habilitation. Care coordination is provided for all aspects of the individual's life and for transitions of care the individual may experience. The IHH is required to assist individuals with their paperwork and guide them through the application process for benefits for which they qualify. The IHH is required to coordinate all services for an individual, including medical, behavioral, and community services regardless of the funding sources for those services.

Integrated Health Home may be provided in:

- Member's home and community
- Cannot be provided in the provider's home

Target Population: adults with serious mental illness and children with serious emotional disturbance.

Ages: All Ages

https://hhs.iowa.gov/ime/members/medicaid-a-to-z/health-home

Mental Health and Disability Services (MHDS) Region of East Central lowa

The East Central Region is a partnership between counties to support children and adults who have brain health challenges and/or intellectual/developmental disabilities, including those with multi-occurring substance use issues, health issues, physical disabilities, brain injuries, and other complex human service needs. MHDS offer funding support for individuals while they are waiting to receive waiver funding or for some services not covered under an individual's specific waiver. The funding requires an application and set parameters must be met to qualify.

Target Population: Individuals waiting to receive Medicaid or who need funding for non-Medicaid covered services.

Ages: All Ages

To apply for region funding visit https://ecriowa.org/apply/

For a breakdown of policies and procedures visit https://ecriowa.org/wp-content/uploads/2020/11/ECR-Management-Plan-Final-Approved-by-MHDS-Commission-6.18.20.pdf

Section 7:

Service Options While on the Waitlist

Private Pay

As you wait for your waiver services to begin, you have the option of utilizing a private pay option to receive services from a provider during the interim. The amount of each service will depend on a pay scale updated yearly. For more information on private pay options contact your case manager or a local provider on available services and cost. Please be aware some organizations have an extensive waitlist and may be unable to provide your private pay needs.

Other Financial Options

Children at Home (CAH)

Children at Home is a grant program designed to support families with a child diagnosed with a disability. The funding is utilized for needed support and services to allow the individual to remain at home. Support and services are defined by the lowa Family Support Network as a purchase of equipment, respite care, supplies, assistive technology, or payment of other costs that relate to the individual's disability.

Eligibility

- Resident of Iowa both child and family.
- One family member must have a child with a disability.
- Child with a disability is defined as someone under the age of 22 and meets the definition of a developmental disability.
- The family's intent is to have their child remain in the home environment and utilize services and support to ensure the child remains in the home.
- The family's Federal Net (not gross) taxable income must be less than \$60,000 from the most recent tax return.

Apply for CAH

 Visit the Children At Home website and complete the steps in the How to Apply and Additional Documents section on the site. https://www.iafamilysupportnetwork.org/families/children-at-home.

Linn County Children's Mental Health Assistance (formerly known as SED or Wraparound funds)

Linn County Children's Mental Health Assistance is a county funded program to fill the gap when insurance and waiver funds do not meet the entire mental health needs of Linn County youth. It helps support youth when there are gaps in insurance or a high deductible plan. It can be used to cover mental health medications, therapy and medication check appointments, autism social skills group, family and individual BHIS services, respite, and respite activity fees, etc. with contracted providers.

Eligibility - Individuals must meet the criteria of Severe Emotional Disturbance (SED), have a mental health diagnosis, be a Linn County resident under the age of 21 and have exhausted all other options for funding. Individuals are eligible for up to \$1,500 each fiscal year (July 1st through June 30th).

Apply for Children's Mental Health Assistance - For more information please call the Linn County Wraparound Coordinator at 319-892-5726



Section 8:

On the Waiver

Congratulations on making it onto the waiver. To move forward with the waiver, you will be asked to complete several steps to begin or maintain waiver funding. Below you will find a breakdown of assessments, annuals, and contact requirements for waiver funding. In addition, you will find a brief breakdown of unit requirements for waiver services. For services on the waiver please see the previous section titled Medicaid Eligible Services.

Assessments:

Each year you will be asked to participate in an annual assessment, also known as a Level of Care (LOC). These assessments go by several names and will vary based on the waiver you are on and the age of the individual receiving services. The Assessments are facilitated by a Core Standardized Assessment (CSA) Assessor from Amerigroup, lowa Total Care, or Telligen. It is extremely important for you to complete the assessments in the time requested to ensure you do not have a gap in services. If assessments are not completed in a timely manner, you will lose access to waiver services until the assessment is completed. After an extended period of time, you may be removed from waiver services and will have to reapply for waiver services, which includes time on the waitlist. On the next page you will find a chart specifying what assessment will be administered based on an individual's waiver:

HCBS Waiver Level of Care Assessment Tools	AGE	AIDS/ HIV	ВІ	HD	PD	Elderly (EW)	СМН	ID
Case Manager	0-3	Х	Χ	Х			Х	
Comprehensive Assessment (or modified PIHH for CMH)	0-4							Х
interRAI - Pediatric Home Care (PEDS - HC)	4-20	Х	Χ	Х				
	18-19							
	18 - 20				Х			
interRAI - Home Care (HC)	21+	Х	Х		Х			
	21-64			Х				
	65+					Х		
interRAI - Child and Youth	4-20					Х		
Mental Health (ChYMH)	16-18							
interRAI - Child and Youth Mental Health (ChYMH) and Adolescent Supplement	12-18						Х	
Supports Intensity Scale Child (SIS-C)	5-15							Х
Supports Intensity Scale Adult (SIS-A)	16+							Х

HCBS Habilitation	HCBS Habilitation and HCBS Waiver (when a member is requesting to participate or is participating in the HCBS Habilitation program and a HCBS Waiver program).								
	AGE	НАВ	AIDS/ HIV HAB	BI HAB	HD HAB	PD HAB	EW HAB	ID HAB	CMH HAB
Child and Adolescent Level of Care Utilization System (CALOCUS)	4-18	х	х	Х	х	х			
Level of Care Utilization System (LOCUS)	19 +	х	х	Х	х	х	Х	х	Х
Supports Intensity Scale Adult (SIS-A)	16+							Х	

Human Services Department (441) ARC 3184C https://rules.iowa.gov/Notice/Details/3184C.

Case Manager Comprehensive Assessment & Social History

Case Manager Comprehensive Assessment & Social History is a fact-finding tool to gather all necessary and pertinent information about the individual receiving services. This tool is used to develop the individuals Person-Centered Service Plan (PCSP). Assessment information includes personal information, communication and language, leisure activities, marital and dating status, developmental milestones, medical and mental health history, behavioral and mental health, hospitalization and emergency room visit history, preventative visits, allergies, physical health, domestic violence, physical, emotional, sexual abuse and trauma, medications, medical support team, substance use or abuse, self-care, ADL's, IDL's, transportation, employment and volunteering, education history, housing, finances, legal information, future identified goals and needs, and identified risks and needs completed through the assessment documentation. Prior to your meeting with the case manager, it will be helpful to have all the information and necessary dates available for the meeting. Beginning July 1, Case Manager Comprehensive Assessments and Social History will be done on all Habilitation and Children Mental Health individuals.

interRAI

interRAI is a clinical assessment instrument completed by a trained Core Standardized Assessment (CSA) Assessor once per year focusing on a person-centered approach to services needed. The screening tool is used to collect information on the individual's specific needs focusing on identifying key factors including clinical and social support, service use, cognitive and mental health, daily activities, and self-care. The assessment results will help in the development of the individuals care plan. The average interRAI takes 1 to 2 hours to complete.

To complete a successful assessment, two reliable respondents are required and can include the diagnosed individual who is able to provide reliable answers, an individual who has known the person being evaluated for at least three months, and an individual who has recently observed the person in one or more environments for substantial period of time (i.e., case manager, parent/guardian, staff, job-coach, teacher, etc.).

For more information on interRAI visit: https://interrai.org.

Level of Care Utilization System (LOCUS) Child and Adolescent Level of Care Utilization System (CALOCUS)

Level of Care Utilization System (LOCUS) and Child and Adolescent Level of Care Utilization System (CALOCUS) have replaced interRAI assessments for individuals on the Habilitation and Children's Mental Health Waivers beginning July 1st, 2022. The assessment tool was developed by the

American Association of Community Psychiatrist (AACP) and is completed by a trained Special Habilitation Assessor once per year. The assessment focusing on a current person-centered approach to ensure services are used efficiently and effectively. The Assessor will address six key domains: risk of harm, functional status, medical – addictive and psychiatric co-morbidity, recovery environment, treatment and recovery history, and engagement and recovery status. In conjunction with four service continuum variables; care environment, clinical services, support services, and crisis resolution and prevention services. These parameters identify an individual's specific needs through a scoring system to determine qualifications and requirements for intensive residential habilitation services (IRHS), determines the level of homebased habilitation service authorization, intensive residential habilitation service and service criteria, options for residential services to minors residing outside of their family home, and the continued need for services.

A LOCUS or CALOCUS scoring is completed by the Accessor based on information in the Case Manager Comprehensive Assessment, Social History, and other records pertinent to the individual (i.e., medical records). An individual will still complete the other assessments necessary for their waiver but will not have a set meeting for the LOCUS or CALOCUS.

For more information on LOCUS visit: https://dhs.iowa.gov/sites/default/files/LOCUS_Levels_Care_Handout.pdf?062820221756.

For more information on CALOCUS visit: https://dhs.iowa.gov/sites/default/files/CALOCUS_Levels_of_Care_Handout.pdf?062820221748.

Mayo-Portland Adaptability Inventory

The Mayo-Portland Adaptability Inventory or Mayo-Portland for short is administered in partnership with the appropriate interRAI. The Mayo Portland focuses on three subscales of ability index, adjustment index, participant index. Currently in its 4th edition, the MPAI-4. The assessment works as an evaluation for individuals diagnosed with a brain injury. Questions in the assessment are ranked utilizing a 5-point Likert scale to rank cognitive, behavioral, emotional, physical, and social problems the individual experiences due to their brain injury. The scale is ranked from 0 to 4 with 0 meaning no functional disabilities for the domain question are indicated and 4 meaning the impairment interferes most of the time for the individual. For those on the Brain Injury Waiver, you should allow 2 to 3 hours of time to complete the interRAI and Mayo-Portland Adaptability Inventory during your yearly assessment meeting.

To complete a successful assessment, two reliable respondents are required and can include the diagnosed individual who is able to provide reliable answers, an individual who has known the person being evaluated for at least three months, and an individual who has recently observed the

person in one or more environments for a substantial period of time (i.e., case manager, parent/guardian, staff, job-coach, teacher, etc.).

For more information on Mayo-Portland Adaptability Inventory visit: https://www.youtube.com/watch?v=URugJrxVDrw.

Off-Year Assessments (OYA)

For those on the ID Waiver, not all individuals will need to participate in a yearly Supports Intensity Scale (SIS) assessment. For the years you are not asked to participate in a SIS, you will have what is referred to as an Off-Year Assessment (OYA). The OYA is a telephonic review conducted by a Core Standardized Assessment (CSA) Assessor. The shortened assessment allows for the level of care to be determined by the responses to questions related to the individuals medical and behavioral diagnoses, medical conditions, functional ability, and risk factors.

Assessors for Amerigroup, lowa Total Care or Telligen typically complete the OYA with the case manager. To complete a successful assessment, one reliable respondent is required and can include the diagnosed individual who is able to provide reliable answers, an individual who has known the person well, or an individual who has recently observed the person in one or more environments for a length of time (i.e., parent, guardian, staff, job coach, teacher, etc.). Amerigroup will complete the OYA with the guardian or an individual who is deemed to know the individual well.

The Assessor will complete the OYA with the case manager. For Amerigroup, the OYA can be completed with the guardian or someone who knows the member (i.e., provider, staff, etc.). Only one respondent is needed to complete the OYA.

For more information on Off-Year Assessments visit: https://dhs.iowa.gov/sites/default/files/470-5276.pdf?050420221446 or <a href="https://dhs.iowa.gov/sites/default/files/1420%20Intellectual_Disability_Waiver_Off-Year_Assessments-final%20version%20for%20LH%20(2)%20(2).pdf?050420221447.

Supports Intensity Scale (SIS), Supports Intensity Scale Adult Versions (SIS-A), Supports Intensity Scale Children's Version (SIS-C)

SIS is a Core Standardized Assessment (CSA) completed by a trained Assessor every 3 years focusing on the strengths of an individual with an intellectual or developmental disability. The SIS assessment focuses on 84 different categories of needed supports. The goal of the SIS is to focus on an individual's strengths and not their opportunities. The results will help to gauge future planning, support and services for the individual. SIS-A

measures supports for individuals 16 years and older. SIS-C measures supports for individuals 5 to 16 years.

To complete a successful assessment, two reliable respondents are required and can include the diagnosed individual who is able to provide reliable answers, an individual who has known the person being evaluated for at least three months, and an individual who has recently observed the person in one or more environments for substantial period of time (i.e., case manager, parent/guardian, staff, job-coach, teacher, etc.).

For more information on Supports Intensity Scale visit: https://www.aaidd.org/sis.

Intake or Annual Person-Centered Services Planning Process (PCSP)

Each year after your LOC/assessment is completed you will be asked to meet with your Interdisciplinary Team (IDT) to review the individual's care plan for case management and all providers. Your IDT team will include the individual receiving services, guardians, case manager, providers, and any additional team members you wish to have present (i.e., some families wish to have their individual staff or teacher present during the meetings. It is not necessary for them to be in attendance, but they are welcome to attend). The meeting will focus on goals for the coming year, changes to service plans, resolving conflicts from the previous year, education on additional services offered, etc. If this is your first time having a PCSP, it may be referred to as an "Intake Meeting". These meetings can last from 1 to 2 hours based on the number of services you receive and providers you have.

Contact Requirements for Providers

To maintain waiver services your provider must have a minimum of one contact per quarter with the individual or their guardian by phone or face-to-face (i.e., a total of 4 per year and can include assessments, PCSP, quarterly contacts, or IEP meetings).

Contact Requirements for Case Management

To maintain waiver services your case manager must have a minimum of one face-to-face meetings with the individual receiving services in their residence at least one time per quarter (i.e., a total of 4 face-to-face visits per year in the individual's home). In addition, the case manager should have a minimum of one contact per month with the individual, their guardian or representative by phone or face-to-face. The quarterly

in home visit counts as a contact for a monthly contact. At the end of the year, you will have a total of 12 contacts with your case manager.

Unit Breakdown

Once an individual has been placed on waiver funding, they will begin receiving a unit allotment for services that can be provided in the home, community, or at a provider's building. Unit allotments will vary based on their waiver and Level of Care (LOC) results. Some waivers and certain services provide a yearly allotment of units, while others provide a monthly allotment of units. Your case manager will provide you with unit allotments and will discuss them at your PCSP meeting. Units go by a set measure of time (1 unit = 15 minutes). To utilize one hour of service, an individual would need four units (4 units = 60 minutes).

The below equation can be utilized to calculate the number of hours you have available in an allotted time frame:

 Total units/4 units = allotment of time in hours available to the individual.

Example 1:

An individual named Joe is on the Health & Disability (HD) Waiver and receives respite services. On the HD Waiver, respite allotments are given at a monthly unit amount. Joe has 40 units of respite available to him monthly.

To calculate the total hour allotment Joe has access to for respite services utilize the below equation:

- Total units/4 units = allotment of time in hours available to the individual.
- 40 total units/4 units =
 10 hours a month of respite services Joe is authorized to use.

Example 2:

An individual named Susie is on the Intellectual Disability (ID) Waiver and receives respite and SCL services. On the ID Waiver, respite allotments are given at a plan year unit amount and SCL allotments are given at a monthly unit amount. Susie has 600 units of respite available to her yearly and 30 units of SCL available to her monthly.

To calculate the total hour allotment Susie has access to for respite services utilize the below equation:

- Total units/4 units = allotment of time in hours available to the individual.
- 600 units/ 4 units =
 150 hours a plan year of respite services Susie is authorized to use.

To calculate the total hour allotment Susie has access to for SCL services utilize the below equation:

- Total units/4 units = allotment of time in hours available to the individual.
- 30 units/4 units = 7.5 hours a month of SCL services Susie it authorized to use.

Unit Requirements

To maintain services, an individual on a waiver is required to utilize I hour of service for every calendar quarter.

Example:

January, February, March = 1 hour/4 units of service required.

April, May, June = 1 hour/4 units of service required.

July, August, September = 1 hour/4 units of service required.

October, November, December = 1 hour/4 units of service required.

Section 9:

Finding a Provider

Provider networks are extensive lists including clinics, pharmacies, primary care providers, waiver providers, etc. This list can vary based on an individual's Managed Care Organization (MCO). You have several options for locating a provider to fit your specific needs.

Utilize the Find a Provider tool for your MCO

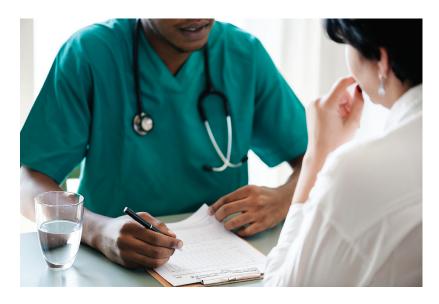
- Amerigroup
 https://www.myamerigroup.com/ia/care/find-doctors-locations.html
- lowa Total Care https://www.iowatotalcare.com/members/medicaid/find-a-doctor. https://www.iowatotalcare.com/members/medicaid/find-a-doctor.
- Molina Healthcare
 https://www.molinahealthcare.com/members/va/en-us/mem/medicaid/helpful-resources/provider.aspx

Utilize the Iowa Medicaid Provider Search https://secureapp.dhs.state.ia.us/providersearche/

Utilize the Iowa Compass Provider Search: https://search.iowacompass.org/

Talk with your case manager to explore waitlists and eligibility with providers in your area.

Call Iowa Medicaid Member Services 1-800-338-8366 (toll free) or 515-256-4606 (Local).



Section 10:

Social Security Administration (SSA) Benefits

Social Security Disability Insurance (SSDI)

What it is – Social Security Disability Income (SSDI) is a federal income supplement program funded by payroll taxes for people who were previously employed but are now unable to work due to a significant physical or mental health condition. The Social Security Administration (SSA) will pay disability benefits to the applicant or their family if the applicant previously worked but is no longer able to do so and meets the eligibility requirements. An adult with disabilities since childhood, with an onset prior to the age of 22 may receive SSDI as a "child's" benefit because it's paid on a parents Social Security earnings record.

Eligibility – The diagnoses must be permanent, present, or expected to last a year or longer, or the diagnoses will result in death. The applicant must not have a partial or short-term disability status, meet the Social Security Administration's definition of a disability, and be under retirement age. To find out if you are eligible to receive SSDI, utilize the Benefit Eligibility Screening Tool (BEST) and answer the questions in the BEST Questionnaire. https://ssabest.benefits.gov

Applying for SSDI - Utilize one of the following options:

- Visit the SSI website https://www.ssa.gov/benefits/disability
- Call the Social Security Administration at 1-800-772-1213, TTY 1-800-325-0778, TRS 1-800-772-1213
- Call your local Social Security Office to schedule an appointment by phone or in person; or

Additional Information – For a complete list of information needed to apply for SSDI visit https://www.ssa.gov/hlp/radr/10/ovw001-checklist.pdf.

Supplemental Security Income (SSI)

What it is - Supplemental Security Income, also known as SSI, is a Federal income supplement program. This program is funded through general tax revenues. To receive SSI Supports, the applicant must be diagnosed with a disability and have little to no income, be 65 years and older, and/or be diagnosed with blindness. The funding received allows an individual to address their basic needs of housing, food, and clothing. For additional SSI eligibility requirements visit https://www.ssa.gov/ssi/text-eligibility-ussi.htm. There is no application fee for SSI.

Eligibility – To find out if you are eligible to receive SSI, utilize the Benefit Eligibility Screening Tool (BEST) and answer the questions in the BEST Questionnaire. https://ssabest.benefits.gov

Applying for SSI - Utilize one of the following options:

- Visit the SSI website https://www.ssa.gov/benefits/disability
- Call the Social Security Administration at 1-800-772-1213, TTY 1-800-325-0778, TRS 1-800-772-1213
- Call your local Social Security Office to schedule an appointment by phone or in person; or
- Utilize the link to see how someone can help you apply for SSI https://www.ssa.gov/ssi/text-help-ussi.htm

Additional Information – For a complete list of information regarding SSI visit https://www.ssa.gov/ssi/text-understanding-ssi.htm.

Supplemental Security Income for Children (SSI for Children)

What it is – Similar to regular SSI, SSI for children is a program designed to support minors under the age of 18 diagnosed with a disability with limited household income and resources.

Eligibility – The minor must be diagnosed with a disability (physical or mental) that limits their activity. The diagnoses must be permanent, present, or expected to last a year or longer, or the diagnoses will result in death.

Apply for SSI for Children – This is a two-step process. The first step will need to be completed prior to the conversation with a member of the Social Security Administration.

- Complete the Child Disability Report https://secure.ssa.gov/apps6z/i3820/main.html
- After the Child Disability Report is submitted, you will be contacted by phone in 3 to 5 business days from the SSA. On the call, they will review your submitted report, verify the household income and resources, and if approved, move you to the next step help complete the SSI application.

Additional Information – For the SSI Child Disability Starter Kit visit https://www.ssa.gov/disability/disability_starter_kits_child_eng.htm.

Survivor Benefits

What it is - Survivor Benefits, is a program designed for social security survivors of eligible workers (i.e., widows, widowers, and dependents)` to receive social security benefits on behalf of the deceased. If the deceased was working and paying benefits into Social Security, some of the taxes paid are for survivor benefits. A spouse, children, and parents may be eligible based on the deceased earnings. For additional Survivor Benefits information visit https://www.ssa.gov/benefits/survivors/. There is no application fee for Survivor Benefits.

Eligibility - To find out if you are eligible to receive Survivor Benefits, visit one of the following options based on your relationship with the deceased:

- Widows/Widowers or Surviving Divorced Spouse's Benefits https://www.ssa.gov/forms/ssa-10.html
- Child's Benefits https://www.ssa.gov/forms/ssa-4.html
- Mother or Father's Benefits https://www.ssa.gov/forms/ssa-5.html
- Lump-Sum Death Benefit https://www.ssa.gov/forms/ssa-8.html
- Parent's Benefits https://www.ssa.gov/forms/ssa-7.html

Applying for Survivor Benefits - Utilize one of the following options:

- Visit the SSI website https://www.ssa.gov/benefits/survivors/
- Call the Social Security Administration at 1-800-772-1213, TTY 1-800-325-0778, TRS 1-800-772-1213
- Call your local Social Security Office to schedule an appointment by phone or in person.

Section 11:

Grants

Children at Home (CAH)

What it is – Children at Home is a grant program designed to support families with a child diagnosed with a disability. The funding is utilized for needed support and services to allow the individual to remain at home. Support and services are defined by the lowa Family Support Network as a purchase of equipment, respite care, supplies, assistive technology, or payment of other costs that relate to the individual's disability.

Eligibility

- Resident of Iowa both child and family.
- One family member must have a child with a disability.
- Child with a disability is defined as someone under the age of 22 and meets the definition of a developmental disability.
- The family's intent is to have their child remain in the home environment and utilize services and support to ensure the child remains in the home.
- The family's Federal Net (not gross) taxable income must be less than \$60,000 from the most recent tax return.

Apply for CAH

 Visit the Children At Home website and complete the steps in the How to Apply and Additional Documents section on the site. https://www.iafamilysupportnetwork.org/families/children-at-home.

Linn County Children's Mental Health Assistance (formerly known as SED or Wraparound funds)

What it is – Linn County Children's Mental Health Assistance is a county funded program to fill the gap when insurance and waiver funds do not meet the entire mental health needs of Linn County youth. It helps support youth when there are gaps in insurance or a high deductible plan. It can be used to cover mental health medications, therapy and medication check appointments, autism social skills group, family and individual BHIS services, respite, and respite activity fees, etc. with contracted providers.

Eligibility – Individuals must meet the criteria of Severe Emotional Disturbance (SED), have a mental health diagnosis, be a Linn County resident under the age of 21 and have exhausted all other options for funding. Individuals are eligible for up to \$1,500 each fiscal year (July 1st through June 30th).

Apply for Children's Mental Health Assistance – For more information, please call or email Terri Godwin at 319–892–5726 or terri.godwin@linncountyiowa.gov.

Money Follows the Person (MFP)

What it is – Money Follows the Person (MFP) is a grant funding program which allows individuals to move out of Intermediate Care Facilities for Persons with Disabilities (ICF/ID) into a home of their choice in the community. Nursing Facilities, Psychiatric Mental Institutes for Children (PMIC), and inpatient hospitals may qualify for MFP. The program provides one year of support for individuals in their new independent living setting.

Eligibility – Individuals must be Medicaid eligible, diagnosed with an intellectual disability or brain injury, live in a qualifying facility for 60 consecutive days, and must express an interest in moving into the community.

Apply for MFP – For more information on how to access MFP resources visit https://dhs.iowa.gov/ime/members/medicaid-a-to-z/mfp.

Section 12:

Resources

This Resource listed below are organized by categories. When possible, links are provided to longer lists of programs, from the lowa Compass and 211 online databases. Links to lowa Compass are marked with . Links to 211 are marked with . You can narrow each list by zip code. Contact lowa Compass and 211 to speak directly to an information and referral specialist about available resources unique to your needs

Iowa Compass 🕢

https://www.iowacompass.org

100 Hawkins Drive 221, Iowa City, IA 52242 · 1-800-779-2001

lowa Compass has free information about programs and services for lowans with disabilities, their families and service providers. Access thousands of local, state and national programs for people with health-related conditions and disabilities. Call, email, chat, text or search the website for answers to your disability-related questions.

2-1-1 2:1:1

https://www.21liowa.org/

A free, confidential service that connects families and individuals to services that can help to stabilize them while meeting basic needs.

ADVOCACY

Access 2 Independence

https://access2independence.org

317 7th Ave SE, Cedar Rapids, IA 52401 · 319-366-0642

Access 2 Independence empowers individuals with disabilities to advocate for themselves in order to achieve greater independence and integrated community participation. In addition, Access 2 Independence connects individuals with direct services to help individuals obtain the skills and supports they choose, in order to accomplish their self-determined goals.

InfoNET: lowa's Disability Policy Resource

https://www.iowaddcouncil.org/infonet

The lowa Developmental Disabilities Council created infoNET (short for information network) in partnership with lowans with Disabilities in Action to give you the information, tools, resources, and opportunities you need to take action on the issues important to you. Their newsletter and network of resources helps advocates with disabilities stay up to date on current issues.

CAMPS

Day Camps 🕙

Residential Camps

<u>Virtual Camps</u>

CRISIS SERVICES

9-8-8

https://suicidepreventionlifeline.org/current-events/the-lifeline-and-988/

988 is the three-digit dialing code routing calls to the National Suicide Prevention Lifeline. When you call, text, or chat 988, you will be connected to trained counselors who will listen, understand, provide support, and connect you to resources if necessary.

CommUnity

https://builtbycommunity.org/

Help Line: 1-800-332-4224 or 319-362-2174

Crisis Phone: 988

Mobile Crisis Outreach: 1-855-581-8111

Business Line: 319-351-2726

Food Bank: 319-351-0128

Food Bank Address: 1045 Highway 6 East, Iowa City, IA 52240

CommUnity Crisis Services is a volunteer-driven organization based in Iowa City, IA providing immediate and non-judgmental support for individuals facing emotional, food, or financial crisis.

Foundation 2

https://foundation2.org

Help Line: 1-800-332-4224 or 319-362-2174

Crisis Center: 1540 2nd Ave SE, Cedar Rapids, IA 52403 · 319-362-2174

Crisis Services: 1714 Johnson Ave NW, Cedar Rapids, IA 52405 · 319-362-1170

Youth Shelter: 3015 12th Ave SW, Cedar Rapids, IA 52404 · 319-366-8797

Foundation 2 is a not-for-profit human service agency that offers crisis prevention and intervention programs to people of all ages. They are committed to positive youth development, suicide prevention, and helping build the foundation for stronger and healthier families and safer communities for everyone.

Your Life Iowa

https://yourlifeiowa.org/

Help Line: 855-581-8111 or Text 855-895-8398

Crisis Center: 1540 2nd Ave SE, Cedar Rapids, IA 52403 · 319-362-2174

Crisis Services: 1714 Johnson Ave NW, Cedar Rapids, IA 52405 · 319-362-1170

Youth Shelter: 3015 12th Ave SW, Cedar Rapids, IA 52404 · 319-366-8797

Your Life Iowa is funded by the Iowa Department of Health and Human Services under the Division of Behavioral Health. Their staff provide free confidential support with gambling, mental health, substance use, suicidal thoughts, or related concerns 24 hours a day, 7 days a week. They connect people to resources meant to help them get their life back on track.

EARLY CHILDHOOD

1st Five

https://idph.iowa.gov/1stfive

Ist Five is a public-private partnership bridging primary care and public health services in Iowa. The 1st Five model supports health providers in the earlier detection of social-emotional and developmental delays and family risk-related factors in children birth to 5 and coordinates referrals, interventions, and follow-up.

For a participating provider in your area visit: https://hhs.iowa.gov/sites/default/files/portals/1/userfiles/88/1stfiveparticipatingprovidersmap2022jun.pdf

Dolly Parton's Imagination Library

https://www.crlibrary.org/children/imagination-library

An early literacy program that delivers one free, age-appropriate book per month to children ages 0 to 5 in Cedar Rapids (zip codes 52401-6 and 52411) and Marion. The Library Foundation covers the costs of books and postage, an average of \$25 per child per year. This FREE service provides 60 books for your child, all age-appropriate during the five years. To enroll, click here: https://imaginationlibrary.com/ (if you are a resident of Marion, you can enroll here as well!).

Early Access

https://www.iafamilysupportnetwork.org/families

1-888-425-4371

Early Access is lowa's system of early intervention services for infants and toddlers with or at risk for developmental delays, connecting families with free statewide information and referral services.

Family Learning Connection (FLC)

https://www.hacap.org/flc

Amie Buckley: Phone: 319-540-2426

Email: familylearningconnection@gmail.com or abuckley@hacap.ora

The family learning groups are free to any family with young children 0–5 years in Linn County. FLC provides Linn County families with group education, resources and connections that can help them raise healthy, school-ready children. Family Learning provides parenting information, advice, and the support parents/caregivers through their free 6–8 week family learning groups. FLC was previously known as Parent Education Consortium.

Linn County Early Childhood Iowa (ECI)

https://www.linncountyiowa.gov/981/Early-Childhood-lowa

1240 26th Avenue Court SW, Cedar Rapids, IA 52404 · 319-892-5721

Contact for information about childcare, in-home services, pre-school, Early Headstart, Headstart, and screening services (dental, developmental, hearing, vision).

Teaching Interventions to Empower and Strengthen Families (TIES) Program

https://www.unitypoint.org/cedarrapids/services-ties.aspx

4050 River Ridge Dr. NE, Cedar Rapids, IA 52402 · 319-558-4861

TIES is a FREE early intervention program targeting children 18 months to five years of age. During program sessions, parents are trained to work in a classroom to actively practice the skills they are learning. It is staffed by both professionals and parents who have completed the program with their own children.

EMPLOYMENT

JAN - Job Accommodation Network

https://askjan.org

800-526-7234 (V) or 877-781-9403 (TTY).

The Job Accommodation Network (JAN) is the leading source of free, expert, and confidential guidance on job accommodations and disability employment issues. Serving customers across the United States and around the world for more than 35 years, JAN provides free one-on-one practical guidance and technical assistance on job accommodation solutions, Title I of the Americans with Disabilities Act (ADA) and related legislation, and self-employment and entrepreneurship options for people with disabilities.

lowa Vocational Rehabilitation Services

https://ivrs.iowa.gov

4444 1st Ave NE #436, Cedar Rapids, IA 52402 · 319-294-9308

The program assists individuals with disabilities with employment and economic independence and determines eligibility of lowa residents who apply for disability benefits under Social Security Disability Insurance (SSDI).

Opportunity Center at Ladd Library

https://www.crlibrary.org/opportunity-center

3750 Williams Blvd SW, Cedar Rapids, IA 52404 · 319-261-7323

The center assists with:

- 1. Job applications
- 2. Resume writing
- 3. Obtaining an education
- 4. Applying for food stamps
- 5. Family Investment Program or Child Care Assistance
- 6. Finding resources
- 7. Healthcare Navigation
- 8. Financial Literacy assistance
- 9. Knowing if you qualify for energy assistance or other income-based support payments
- 10. Transportation for work or school
- 11. Feeding your family
- * Some services require an appointment in advance. Please call ahead.

O*Net Online

https://www.onetonline.org

O*NET OnLine has detailed descriptions of the world of work for use by job seekers, workforce development and HR professionals, students, developers, researchers, and more. Find, search, or browse across 900+ occupations based on your goals and needs. Then use comprehensive reports to learn about requirements, characteristics, and available opportunities for your selected occupation.

FINANCIAL INFORMATION AND SERVICES

Frank A. Varvaris and Associates

http://www.disabilityplanning.org/home.aspx

311 3rd Ave SE, Cedar Rapids, IA 52401 · 319-862-0363

The organization provides clients with specialized estate planning, financial planning, and benefits planning assistance to impact their lives and enhance their well-being more favorably.

Horizons Family Services

https://horizonsfamily.org

819 5th Street SE, Cedar Rapids, IA 52406 · 319-398-3943

A Family Service Alliance has been dedicated to providing opportunities to improve the lives of individuals and families. Horizons provides a variety of human services across Eastern lowa including transportation, financial wellness center, Meals on Wheels programs, elder services, etc.

HEALTH AND MEDICAL SERVICE

COMMUNITY HEALTH CLINICS 211

UIHC Stead Family Children's Hospital - Center for Disabilities and Development

https://uichildrens.org/medical-services/center-disabilities-and-development

213 CDD - 100 Hawkins Drive, Iowa City, Iowa 52242

1-855-543-2884 (855 KID AT UI) or 1-319-356-1346 (Medical records)

The Center for Disabilities and Development at University of Iowa Stead Family Children's Hospital is dedicated to improving the health and independence of people with disabilities and creating a life with opportunities for everyone. The center has been designated the state's University Center for Excellence on Developmental Disabilities and strives to be the state's most trusted resource for health care, training, research, and information for people with disabilities.

Eastern Iowa Health Center

https://easterniowahealthcenter.com

1201 3rd Avenue SE, Cedar Rapids, Iowa 52403 · 319-730-7300

Eastern lowa Health Center provides comprehensive family medicine, pediatrics, OB/GYN, behavioral health, and dental care. Eastern lowa Health Center offers discounts based upon your family size and income. They accept Medicaid, Medicare, lowa Health and Wellness and most private insurance plans. Their doors will always be open to serve your health needs, regardless of ability to pay.

HOUSING SERVICES

RENT PAYMENT ASSISTANCE 2111

UTILITY PAYMENT ASSISTANCE 211

Waypoint Services

https://www.waypointservices.org

318 5th Street SE, Cedar Rapids, IA 52401

Main Office: 319-365-1458

Domestic Violence Resource & Support Line: 800-208-0388 or 319-363-2093

Housing Services: 319-366-7999 or 1-833-739-0065

KidsPoint Child Care: 319-365-1636 Survivors' Program: 319-365-1458

Waypoint is a comprehensive organization offering support with housing services, domestic violence victim services, KidsPoint Child Care Program, and survivor programs.

INFORMATION & REFERRAL **1**

Click on "INFORMATION & REFERRAL" to access specialized information and referral sources. The link will take you to a comprehensive list.

LONG TERM SUPPORTS AND SERVICES **(4)**

Click on the below title links to access specialized information for each program.

- Adult Day Programs
- <u>Day Hab Programs Chronic Mental Illness</u> or Day Habilitation for Adults with Chronic Mental Illness
- <u>Day Hab Programs Developmental Disabilities</u> or Development Disabilities Day Habilitation Programs
- Consumer Directed Attendant Care (non-skilled) or Personal Care
- Consumer Directed Attendant Care (skilled) or In-Home Nursing
- Host Homes for Adults or Adult Foster Homes

- Hourly-Based Supported Community Living or Supported Living Services
- <u>Site-Based Supported Community Living</u> or Semi-Independent Living Services for Adults with Disabilities
- Residential Care Facilities or Group Residences for Adults with Disabilities
- Residential Based Supported Community Living or Group Homes for Children and Youth with Disabilities
- Intermediate Care Facilities or Intermediate Care Facilities for Individuals with Developmental Disabilities

MENTAL HEALTH SERVICES

ABBE Center for Community Mental Health

https://www.unitypoint.org/cedarrapids/abbe-mental-health-center.aspx

520 11th Street NW, Cedar Rapids, IA 52405

Main Office with Emergency/Crisis Services 24 hours/7 days a week: 319-398-3562

Abbe Center for Community Mental Health is a state accredited community mental health center, serving clients of all ages for 70 years. They currently have locations in eight counties throughout Eastern Iowa. They offer a variety of behavioral health service options to provide help and healing to you and your family. Their diverse group of professionals have expertise in nearly all aspects of counseling, mental health and psychiatric treatment.

Circle of Care: A Guidebook for Mental Health Caregivers

https://www.nami.org/Support-Education/Publications-Reports/Guides/Circle-of-Care-Guidebook

NAMI has partnered with the National Alliance for Caregiving (NAC) to create "Circle of Care: A Guidebook for Mental Health Caregivers." This guidebook emerged from the national study on mental health caregiving, "On Pins and Needles: Caregivers of Adults with Mental Illness." This study's findings were released in February 2016. It was the first national survey of mental health caregivers conducted in the United States, and it identified numerous challenges faced by these caregivers. The guide is available in English and Spanish.

Mental Health/Disability Services of the East Central Region (MH/DS of the ECR)

https://ecriowa.org

The East Central Region (ECR) is a partnership between 9 counties to provide comprehensive brain health and disability services to individuals in eastern lowa. Iowans have a regional base of services which meet statewide standards to address their needs. Counties pool their resources and offer an array of services to improve the health of lowans.

Mindspring Mental Health Alliance

https://www.mindspringhealth.org

Mindspring provides no-cost mental health education, support, and advocacy programs. All of Mindspring's programs feature evidence-based curriculum and are available to all community members.

Riverview Center

https://riverviewcenter.org

Highley Building, 118 3rd Avenue SE, Suite 500, Cedar Rapids, IA 52401 319-540-0080

Riverview Center is a nonprofit agency committed to providing compassionate, client centered care for individuals affected by sexual assault in lowa, and for individuals affected by sexual and domestic violence in lowa and Illinois.

MENTAL HEALTH SERVICES FOR CHILDREN

<u>Autism Therapy (Applied Behavior Analysis: ABA)</u>

Behavioral Health Intervention Services (BHIS)

Psychiatric Medical Institutions for Children (PMIC)

Four Oaks Family and Children's Services

https://www.fouroaks.org

1924 D Street SW, Cedar Rapids, IA 52404 · 319-363-0636

The organization provides support for children with behavioral health needs.

Tanager Place

https://tanagerplace.org

2309 C Street SW, Cedar Rapids, IA 52404 · 319-365-9164

When mental health challenges disrupt the well-being of children, Tanager Place provides the tools and support to face them with confidence. Through a mix of prevention, treatment, and outreach, they build understanding and hope within the community. Because when parents have a strong network of support, children have the best chance to overcome these obstacles and build a brighter future.

PARENTING RESOURCES

Family Learning Connection (FLC)

https://www.hacap.org/flc

Amie Buckley

Phone: 319-540-2426

Email: familylearningconnection@gmail.com or abuckley@hacap.org

The family learning groups are free to any family with young children 0–5 years in Linn County. FLC provides Linn County families with group education, resources and connections that can help them raise healthy, school-ready children. Family Learning provides parenting information, advice and the support parents/caregivers through their free 6–8-week family learning groups. FLC was previously known as Parent Education Consortium.

Safe Kids Worldwide

https://www.safekids.org/coalition/safe-kids-linn-county

505 1st St. SW, Cedar Rapids, IA 52404 · 319-286-5434

Safe Kids Linn County is led by the Cedar Rapids Police Department, which provides dedicated and caring staff, operation support, and other resources to assist in achieving our common goal: keeping your kids safe. Based on the needs of the community, this coalition implements evidence-based programs, such as car seat checkups, bicycle helmet giveaways, and safety presentations that help parents and caregivers prevent childhood injuries.

PSYCHOLOGICAL EVALUATIONS

View the below list of professionals or click the link for additional support:

Find more therapists

Center for Disabilities and Development University of Iowa Children's Hospital

100 Hawkins Drive 213 CDD, Iowa City, IA 52242 · 319–356-1347 Age: Children and up

Davis Psychological

809 5th Avenue, Grinnell, IA 50112 · 641-236-0632 Age: 6 and up

Family Psychology Associates

1221 Center Point Road NE, Cedar Rapids, IA 52404 · 319-378-1199 Age: 6 and up

Mercy - Luke Hansen, PsyD

701 10th St SE, Cedar Rapids, IA 52403 · 319-369-4777 Age: 6 and up

Mercy - Ronald Ridder, PhD

701 10th St SE, Cedar Rapids, IA 52403 · 319-369-4777 Age: 6 and up

Orchard Place Child Guidance Center

808 5th Avenue, Des Moines, IA 50309 · 505-244-2267 Age: 3 and up

Seashore Hall – University of Iowa

335 E. Jefferson Street, Iowa City, IA 52242 · 319-335-2467 Age: 3 and up

SUPPORT OPTIONS

Peer to Peer Networking 1

Support Groups 1

Service Animal Providers

Service & Support Animals

Many of our families have questions on emotional support, service, and therapy animals. Below you will find websites to access and a brief breakdown of each group.

http://publications.iowa.gov/13700/1/Factsheet%2520Service%2520Animals.pdf

https://www.ada.gov/resources/service-animals-faqs/

https://www.akc.org/expert-advice/news/everything-about-emotional-support-animals/

https://www.avma.org/resources-tools/animal-health-and-welfare/service-emotional-support-and-therapy-animals

Section 13:

Daycare

For any parent, daycare services are a primary service needing to be accessed to help assist them with care of their child. For those individuals diagnosed with a disability, it can be hard to locate daycare services that will provide the necessary care they need, support beyond the regular daycare age of 10 and under or daycare services in post education scenarios. Below you will find options based on age ranges.

Early Childhood (Birth to Pre-Kindergarten)

- Family Member or Private Pay
- Licensed Childcare Facility or In-home Childcare

Kindergarten - 12th Grade

- Family Member or Private Pay
- Licensed Child Care Facility or In-home Childcare

Post-Secondary Adult Daycare

- Family Member or Private Pay
- Licensed Child Care Facility or In-home Childcare

Family Member or Private Pay

Family members are a large part of the daycare experience for individuals who are fortunate enough to have their support. Many times, one parent will choose to stay home, or they will utilize aunts, uncles, or grandparents to help with childcare. If family members are not available, private pay options may be utilized. This can be a nanny who comes into the home while the caregiver is working or a live-in nanny.

Licensed Childcare Facility or In-home Childcare

For families that choose to utilize a licensed childcare facility or in-home childcare, it can be difficult to locate providers who will accept an individual diagnosed with a disability. The lowa Department of Human Services has a website portal and phone number you can contact to help assist you in locating a provider. Please see the information below for The Arc of East Central lowa's services.

Important note, if you are approved to use respite services for daycare by your case manager and MCO, one parent must not be working at the time funding is utilized. For more information, speak with your case manager or provider.

The Arc's Daycare Enrichment Program

- During the academic year, the program is open Monday through Friday, after school until 6:00 pm at The Arc of East Central Iowa, 680 2nd St SE, Cedar Rapids, Iowa. Program hours are 7:00 AM to 6:00 PM on days school is not open and during the summer months.
- Please Note: The after-work enrichment portion of the program is for individuals 18 years old and up is not DHS licensed, but follows a similar format and regulations set by DHS.
- Ages: 5 years old and up

The Arc's School Age Summer Program

- Licensed by the Department of Human Services with the primary purpose to provide a fun, safe, and structured environment for individuals with intellectual and developmental disabilities.
 Offer a low staff to participant ratio which surpasses all daycare requirements.
- Ages: 5 to 21 years and be attending school or a transition program next fall..
- Dates: mid-June through late-July
- Times: Monday through Friday 7:00 AM to 5:30 PM
- Location: Cedar Rapids

Iowa Department of Human Services Childcare Client Portal

lowa DHS has a portal available to help families locate available childcare in their area. You can visit their website, or they encourage families to call Child Care Resource and Referral Parent Specialist to discuss options in your area 1-855-CHILD-01 (1-855-244-5301). http://ccmis.dhs.state.ia.us/ClientPortal/ProviderSearch.aspx

Adult Daycare

After an individual graduates from high school, they have several post-secondary options. For those not continuing to a day habilitation or college program but need additional assistance while their caregiver is at work, adult daycare is an option.

There are limited adult daycare options available in our area. Speak with your case manager to find availability and to request a referral to the available provider(s).

Utilize the below links for additional programs in our area:

- Adult Day Programs
- <u>Day Hab Programs Chronic Mental Illness</u> or Day Habilitation for Adults with Chronic Mental Illness
- <u>Day Hab Programs Developmental Disabilities</u> or Development Disabilities Day Habilitation Programs



Section 14:

K-12 Education

Education Protection

Education acts have been put into place or amended since 1973 to ensure students with disabilities receive equal access to education. Below you will find a brief overview of each act.

The Vocational Rehabilitation Act & Section 504 of 1973 prohibits discriminations against any student with a disability, provides a clear definition for the term 'appropriate education', and mandates a student diagnosed with a disability has equal access to education. This act ensures a student with a disability is provided the same education access as a child without a disability.

The Education Amendments Act of 1974 ensured students and their families have the right to due process in special education cases.

The Education for All Handicapped Children Act of 1975 includes Individualized Education Programs (IEP), free and appropriate public education for students with a disability age 5 to 15 and defines the Least Restrictive Environment (LRE). LRE is a framework ensuring students with disabilities should spend as much time as possible with their neurotypical classmates in a typical classroom setting.

Education of Handicapped Act Amendments of 1986 included free and appropriate education for students with disabilities ages 3 to 5 and early intervention programs from birth to age two for children with disabilities.

The Americans with Disabilities Act of 1990 prohibits discrimination against people with disabilities in the work environment and provides equal opportunities for accommodations, services, and transportation.

The ADA laws for discrimination apply to school systems as well.

Individuals with Disabilities Education Act (IDEA) of 1990 includes extension to the special education services offered at school (i.e., social work, rehabilitation, etc.), transition program for students at age 16, confidentiality in student information, bilingual education programs, and due process for all students and their families.

Individuals with Disabilities Education Act (IDEA) of 1997 amended the 1990 act. Changes include general education teachers are included in a student's IEP team, students with disabilities take state standardized tests, mediation to resolve difference, behavior management plans, students with a disability can continue services even if expelled from school.

No Child Left Behind Act of 2001 increased accountability on schools to ensure students success, mandated highly qualified teachers, implemented an early intervention reading program, and school choices for students to ensure all students can attend successful schools.

IDEA Improvement Act (IDEIA) of 2004 required higher standards for special education teachers through licenses and certifications, increased funding for early intervention services, and the use of Response to Intervention (RTI) programing at school.

Every Student Succeeds Act (ESSA) of 2015 transitioned the control of standardized testing to each state. Only 1 percent of all students can be given alternative assessments with the implementation of the act. An antibullying prevention plan is also included is ESSA.

Supports Available in the School System

There are two primary types of plans a student may need throughout their education journey an Individualized Education Plan (IEP) or a 504 Plan. An IEP will be recommended if the student requires accommodation and specific instructions. A 504 Plan will be recommended if the student only requires accommodation. In both cases a team of people should be present at your IEP or 504 meeting. Team members should include parents, teacher, special education teacher, paraprofessional, case manager, and an advocate if desired.

Individualized Education Plan (IEP) is a legal document that is a plan of action to help assist the student and the educator team in supporting the student throughout their education journey. An IEP is updated yearly, but a guardian can request a meeting at any time. The IEP includes the following items:

- · Statement of Services with rationale
- Short/Long term goals
- Present Level of Educational Performance (PLEP)
- · Dates of IEP
- Accommodation is a change in how a student can access tests or classroom information. Some examples of accommodations include:
 - Seating Student can be moved to a preferential seating option in the classroom to see the teacher clearly.
 - Audio Books Students can have access to an audio book to help facilitate their learning. This option is available from kindergarten to 12th Grade. Audio books can include a picture book to a textbook.

- Extended testing time Students can be offered the option of having extra time added to any test they take, or it can be specific to certain subjects they might find challenging.
- Open book tests Students can have access to a textbook or supporting education documents when taking a test.
- Modifications are a change in content and learning for a student.
 Some examples of modifications include:
 - Alternative reading materials A student can have tailored alternatives to reading materials to match the student's reading level or interest.
 - Retake quizzes A student can have the ability to retake quizzes if unable to pass the first time without the fear of a one and done system.
 - Reduced problems on quizzes A student can have a quiz tailored to their level of understanding.
- Curriculum is broken down into emergent and functional curriculum.
 The division allows for a slower pace learning environment to support the student's needs.
 - Emergent Curriculum focuses on a student's interest. The style of teaching is based on listening to the student's interest and ideas (i.e., a student is out on the playground and becomes interested in birds flying around, the teacher can build a lesson around birds).
 - Functional Curriculum focuses on skills a student needs to be successful outside of school and/or in a post-secondary environment by assisting with social skills, independent living skills, community participation (i.e., creating lessons focusing on how to go grocery shopping, wash clothes, keep a clean house, correct behavior at work or in the community, etc.).
- Environment can play a large role for students, particularly for those in need of sensory support. Adjustments can be made to provide necessary support to ensure the student remains successful.
 Environment supports can include:
 - Distractions Removing distractions that may overwhelm the student or impede their ability to focus on class.
 - Labels To help support the student to find materials they need to perform classroom duties.

- Schedules A set schedule or a written schedule on the board or given to the student to help them during the day and throughout each class.
- Music On the radio for the whole classroom to hear or if appropriate can be headphones during quiet time in the classroom or for help while focusing on a test or assignment.
- Protocols for classroom A set schedule or a written schedule
 of tasks and speaking rules given to the student by each teacher
 to help them stay focused during each class.
- Lighting For students who are visually impaired and may not be able to focus due to the brightness in the room.
- Seating Students get preferential treatment with classroom seating arrangements.

504 Plan is based on Section 504 of the Rehabilitation Act of 1973, also known as Section 504. Section 504 is a federal law protecting the rights of individuals diagnosed with a disability in activities and programs financed through federal assistance (state and local education). To qualify for Section 504, the student must be diagnosed with a disability and the disability must result in limitation of a major life function. 504 plans are utilized if a student is only in need of accommodations to their education.

- Accommodation is a change in how a student can access tests or classroom information. Some examples of accommodations include:
 - Seating Student can be moved to a preferential seating option in the classroom to see the teacher clearly.
 - Audio Books Students can have access to an audio book to help facilitate their learning. This option is available from kindergarten to 12th Grade. Audio books can include a picture book to a textbook.
 - Extended testing time Students can be offered the option of having extra time added to any test they take, or it can be specific to certain subjects they might find challenging.
 - Open book tests Students can have access to a textbook or supporting education documents when taking a test.

Behavior Intervention Plan (BIP) is a plan based on a student's Functional Behavioral Assessment (FBA). The BIP will include a description of the problem behavior, hypothesis (global and specific) reasoning behind the behavior, intervention strategies for positive behavioral support and additional support services.

Assistive Technology allows a student the opportunity to have an increase in learning, performance, and productivity. Examples of assistive technology can include:

- Applications (Apps)
- Audio Books
- Calculators
- Communication Boards
- Crutches
- Large Print Materials
- Personal or Voice Amplification System
- Screen Reading Software
- · Speech Generating Device
- Switches
- Tablets
- Walker
- Wheelchair

Seclusion and Restraint continue to be topics of discussion at the State and Federal levels. In 2020, the state of lowa updated Chapter 103 on Corporal Punishment, Physical Restraint, Seclusion, and Other Physical Contact with Students. Visit https://www.legis.iowa.gov/docs/ACO/chapter/281.103.pdf to review the law in its entirety or visit https://educateiowa.gov/sites/default/files/documents/Top10PointsAboutChapter103_7-7-21.pdf for the Top 10 Points About Chapter 103.

Least Restrictive Environment (LRE) requires public schools to provide students diagnosed with disabilities access to a classroom setting with their nondisabled peers, in their neighborhood schools. Classroom settings will be agreed upon based on the maximum appropriateness and may include alternative education opportunities based on a student's needs (i.e., part-time special education classroom, full-time special education classroom, special education school, or residential home school setting).

Transition Planning will begin for students on an IEP around the age of 16 to start the process of preparation for their future transition after high school. This plan will vary based on how long a student decides to remain in school.

Graduation Age Requirements differ for individuals diagnosed with a disability. Federal law entitles a student diagnosed with a disability the right to remain in school until the end of the school year on the age of their 21st birthday. A student can choose to accept their diploma earlier, but no school can force a student to graduate earlier than 21. If assistance is needed in the transition or graduation requirements, contact your Service and Support Coordinator and Case Manager.

Spanish Resources for school are available from The Arc of the United States School Homepage https://thearcatschool.org/en-espanol.

Supports Available at School

Occupational Therapist (OT) assists in helping their patients perform, adapt, modify, and/or change their daily activities to allow an individual the ability to participate in activities of their choosing through movement and coordination. Examples of occupational therapy may include:

- Improving hand-eye coordination
- · Increasing attention span
- · Learning nonverbal queues
- Teaching steps to help assist in being able to get dressed
- Use of the restroom independently

Paraprofessional (Para) is a certified member of the education staff in the education system. Paraprofessionals are trained to provide support, instruction, management, and organization to assist educators and students in a classroom setting. Paraprofessionals may be in a classroom to provide support to some or all the class or they may provide individualized one-on-one support to one student. In some local districts a one-on-one paraprofessional will remain with the student throughout their education journey from kindergarten to 12th grade.

Special Education Teacher is a teacher who has received a college degree specializing in the field of providing education to students diagnosed with emotional, learning, mental, or physical disabilities. Special Education teachers adapt general education lessons and skills to match the needs of each student.

Speech and Language Therapist/ Speech and Language Pathologist (SLP) assist in helping their patients improve language and communication skills.

Examples of speech and language therapy may include:

- Helping a patient who is diagnosed with muteness
- Supporting a patient with their aphasia diagnosis
- Testing to diagnose a swallowing disorder
- · Working with a patient on their apraxia of speech diagnosis
- Utilizing books and letter cards to help a patient with a lisp
- Using assistive technology (i.e., communication device to express needs and wants)

Physical Therapist (PT) assist in helping their patients by prescribing exercises, treating specific areas of concern, and/or utilizing a hands-on-care concept. Examples of physical therapy may include:

- Adaption to an artificial limb
- · Managing a chronic illness
- Rehabilitation after an accident
- · Relieving pain
- Use of assistive devices (cane, walker, wheelchair, etc.)

Local Educational Resources:

Cedar Rapids Community School District Transition Center

319-558-1247

The Transition Center provides opportunities for students with disabilities—aged 18 to 21—who have completed four years of high school and continue to qualify for services and supports aligned to unmet needs in the areas of living, learning, and/or working. Examples of support can include integrated employment, community experiences, and independent living skill development to assist with the transition into adulthood.

College Community School District PrairieWood Transition Center

https://phs.crprairie.org/programs/prairiewood-transition-center

401 76th Avenue SW Cedar Rapids, IA 52404 · 319-848-5200

PrairieWood Transition Center provides community-based education and training for students who participate in special education. Each student has an Individualized Education Program (IEP) with an emphasis on increasing independence in his or her home and community.

Grant Wood Area Education Agency

https://www.gwaea.org

4401 6th Street SW, Cedar Rapids, IA 52404 · 319-399-6700

lowa's Area Education Agencies were created by the 1974 lowa Legislature to ensure all children have equal educational opportunities. Grant Wood Area Education Agency is one of nine AEAs in the state and serves as an intermediate agency providing educational services to local schools. Grant Wood AEA staff are committed to unlocking the potential of each and every learner.

LinnMar Community School District Transition Services

https://www.linnmar.k12.ia.us/transition-services

2999 N 10th Street, Marion, IA 52302 · 319-447-3359

Transition Services provides a variety of services to our students as well as our families in an effort to assist in the many transitions that occur during a student's educational career.

Transition Iowa

https://www.transitioniowa.org

Transition lowa is a website providing information and resources to support transition planning for youth with disabilities and their families, and the educators and professionals who support them.



Section 15:

Post-Secondary Options

Registered Apprenticeship Programs

https://www.earnandlearniowa.gov/apprentice

Post-Secondary Community College 4+ Transition Programs

Des Moines Area Community College - STRIVE Academy

https://www.dmacc.edu/strive/Pages/strive_academy.aspx

Eastern Iowa Community College District - ACCESS Program

https://www.eicc.edu/future-students/high-school-students/access.aspx

Indian Hills Community College - Raise Individual Student Expectations (RISE)

https://www.indianhills.edu/academics/highschool/rise.php

lowa Lakes Community College - Student Alternative Vocational Education (SAVE) Program

https://iowalakes.edu/student-services/special-needs-services/

Kirkwood Community College – Vocational Individualized Training and Learning Services (VITAL)

http://www.kirkwood.edu/vital

Northwestern Iowa Community College – 4+ Program

https://nwicc.edu/high-school/four-plus/

Southeastern Community College – Secondary Transitional Education Program (STEP)

https://www.scciowa.edu/highschool/succres/step.aspx

Western Iowa Tech - Project SUCCESS

https://www2.witcc.edu/project-success/

Comprehensive Transition and Postsecondary (CTP) **Programs**

UI REACH at The University of Iowa

UI REACH (Realizing Educational and Career Hopes) is a comprehensive transition program for students aged 18-25 years old with intellectual, cognitive, and learning disabilities. UI REACH offers an integrated college experience in a caring and structured environment.

Academics, career and transition, and student life are areas of focus and upon completion students receive a two, three, or four-year certificate.

Phone: 319-335-3500

Website: https://education.uiowa.edu/reach

Email: ask-education@uiowa.edu

Northwestern NEXT

NEXT is a two-year program at Northwestern College in Orange City for students with intellectual or developmental disabilities offering specialized classes in life skills, audit up to 9 credits of preapproved courses from the college catalog and participation in campus activities, social events, and residence hall experiences with same-aged peers.

The mission of the Northwestern NEXT program is to provide a personalized inclusive college experience for students with intellectual and developmental disabilities in a supportive Christian environment.

CONTACT:

- John Menning: 712-707-7454 · john.menning@nwciowa.edu
- Sherry Lang: 712-707-7456 · herry.lang@nwciowa.edu
- Julia Zora: julia.zora@nwciowa.edu
- Website: https://www.nwciowa.edu/next

Day Habilitation (Day Hab)

Day Habilitation for Adults with Chronic Mental Illness



<u>lowa Compass resources: Day Hab for people with Chronic Mental Illness</u>

Development Disabilities Day Habilitation Programs



<u>lowa Compass resources - Day Hab Programs for people with Developmental</u> Disabilities

The Arc of East Central Iowa's Day Habilitation Program is a yearround program Monday - Friday dedicated to supporting individuals diagnosed with intellectual disabilities to explore and engage in the community safely with the assistance of support staff. Areas of focus for services include behavior management, community integration, daily living activities, intellectual and cognitive functioning, language and communication, mobility development and improvement, physical and emotional support, responsibility and self-direction, self-advocacy, and socialization. For a detailed list of information on Day Habilitation Services through The Arc visit https://arceci.org/ programs-services/ day-habilitation.

Employment Support

Iowa Compass Employment Resources



List of organizations providing employment services throughout the community. For additional information on other programs not listed below in our area, utilize the hyperlink above or contact your case manager.

The Arc of East Central Iowa's Employment Support aids individuals in finding and retaining fulfilling employment with help from a team of professionals to assist in creating and attaining an individual's goal of thriving in the workplace. Employment services include job coaching, Project SEARCH, and employment support.

For a detailed list of information on Employment Support services through The Arc visit https://arceci.org/programs-services/ employment-support.

Job Coaching is a program designed to focus on providing an individual with support on their employment journey. Individuals will receive dedicated support from a job coach who will assist them in building skills for a specific job, creating and developing successful work habits, and socialization and communication skills. The job coach will support the individual as they adjust to their new job and will provide any assistance needed to maintain employment and thrive in their employment opportunity.

Project SEARCH is provided by The Arc of East Central Iowa in partnership with UnityPoint Health - St. Luke's Hospital and Iowa Vocational Rehabilitation Services. Project SEARCH helps individuals build skills to succeed on the job by providing nine months of classroom instruction and workplace internships at UnityPoint Hospital in Cedar Rapids Iowa. Interns will learn and practice real-world skills, increase independence, confidence, and self-esteem, make professional

relationships and friendships, receive individualized coaching and feedback every day, search for and apply for secure employment in non-traditional jobs for people diagnosed with a disability. To be considered for Project SEARCH an individual must be between the ages of 18 to 30, have a developmental or intellectual disability, and have graduated from high school or have a GED.

Supported Employment is a program to assist individuals in gaining employment opportunities matching their goals and preferences by focusing on an individual's strengths, choosing the right job for them, and maintaining employment in an integrated community employment setting. The program includes assessment services to gather information about the individual's interests, skills, and preferences for a job, job shadowing in different workplace settings, short paid workplace assessments to determine if the job is a good fit for employee and employer, optional work adjustment training to identify and overcome barriers, and transportation training to learn public transportation to get to and from work independently.

ADA and Employment Protection

Title I of the ADA prohibits private employers, state and local governments, employment agencies, labor unions, or employers with 15 or more employees from discriminating against qualified individuals with disabilities. This includes advancement opportunities, application process, compensation, hiring & firing, layoff & leave, recruitment, tenure, training, and any privileges givento non-disabled employees.

A qualified individual would include someone who could complete the skills of the position, has experience, education, or other requirements necessary for the position, and can perform essential job functions with or without reasonable accommodations. The ADA requires covered employers to provide reasonable accommodation for individuals with disabilities.

Accommodation is any modification to the job or work environment to help an employee with a disability perform their job or enjoy the same benefits and privileges of employment as another employee without a disability. Some examples of modifications include additional training, modifying an employee work schedule, modification to the employee's workstation, etc. If you are currently employed and feel accommodation is needed in your work environment, contact your human resource department for further steps. For more information on Title 1 visit https://www.gpadacenter.org/employers.

Section 16:

Housing

After graduation an individual has multiple options for housing. The decision on where to live should be made as a team (individual, guardian, with location support from a case manager or provider). Individuals diagnosed with a disability have the right to choose where they would like to live, but support from family and steps for moving are a vital part to the success of this new transition. If the individual has a legal guardian, approved through the court system, the guardian will make the decision on where the individual will reside.

Housing Options for Adults

Assisted Living allows for the individual to live in their own apartment in a building complex with each resident utilizing on-site staff when needed to assist with some daily needs (i.e., bathing, cleaning, medications, etc.). In most assisted living locations, individuals can cook in their unit or have access to a community dining room. Certain assisted living programs will be diagnosis specific (i.e., dementia).

Group Homes or Supported Housing allows for the individual to live outside of the family home with a small group of individuals also diagnosed with a disability. The homes are staffed with part-time or full-time staff to help provide live-in assistance for each house member. Group homes provide a social setting beyond their family unit with private pay or state paid program options.

Independently in the Community allows for the individual to live outside of the family home alone in a residence of their choosing (i.e., house, condominium, mobile home, or apartment). If families are able, they may choose to purchase a property for their family member to reside in. If the family is unable to purchase, they may look at Section 8 Housing. More information is included below in the Finance Options for Housing section.

Remaining in Home allows the individual to continue to reside with their family in the family home environment. This is a common option for many families after graduation. It is important to remember planning for the future with aging caregivers will be an important step down the road with housing.

Skilled Nursing or Nursing Home allows the individual to receive 24 hours of skilled medical care. This choice may be considered if the level of needed care is unable to be met in the home environment. Funding for skilled nursing can be \$10,000 a month or higher. Individuals may qualify to be covered under Medicaid for the cost of a skilled nursing facility.

Finance Options for Housing

Section 8 Housing Choice Voucher Program (Section 8 or HCV) ois a section of the Housing Act of 1937. Section 8 assists individuals with low-income, elderly, and/or those diagnosed with a disability to reside in an affordable, safe, and sanitary housing options in their community.

Section 8 housing can be a single-family home, townhouse, or apartment. The individual can choose any housing choice if it meets the requirements of the Section 8 program.

Section 8 Housing Choice Vouchers are managed by public housing agencies (PHAs). PHA's are funded from the U.S. Department of Housing and Urban Development (HUD). Waitlists are possible for Section 8. In some locations waitlists are closed to new individuals at this time. Contact your local office for additional information.

- Eligibility Requirements:
 - An individual and/or household must qualify under HUD and PHA total annual gross income and family size.
 - The household income must meet the limits at or below HUD requirements.
 - An individual must be a U.S. Citizen or meet specific categories of non-citizen eligible immigrant status.
 - In most locations, the household income may not exceed 50% of the median income for the county or metropolitan area.
 - PHA is required by law to provide 75% of vouchers to applicants whose income does not exceed 30% of the median income of the area of residence (HUD publishes median income levels and each will vary by location).
 - Contact your local PHA for additional information. Cedar Rapids contact information is listed as Cedar Rapids Housing Services in Local Housing Resources below.

Section 811 Project Rental Assistance (PRA) Program is a supportive housing program focused on expanding, supplying, and supporting housing for low-income individuals diagnosed with a disability. Section 811 PRA is a referral-based program and varies by city and state. Section 811 PRA partners with state housing agencies (Medicaid and DHS) to identify individuals who may benefit from the program. The information gathered allows for an allocation of units in affordable housing projects with capital costs being funded through federal, state, and/or local funding.

- Eligibility Requirements:
 - An individual must be 30% or below the Area Median Income (AMI).
 - One member of the home must be diagnosed with a disability.
 - Individuals diagnosed with the disability must be eligible for Medicaid, state funded services or services listed in the specific Section 811 PRA partnership agreement.
- For more information on Section 811 PRA visit: <u>www.hudexchange.info/programs/811-pra/</u>

The HCBS Rent Subsidy Program oprovides monthly rent assistance payments to individuals who receive services under a federal Medicaid waiver program and who are at risk of nursing facility placement until they become eligible for any other local, state, or federal rent assistance.

- Eligibility Requirements:
 - Be 18 years of age or older.
 - Currently be an adult recipient of one of the home-and communitybased service waiver programs, including HCBS Habilitation Services Program or Money Follows the Person.
 - Provide evidence that you are responsible for paying more than 30% of your income for rent, and have been determined ineligible, or have been placed on a waiting list, for U.S. Department of Housing and Urban Development (HUD) Housing Choice Voucher or any other available rental subsidy programs.
 - Live in a qualified rental unit (an apartment, mobile home, or private room for which a signed written rental agreement exists, and which is governed by Iowa Code Chapter 562A Uniform Residential Landlord and Tenant Law).
 - · Live in Iowa.
- Cannot serve individuals who:
 - Are receiving federal rental assistance at the time of, or prior to the time of application to the HCBS Rent Subsidy program.
 - Decline a HUD Housing Choice Voucher or fail to respond to a notice from the public housing authority when a voucher becomes available.
 - Live in a home owned by a family member or someone who is currently living in the home.

For more information on HCBS Rent subsidies visit https://www.iowafinance.com/renter-programs/home-and-community-based-services-rent-subsidy-program/

Public Housing of is rental housing for families, older adults, and people with disabilities who have low incomes. Public housing in lowa is often large multi-unit complexes but can also be single-family homes or small supportive housing arrangements ("group homes"). The property owner is often the local public housing authority (PHA), but they may contract or transfer ownership of the property to a private landlord or organization.

The U.S. Department of Housing and Urban Development (HUD) gives federal aid to PHAs to develop and manage public housing following public housing rules. People apply for public housing at their local PHA or by contacting the HUD Field Office. If eligible, people pay about 30 percent of their income on rent at public housing properties.

Find and apply for public housing through the local public housing authority or by contacting the Des Moines HUD Field Office at (515)284-4512.

For more help with HUD rental programs contact the Public and Indian Housing Information Resource Center at (800)955-2232.

Local Housing Resources

Iowa Compass 🕙

<u>Disability Resource Database - Iowa Compass - Ul Health Care</u>

100 Hawkins Drive 221, Iowa City, IA 52242 · 1-800-779-2001

lowa Compass has free information about programs and services for lowans with disabilities, their families and service providers. Access thousands of local, state and national programs for people with health-related conditions and disabilities. Call, email, chat, text or search the website for answers to your disability-related questions. For specific information on residential facilities & housing services, click on the above link, enter your zip code and age, select Residential Facilities & Housing Services. You will be provided with a selection of resources and can click on the menu item to fit your requested need.

2-1-1 211

https://www.21liowa.org/

A free, confidential service that connects families and individuals to services that can help to stabilize them while meeting basic needs. For housing specific support, select resources, enter your zip code, select housing and select the specific area of housing you wish to receive further information on.

Section 17:

Food

Having healthy food options is one of the most effective ways to maintain good health for all individuals. For those who are needing additional assistance to help ensure they maintain a healthy diet, multiple options are available in our community to support each person to prevent hunger. Below you will find a breakdown of nutritional assistance programs, food pantries, and additional food resources available in our area.

Nutritional Assistance Programs (NAP)

NAP's have been put in place by the federal, state, and local government to support individuals and their families who are designated as low-income to ensure they have access to nutritional foods to maintain good health. There are a variety of programs available listed below.

- Supplemental Nutritional Assistance Program (SNAP) previously known as food stamps, is a program offered to individuals designated as low-income to buy food to ensure they maintain good health. Individuals on the program will receive an electronic card that operates like a debit card to purchase food from their local grocery store.
 - Applications for SNAP are available at the Social Security office.
 If you already receive Supplemental Security Income (SSI), your local Social Security office can assist you in completing an application to your local SNAP office. If you do not receive SSI, you can complete the application on your own and send it to your local SNAP office.
 - To check your SNAP eligibility, visit https://dhsservices.iowa.gov/apspssp/ssp.portal for their pre-screening eligibility tool or call the lowa's SNAP information line at 877-347-5678.
- Special Supplemental Nutrition Assistance Program for Women, Infants, and Children (WIC) is a federal grant program managed by each state to provide supplemental food, nutrition education, and health care referrals to low-income pregnant, breastfeeding, non-breastfeeding, or postpartum women, and infants and children to age five who are considered to have nutritional risk. In some locations WIC Farmers' Market Nutritional Program is available for WIC participants to receive coupons to purchase local, healthy produce (fruits, vegetables, herbs) from local farmer's markets or roadside farm stands.

- Eligibility requirements are based on income, state residency, determination of nutritional risk by a health care professional or trained health official.
- To check your WIC eligibility, visit: www.fns.usda.gov/wic/women-infants-and-children-wic.
- Other NAP's include Commodity Supplemental Food Program (CSFP), Children and Adult Care Food Program (CACFP), National School Lunch Program (NSLP), School Breakfast Program (SBP), Summer Food Service Program (SFSP), Senior Farmers' Market Nutrition Program (SFMNP), The Emergency Food Assistance Program (TEFAP). Visit www.socialsecurity.gov to see what programs you may qualify for.

Local Food Pantries

Utilize the below links for access to local food resources:

Food Pantries 211

Free Meals 211

Food Vouchers 2111



Section 18:

Finance

Financial Support Programs or Accounts

Achieve a Better Life Experience (ABLE) Account, IABLE, or 529A Able is a tax-advantage savings program. Individuals diagnosed with a disability prior to the age of 26 can save for the future without impacting their Social Security Income (SSI), Department of Housing and Urban Development (HUD), Free Application for Federal Student Aid (FAFSA), or Medicaid funding. Funds can be used to pay for qualified disability services (i.e., assistive technology, education, housing, legal fees, transportation, valid funeral, or burial expenses, etc.). No documentation is required to open an account. \$16,000 annually can be saved into a tax-free account to reach a max balance of \$100,000. You can choose from 7 investment options designed to meet long-term and short-term savings goals.

To learn more about IAble visit their website at www.iable.gov. Watch this video to see an overview of ABLE accounts https://www.youtube.com/ watch?v=aMNzVf8qy0E. To Understand ABLE Accounts, Special Needs Trusts, and Pooled Trusts visit https://www.ablenrc.org/understanding-able-accounts-special-needs-trusts-and-pooled-trusts/.

Low-income Home Energy Assistance Program (LIHEAP) is for low-income households with heating and cooling energy costs, bill assistance, energy crisis assistance, weatherization, and energy home repairs. If an individual or their family member is eligible for Supplemental Nutrition Assistance Program (SNAP), Social Security Income (SSI), Temporary Assistance to Need Families (TANF), they may be automatically eligible for LIHEAP. To learn more visit lowa's LIHEAP https://humanrights.iowa.gov/dcaa/liheap.

Payee Services can play a vital role in successful independence for individuals who choose to remain in their family home or look at independent options outside of the home. A payee helps assist in money management, budgeting, and bill pay. A list of available payee options is listed below.

Representative Payee Services

Utilize the above link for access to representative payee services in our area.

Section 19:

Adaptive Equipment or Assistive Technology

Adaptive Equipment and Assistive Technology are at times used interchangeably to describe tools, devices, product systems, or machines to support an individual diagnosed with a disability and individuals who are in the aging population. While they have similar functions, they are both unique.

Adaptive Equipment is a tool, device, product system, or machine specifically created or designed to help assist an individual in increasing, maintaining, or improving their functional capabilities to remain independent.

- Examples of Adaptive Equipment include:
 - Cochlear Implants
 - Glasses
 - Grabber
 - Hearing Aids
 - · Prosthetic Leg
 - Wheelchair

Assistive Technology is a tool, device, product system, or machine made for the general population that is modified or customized to help assist an individual in increasing, maintaining, or improving their functional capabilities. Adaptive technology is a subset of Assistive Technology and focuses on electronic and technology access.

- Examples of Assistive Technology include:
 - Magnifying Bars
 - Pencil grip
 - Talking Calculator
 - Speech Recognition Software
 - Switches
 - Text-to-Speech

Adaptive Equipment and Assistive Technology Resources

<u>lowa Compass Adaptive Equipment and Assistive Technology</u> <u>Resources</u>

Utilize the above link for a list of adaptive equipment and assistive technology resources.

AIM Healthcare

AIM Healthcare has been serving Cedar Rapids and surrounding areas home medical equipment and pharmaceutical supplies since 1970. As one of the area's largest retail suppliers of home health products and services, they provide superior customer service and top quality, state-of-the-art medical equipment and supplies.

617 8th Ave SE, Cedar Rapids, IA 52401 · 319-364-4008 https://aimhealthcare.com

Apria Healthcare

Apria is a leading provider of home healthcare equipment and related services across the USA, serving approximately 2 million patients from 280 locations. One of Apria's primary goals is for their patients to receive the best possible health outcomes. Through Apria's comprehensive patient education, clinical assessments, and ongoing monitoring, Apria's Care Team members are able to support their patients' treatment plans and supplement with additional services, if needed.

1515 Blairs Ferry Road, Marion, IA · 319-377-9433 https://www.apria.com

CarePro Health Services

CarePro Health Services' mission is to provide individuals with the services and products they and their family need for a happier, healthier life. They provide home medical equipment, home infusion, home health and compounding services.

402 10th Street SE Suite 600, Cedar Rapids, IA · 319-298-0953 https://www.careprohs.com/services/carepro-home-medical

Cedar Valley Mobility

Cedar Valley Mobility's mission is to help resolve all accessibility and mobility needs, to make the individual's life better. They offer equipment and supplies that can give greater independence and peace of mind.

319-291-7210 or 800-603-9857

http://www.mobilitystore.com

CompuPlace

CompuPlace provides a computer resource center for individuals with disabilities. Activities are tailored to meet the specific needs of each individual, stimulating the development of literacy, language, reasoning, and academic, information-age and creative skills. CompuPlace uses touch screens, speech output, switches, screen magnifiers, voice recognition, and specialized instructional to support individuals. Internet access and e-mail help individuals keep in touch with family and friends! The Internet offers prime opportunities for teaching literacy and general computer skills.

601 Second Avenue SE, Cedar Rapids, IA · 319-366-2651

http://www.ecc-cr.net/compuplace.php

Digital Accessibility @ Iowa - The University of Iowa

IT Accessibility Group provides leadership and assistance with policy and technical guidelines, training, consultation, and advocacy for accessibility efforts in lowa.

319-384-3323

https://itaccessibility.uiowa.edu

Easterseals Iowa

Easterseals lowa offers the highest-quality services designed to meet the individual needs of children and adults with disabilities. They help each person overcome obstacles, become independent and reach goals.

401 NE 66th Ave, Des Moines, IA 50313 · 515-289-1933

https://www.easterseals.com/ia

Job Accommodation Network

The Job Accommodation Network (JAN) is the leading source of free, expert, and confidential guidance on workplace accommodations and disability employment issues.

800-526-7234 (V) in the United States

877-781-9403 (TTY) in the United States

https://askjan.org

Hamilton Relay Iowa

Hamilton Relay provides telecommunications relay services for the state of lowa including TTY, Voice Carry Over (VCO), Hearing Carry Over (HCO), Speech-to-Speech (STS), Visually Assisted Speech-to-Speech (VA STS), Spanish and CapTel[®].

https://hamiltonrelay.com/iowa

Dial 711

Heartland Hearing Center

The audiologists of Heartland Hearing Center have been helping the Cedar Rapids and lowa City communities hear better for more than 30 years. Having dedicated themselves to this neighborhood for so long, they founded Heartland Hearing to better provide the community with an honest and clear path for hearing loss and tinnitus treatment. As a local, independently owned, and operated hearing center, they have the time and freedom to make decisions in your best interest; you won't find private label devices there. They operate from a philosophy that hearing is essential for your quality of life and that your hearing loss is a personal experience.

1350 Blairs Ferry Road Suite C, Hiawatha, IA · 319-409-5786 https://heartlandhearingiowa.com

JVA Mobility, Inc.

JVA Mobility, Inc. strives to provide durable mobility & medical equipment and care services focusing on increasing abilities and improving the health status of the disabled population in the communities they serve.

4701 J Street SW, Cedar Rapids, IA · 319-366-3533 or 866-418-3533 https://www.jvamobility.com

National Seating and Mobility

National Seating and Mobility delivers personalized solutions to individuals with mobility challenges by bringing industry-leading expertise, uniquely engineered systems, and breakthrough technologies. Their products and services provide independence and self-reliance to clients; reassurance to family and caregivers; and responsive, flexible, and highly professional clinical support to their referral sources.

2415 Heinz Road, Suite 1, Iowa City, IA · 319-471-4530 https://www.nsm-seating.com

NuCara

They are passionately committed to providing diverse pharmacy and other health care products and services, emphasizing excellence, innovation, and creativity for the benefit of their patients.

1900 James Street, Suite 9, Coralville, IA · 319-358-8000 or 855-298-6283 https://www.nucara.com/coralville-ia-hme

Siebert Mobility of Iowa LLC

Siebert Mobility of Iowa LLC offers a unique blend of quality products, trained staff and a sense of understanding and compassion to help customers select the best solution to meet their mobility needs. The company specializes in vehicle modifications and wheelchair accessible vans that enable passengers and drivers to overcome challenges that limit their mobility.

3554 Dolphin Drive Suite A, Iowa City, IA · 319-351-3159 or 877-543-8826

https://www.iowawheelchairvans.com

Talk to Me Technologies

Speech-generating devices for children and adults, with the widest variety of access options available - from keyguards, head mouse, switch scanning and eye-tracking to auditory scanning and auditory fishing. Their extensive line of dedicated devices (-D) are approved for funding through Medicare, Medicaid, and private insurance programs. Model communication systems can also perform smart home functions such as controlling your TV, DVD, stereo, bed, lights and more.

3508 Terrace Drive, Cedar Falls, IA 50613 · 877-392-2299 https://www.talktometechnologies.com

Telecommunications Access Iowa

Telecommunications Access Iowa's goal is to provide access and assistance to individuals in selecting equipment that best suits their communication needs. Qualified individuals can receive a voucher that pays approximately 95% to 99% of the average cost of specialized telecommunications equipment.

Telecommunications Access Iowa (TAI) is a program of the Iowa Utilities Board and is administered by Deaf Services Unlimited, Inc. This program was established as a result of the Americans with Disabilities Act (ADA) to work in conjunction with Relay Iowa.

6925 Hickman Road, Des Moines, IA · 515-282-5099

www.teleiowa.com

The Iowa Library for the Blind and Print Disabled

The Library is a Regional Library of the National Library Service for the Blind and Print Disabled. The Library provides books, magazines and other informational materials in Braille, audio, large print, and electronic formats to lowa residents who are unable to use standard print materials because of a disability. Playback equipment for use with audio materials is also available on loan. The library's collection is home to 300,000 items – all available by

mail, free of charge. Textbooks and other educational materials for K-12 and college students are available through the library's Instructional Materials Center (IMC). The IMC also produces vocational materials in accessible formats for job seekers and employed lowans upon request.

524 Fourth Street, Des Moines, IA · 515-281-1323 or 800—362-2587 https://iowalibrary.blog

UnityPoint at Home - Home Medical Equipment

UnityPoint at Home knows there really is no place like home. Their Home Medical Equipment professionals understand your home care needs. That is why they offer the finest, most comprehensive home-based medical services in this area.

298 Blairs Ferry Road NE, Cedar Rapids, IA · 319-369-8686 https://www.unitypoint.org/cedarrapids/services-unitypoint-at-home.aspx

WRAP - Wheelchair Ramp Accessibility Program

The Wheelchair Ramp Accessibility Program (WRAP) provides timely home access to people in need. They are a coalition of volunteers and service organizations who work together to build custom wheelchair ramps and stairs, giving people with limited mobility the freedom to enter and leave their homes safely.

1026 A Avenue NE, Cedar Rapids, IA · 319-369-7377 http://wrapiowa.org

Section 20:

Adaptive Recreation

<u>Iowa Compass Recreation and Sports resources</u>



Adaptive Sports Iowa

To provide statewide leadership in the planning, promotion, education, and organization of sports and recreation opportunities for lowans with physical disabilities.

1421 S. Bell Ave, Ste. 104, Ames, Iowa 50010 · 1-888-777-8881

https://www.adaptivesportsiowa.org

AYSO VIP Soccer

The AYSO Very Important Players (VIP) program provides a quality soccer experience for children and adults whose physical or mental disabilities prevent them from successful participation on mainstream teams. VIP teams may include individuals with down syndrome, autism, cerebral palsy, emotional disturbances, visual impairments, or other conditions that limit mobility, strength, and/or comprehension. AYSO VIP players get the unique opportunity to be part of a soccer team for a full season.

https://www.ayso-cr.org/pages/vip-program.php

Miracles in Motion

Miracles in Motion has served hundreds of students over the years with a work force of over 300 volunteers and a herd of 10-15 horses and 3 miniature horses. Students come from Linn, Johnson, and other eastern lowa counties. and consist of children and adults with physical, emotional, and cognitive challenges. As lowa's first Premier Accredited Center, Miracles in Motion meets the highest standards for safety and therapy set forth by the Professional Association of Therapeutic Horsemanship International (PATH, formerly NARHA). PATH provides continuing education for staff and instructors.

2049 120th Street NW, Swisher, IA 52338 · 319-857-4141

https://miraclesinmotion.com

Rollin' Recmobile

During the summer, two Rollin' Recmobiles take to the streets to bring recreational activities to local neighborhoods. The vans, loaded to the top with recreation equipment and games, bring staff to lead activities at 16 different parks. The vans also have a WIFI hot spot that you can use during park visits.

319-286-5566

https://www.cedar-rapids.org/residents/parks_and_recreation/rollin_recmobile.php

Special Olympics Unified Sports

Dedicated to promoting social inclusion through shared sports training and competition experiences, Special Olympics Unified Sports® creates an opportunity for people without intellectual disabilities to join in the sports experience by playing on a team with athletes with intellectual disabilities. It was inspired by a simple principle: training together and playing together is a quick path to friendship and understanding.

https://www.soiowa.org/special-programs/unified-sports

The Kiwanis Miracle League at Prospect Meadows

KML@PM has organized spring and fall seasons to provide opportunities for children with disabilities to play Miracle League baseball, regardless of their abilities. Six weeks of games will begin around the first week of May through June and around the middle of August through September for the fall season. To participate, see below.

https://www.prospectmeadows.com/miracle-league

Section 21:

Sexual Health

Sexual health is an important part of every individual's life. Providing a safe, thorough, and thoughtful approach to sexuality and sexual health ensures everyone remains safe, healthy, in positive relationships free of any form of violence, with respect for one another. It is not uncommon for students in special education classes to be left out of the room during human growth and development lessons. The lack of education has led to increased numbers of sexual violence for the disability community. We have many local and national resources available to support individuals on their sexual health journeys.

Local Resources

Birthright of Cedar Rapids

375 Collins Road NE Suite 107, Cedar Rapids, IA 52402 319-393-3251 · 800-550-4900 (24 Hour Line)

https://birthright.org/cedarrapids

At Birthright, they understand the challenges related to unplanned pregnancies. Birthright is available to women for as long as they need them. They offer love, friendship, and support to women who are pregnant or think they may be pregnant. Birthright is interdenominational and is not involved in any political activities, or lobbying. Birthright's focus is on loving the mother, reminding her that there is hope and ensuring she is not alone.

Bridgehaven Pregnancy Support Center

4250 Glass Road NE Suite 100, Cedar Rapids, IA 52402 · 319-364-8967

https://bridgehavencr.org

Bridgehaven Pregnancy Support Center offers compassion, hope, and help in the circumstances before, during, and after pregnancy in the Cedar Rapids area. They serve both women and men. Services are always free and confidential.

Community Health Free Clinic

Clinic 947 14th Avenue SE, Cedar Rapids, IA 5240 · 319-363-0416 https://www.communityhfc.org

Founded in 2002, Community Health Free Clinic (CHFC) is a public 501(c) (3) nonprofit organization that provides free medical, dental, vision and

prescription services for those without access to or the ability to pay for healthcare in our community. CHFC never charges for our services and is not reimbursed by the government. We are funded through the generosity of individuals, foundations, and corporations.

Domestic Violence Intervention Program (DVIP)

1105 S Gilbert Court, Suite 300, Iowa City, IA 52244 800-373-1043 (Crisis Line) · 319-351-1043 (Office)

https://dvipiowa.org

DVIP provides services to victim/survivors of domestic violence, dating violence, stalking and human trafficking. Today, intimate partner violence is widely known to be one of the greatest physical dangers to women. Women, men, and children are murdered each year and the risk of child abuse is much greater in households where domestic violence occurs. Responding to intimate partner violence is critical and requires a community-wide effort. Support for victims of intimate partner violence and their loved ones is available in Johnson, lowa, Cedar, Des Moines, Henry, Lee, Van Buren, and Washington Counties through the Domestic Violence Intervention Program.

Eastern Iowa Health Center

1201 3rd Avenue SE, Cedar Rapids, IA 52403 · 319-730-7300

https://easterniowahealthcenter.com

Eastern lowa Health Center's mission is to provide exceptional and accessible, patient-centered healthcare for all. Services include family medicine, pediatrics, obstetrics and gynecology, labor and delivery, behavioral health, and dental care. Eastern lowa Health Center offers discounts based upon your family size and income. They accept Medicaid, Medicare, lowa Health and Wellness and most private insurance plans.

His Hands Free Clinic

1245 2nd Avenue SE, Cedar Rapids, IA 52403 · 319-862-2636

https://hishandsclinic.org

Since 1992, His Hands Free Clinic has been seeking to honor God by helping the uninsured and underinsured in the community. The clinic is a 501(c)3 nonprofit ministry providing free healthcare to Cedar Rapids and surrounding communities. They are members of the Linn County State Innovation Model, Linn County Housing Continuum of Care, Free Clinics of Iowa, Christian Community Health Fellowship, and the National Association of Free Clinics.

Hillcrest Family Services

317 7th Avenue SE Suite 202C, Cedar Rapids, IA 52401 · 319-362-3149 https://hillcrest-fs.org

Hillcrest provides health services through building confidence in troubled youth through their foster group care programs, giving hope to the homeless and promise to those wanting a family. Hillcrest builds character in adults who have lost their dignity and adds stability to the lives of families in need of mentoring. Hillcrest helps people of all ages who want to feel better emotionally. Their brain health counselors can make the prospects of a better life a reality.

Linn County Public Health

1020 6th Street SE, Cedar Rapids, IA 52401 · 319-892-6000

https://www.linncountyiowa.gov/health

Linn County Public Health (LCPH) provides many unique services to improve the health of Linn County residents. Their efforts within the community are strengthened by relationships established with other community organizations within the public health system. Through these relationships, LCPH is able to address the public health issues that are present within Linn County at multiple levels.

Linn County Ryan White Program

1240 26th Avenue Court SW, Cedar Rapids, IA 52404 · 319-892-5770

https://www.linncountyiowa.gov/231/8192/Ryan-White-Medical-Case-Management#:~:text=The%20Linn%20County%20Ryan%20White,income%20and%2For%20financial%20resources

Newly diagnosed or looking for HIV/AIDS information, resources, or services? The Linn County Ryan White Program offers confidential services to anyone in lowa living with HIV/AIDS. Services are free of charge, regardless of income and/or financial resources.

Planned Parenthood of the Heartland

3425 lst Avenue SE Suite 100, Cedar Rapids, IA 52402 · 877-8498-0765 850 Orchard Street, Iowa City, IA 52246 · 877-811-7526

https://www.plannedparenthood.org/health-center/iowa/cedar-rapids/52402/cedar-rapids-health-center-3969-90720

Planned Parenthood is one of the nation's leading providers of high-quality, affordable health care, and the nation's largest provider of sex education. With or without insurance, you can always go to them for your health care.

Positive Iowans Taking Charge (PITCH)

https://www.pitchiowa.com

To create an atmosphere where people living with HIV can unite, advocate, and assist others living with HIV to achieve better health and wellness. PITCH seeks to be a source of encouragement, provide educational opportunities, camaraderie, and a sense of community to lowans living with HIV/AIDS.

Rape Victim Advocacy Program (RVAP)

332 S Linn Street Suite 100, Iowa City, IA 52240 319-335-6000 or 800-228-1625 (Crisis Line) 800-284-7821 (Iowa Sexual Abuse Hotline)

https://rvap.uiowa.edu

RVAP is a sexual assault victim advocate and prevention education agency. They serve anyone impacted by sexual violence — survivors and/or their loved ones in the following eastern lowa counties: Cedar, Des Moines, Henry, lowa, Johnson, Lee, Washington, Van Buren. This includes but is not limited to individuals of any age, gender, identity, culture, etc.

Riverview Center

Highley Building, 118 3rd Avenue SE Suite 500, Cedar Rapids, IA 52401 319-540-0080

https://riverviewcenter.org

Riverview Center provides sexual assault services in a 14 county Northeast Region of Iowa, as well as sexual or domestic violence services in Jo Daviess and Carroll Counties in Illinois. Services are free regardless of biological sex, gender identity/expression, sexual orientation, immigration status, English proficiency, race and/or ethnicity, incarceration status, disability, or background. Riverview Center is a safe space.

Sexual Health Alliance of Linn and Johnson Counties

http://www.shacoalition.com

The Sexual Health Alliance is a collaborative group that promotes and supports healthy relationships and sexual behaviors in Linn and Johnson counties through community engagement.

Waypoint Domestic Violence Program

318 5th St SE, Cedar Rapids, IA 52401
319-365-1458 (Crisis Line) · 319-363-2093 (Office)
https://www.waypointservices.org

Impacting thousands of lives throughout seven Northeast Iowa counties each year, Waypoint's Domestic Violence Victim Services Program (DV Program) offers free, confidential services to domestic violence victims and survivors, as well as their families. Through a safety net of supportive services, the DV Program helps empower victims and survivors to safely move forward in their lives. These services, provided by dedicated, certified Victim Advocates, include Support groups, 24/7 Resource & Support Line, Peer counseling, Legal advocacy, medical advocacy, information, and referrals.

YPN (previously Young Parents Network)

420 6th Street SE Suite 260, Cedar Rapids, IA 52401 $\,\cdot\,\,$ 319–364–8909

https://www.ypniowa.org

YPN was founded in 1985 by community leaders who recognized that there was a lack of support for young families in Cedar Rapids. Since that time YPN has taken on a leadership role in East Central lowa as the provider of ongoing comprehensive year-round programs that meet the most critical needs of thousands of families within our community.

National Resources:

Access, Autonomy, and Dignity: Comprehensive Sexuality Education for People with Disabilities

https://www.nationalpartnership.org/our-work/resources/health-care/repro/repro-disability-sexed.pdf

Model Systems Knowledge Translation Center (MSKTC)

https://msktc.org

The (MSKTC) has various factsheets (in English and Spanish) on pregnancy, sexuality and sexual function, and/or reproductive health for people with spinal cord injuries (SCI), traumatic brain injuries (TBI), and burn injuries.

National Center for Disability and Pregnancy Research (NCDPR)

https://heller.brandeis.edu/disability-and-pregnancy/index.html

The (NCDPR) is a cross-disability initiative to address gaps in the knowledge about pregnancy and disability, enhance the experience of pregnancy in women with disabilities, and promote optimal pregnancy-related outcomes for pregnant people with disabilities.

National Rehabilitation Information Center

- Curated List of factsheets, articles, guides and books related to Sexual/ Reproductive Health and Disabilities
- Curated list of international research on reproductive health and disabilities
- NIDILRR-funded Consumer Products for the LGTBQIA2S+ and Disability Communities
 - https://naricspotlight.wordpress.com/2022/06/16/nidilrr-fundedconsumer-products-for-the-lgbtqia2s-and-disability-communities
- Answered Questions for February 2022: Intimacy and People with Disabilities
 - https://naricspotlight.wordpress.com/2022/02/24/answeredquestions-for-february-2022-intimacy-and-people-with-disabilities
- · Flowers, Chocolates, Romance...and Disability
 - https://naricspotlight.wordpress.com/2017/02/13/flowers-chocolatesromance-and-disability

SAFE - My Rights My Life

https://myrightsmylife.safeaustin.org

Research about abuse, violence prevention education, and people with intellectual and developmental disabilities (IDD) is somewhat limited. However, we know that people with disabilities are at high risk for abuse, and that education on safety and sexuality can decrease that risk. For 25 years, SAFE's Disability Services program has provided personal safety and sexuality education for youth and adults with disabilities in Central Texas and beyond. Those trainings and important research and studies on these topics laid the foundation for the contents of the My Rights My Life (MRML) curriculum.

Sex Ed for People with IDD

https://www.youtube.com/playlist?list=PLuEvYNNQ-dHeVhbyeJHx9s8oqsvBk621v

The National Council on Independent Living's and Rooted in Rights supported by the WITH Foundation created a ten-part video series to help people with intellectual and developmental disabilities (I/DD) learn about sex.

Sexual Education for Young People with Disabilities

https://www.advocatesforyouth.org/resources/fact-sheets/sexual-health-education-for-young-people-with-disabilities

Research and Resources for Educators

Sexuality Education for Students with Disabilities

https://www.parentcenterhub.org/sexed

The Center for Parent Information & Resources created a resource library to support individuals and their families. Resources include the basics of human sexuality, sexuality and disability, the special role of the parent, the content to be taught, materials on specific disabilities, and commercial products.

Temple University Collaborative on Community Inclusion for People with Severe Mental Illness

http://www.tucollaborative.org

<u>Toolkit for direct care personnel</u> (PDF) that focuses on discussion on sexuality, intimacy, and reproductive health with people with mental health conditions.

The Arc of the United States - Sexual Violence

https://thearc.org/our-initiatives/criminal-justice/talk-about-sexual-violence

Talk About Sexual Violence provides practical tools to address this silent epidemic through a supported decision-making lens that supports victim-centered approaches. This website provides easy-to-use access tools that include:

- Short training videos for healthcare professionals
- Charts and other tools for guided conversation
- · Focus group findings: video and reports
- Annual project reports

Thresholds Health Literacy and Wellness Promotion Center

https://www.thresholds.org

Addresses the health and wellness of individuals in recovery of psychiatric disabilities with other co-occurring disabilities and physical health conditions, focusing on health literacy and wellness as a means to enhance recovery and function in the community. Although they look at the whole person, they do have resources related to reproductive health that include factsheets on cervical health, mammography and breast health, men's health, etc.

Section 22:

Future Planning

Future Planning allows the individual diagnosed with the disability, their family, and care team an opportunity to come together and create a current and future plan for the individual. This plan will allow for consistency across the team as a framework to ensure the individual's wishes are identified and respected when decisions need to be made in the future and to receive professional support if necessary. It is recommended to review the plan every three years.

A plan should be in place in the event a caregiver is no longer able to provide care to an individual due to circumstances outside of the caregiver's control (i.e., nursing home, deceased, etc.).

Future Planning is not a replacement for any legal documents described in Section 23: Estate Planning of this guide, but many include the documents or locations of the documents listed in the Future Planning Care Plan.

Future Plan should include the following:

Activities, Hobbies, or Interests

A list of current activities, hobbies, or interests. If the activity, hobbies, or interests take place at a certain location or with an organization include name, address, phone number, and contact name for each.

Behaviors

A list of any behaviors of important note for the individual. What the behavior is, triggers, resolution and/or supports. If a behavioral plan is in place, it should be included in the care plan or supporting documents.

Daily Routine

The individual's daily routine for 24 hours, 7 days a week. If a caregiver is not available for support, this is a breakdown of what occurs throughout the day in its entirety and would allow someone to support the individual and create the least amount of disturbance to their routine.

Decision Making Support

A list of decision-making supports the caregiver providers throughout the day or for larger decisions with the individual. For some caregivers, it is easier to include this with the daily routine. Decisions large and small can be included in this section.

Education

Schools attended, address, phone number, graduation date. If currently in school, information should include contact information for the current school, teacher, school counselor and/or administrator.

Employment

A resume with past and present employers name, address, phone number, position held, date position held, pay, etc. For current employer contact information should be provided in the event contact with the employer is necessary.

Finances

A list of all financial institutions' names, address, phone number, how or who has access to the accounts.

Important Documents

A list of all legal documents (i.e., will, guardianship, power of attorney, etc.) and any personal identification documents (i.e., social security card, driver's license, birth certificate, etc.). Location and holder of the important documents.

Living Arrangements

Current address, phone number, and list of individuals residing in the residence. Information should include a list of past addresses, phone numbers, and individuals lived with. It is highly recommended to include a request or recommendation for living arrangements in the event the caregiver is no longer able to help in the decision-making process.

Medical Team

All professional medical providers the individual receives services from (i.e., primary physicians, specialists, hospitals, clinics, therapist, counselors, etc.). Information should include name, address, phone number, and if HIPPA forms are signed if needed.

Relationships

All family members, close friends, neighbors, or significant others of the individual. Information should include name, address, phone number, and relationship to the individual.

Religion

The individuals' religious beliefs, name, address, phone number of their religious center, any important religious date or anniversary, and if they would like to continue to attend.

Supports

All professional services support the individual receives. Service providers, case managers, etc. Information should include name, address, phone number, and relationship to the individual.



Section 23:

Estate Planning

Estate Planning is meant to serve as a plan to assist in the transfer of property, finances, and in some cases tax planning at the time of an individual's death. Estate Planning may require an individual to connect with a variety of professionals to address each service need, including an accountant, attorney, banker, financial planner, life insurance advisor, etc. For those in the disability community, some portions of estate planning will be necessary to set up prior to end stages of life for the individual diagnosed with the disability and their caregiver(s). Regardless of the age or health of the caregiver or individual, it is recommended to have your estate in place as an additional safety measure.

This guide is intended for general information only and is not intended, nor should it be construed or relied on, as legal advice. You should seek the appropriate counsel prior to making any decision and should contact an attorney if seeking legal advice.

Adult Support

When an individual reaches the age of 18, they are considered an adult. At that time, individuals can enter contracts, make their own medical decisions, manage personal finances, enter relationships or marriage, etc. If the individual or an adult in their life believes additional supports are needed because the individual is unable to manage their needs or communicate them, there are multiple options to help support them (i.e., Payee, Conservatorship, Guardianship, etc.).

If it is decided to remove decision making from an individual, certain facts and parameters must be met for those rights to be relinquished to another adult. The decision cannot be solely based on a specific diagnosis or medical condition. These parameters could include functional limitations (i.e., financial decisions, mobility, independent living, etc.) and if the individual's limitation will be continuing indefinitely. This may be done through the court system and can range in restrictions from a designated payee to guardianship.

It is recommended to contact legal counsel six months prior to an individual's 18th birthday if seeking additional support after they reach adulthood. When meeting with an attorney, they will provide their recommendation and walk you through the process to file the necessary paperwork.

If over time an individual has reached the ability to make independent decisions, restrictions can be terminated.

Conservatorship & Guardianship

The lowa Developmental Disabilities Council publication on Guardianship:

https://www.iowaddcouncil.org/guardianship-and-conservatorship-in-iowa

Office of the Public Guardian:

https://iowaaging.gov/elder-justice-adult-protective-services/office-publicguardian

Conservatorship and Guardianship are two of the most common items discussed when an individual reaches the age of 18. A brief description of both is provided below.

Conservatorship is a legally binding document through the court system giving a responsible adult, known as a conservator, the authority to manage an individual's financial affairs (property and personal assets) on behalf of the individual "ward". To seek conservatorship, the conservator must prove the ward is unable to make decisions with clear and convincing evidence. Conservatorship requires extensive work to maintain and account for all the ward's funds. If an individual is under a conservatorship, it means the individual is not able to care for themselves. Conservatorship is not permanent, and a decision can be made through the court to relinquish.

Guardianship is a legal document through the court system giving a responsible adult known as a guardian(s) the authority to manage personal and/or finances of an individual. The individual may be an adult diagnosed with a disability. The courts will try to limit guardianship to the specific areas the individual needs assistance with and will have the final decision on the quardian based on the best interest of the individual.

Limited guardianship means the appointed guardian(s) can only make decisions specifically stated in the court order. A plenary guardian can make all decisions (medical, financial, and personal). In plenary guardianship there is guardianship of the estate and guardianship of the person. Guardianship of the estate focuses on the legal and financial affairs of the individual. Guardianship of the person focuses on health care and personal affairs of the individual.

Guardianship should always be considered the last resort. If an individual is under guardianship, they still have a set of rights by law. These rights include participating in decisions about their life, having personal privacy, having and/or maintaining personal relationships, the right to vote, etc. Guardianship is not permanent, and a decision can be made through the court to relinquish it.

Guardianship may not be an option for families due to several factors; the guardianship is too restrictive, the individual does not want to be placed under guardianship, the courts deny guardianship, or the option is too costly for some families, and they do not have the capability to cover the amount needed. With any of these options, it is recommended to look at alternatives to ensure the individual is protected, while still maintaining their desired level of independence.

Alternatives to Conservatorship & Guardianship

If conservatorship or guardianship is not necessary, the below list of alternatives is available to support an individual and allows them to maintain a level of independence.

Advanced Treatment or Advanced Healthcare Directives is a vital part of supporting an individual when a more restrictive guardianship is not needed. Having Advanced Treatment Directives in place prior to a medical emergency ensures if a situation arises, the patient will receive their desired level of care. Living Wills and Medical Power of Attorney make up the advanced treatment directives or advanced healthcare directives.

- Living Wills provides written documentation for specific medical treatments, medications, and procedures you wish to receive or refuse if you are incapacitated and unable to make the decision for yourself. Unlike a Power of Attorney there is not a set individual (agent) making decisions on your medical care in the moment. The document is a set plan you have created for your healthcare team to make medical decisions when you are incapacitated. It is recommended to have a Medical Power of Attorney to help resolve any disagreements on the decisions in your Living Will. Decisions include cardiopulmonary resuscitation, artificial nutrition and/or fluids provided to you, brain activity, body disposition, etc. By completing your advanced directive now, you know your wishes are being met if you reach the point of being unable to make decisions for yourself. The Living Will only applies to medical situations and has no bearing on financial decisions. You can make changes to your living will at any time.
- Iowa Physicians Order for Scope of Treatment (iPost) is a form listing the wishes of an individual in need of life sustaining care. This is a recommended form if a living will has not been created. Medical staff utilize the form to maintain the wishes of the patient in the event the patient is unable to express their desires. Items listed on the iPost include administration of cardiopulmonary resuscitation (i.e. what happens in circumstances where the patient has no pulse and is not breathing), level of medical interventions in the event of a medical emergency (i.e. comfort measures only, limited interventions, or

full treatment), use of medically administered nutrition by tube (i.e. – artificially administer nutrients for patients who cannot take oral nutrition or hydration by mouth), and the rational for the orders.

• Medical Power of Attorney information is listed in alphabetical order in this section under Power of Attorney.

Health Insurance Portability and Accountability Act of 1996 (HIPAA) is a federal law protecting sensitive patient health information. A patient's information cannot be released without consent or knowledge. An individual has the option of signing HIPPA releases to allow people they trust to access their medical records (i.e., an independent adult can sign a HIPPA release allowing their parent to have access to their medical records from the doctor's office to ensure they maintain proper health).

Microboard is a small, nonprofit group of people serving one person who has a disability. The board makes sure the person has all the necessary support and services. Support can be unpaid "natural" support from family and friends, or paid staff can be hired to provide support. Widespread use of the microboard model began in Canada with the Vela Microboard Association. Today, there are several state microboard groups and many single microboards throughout the United States. https://velacanada.org/resources/microboards

Power of Attorney (POA) is a legal document allowing an individual (principal) to choose someone (agent) who manages their financial, medical and/ or property affairs. There are 4 general POA's and what the agent can and cannot do is based on the specific POA. In some cases, the agent will only manage the affairs if the principal is rendered incapacitated or only approved to act on behalf of the principal in a limited timeframe. POA can be permanent or temporary and can go into effect immediately or after the occurrence of an event (i.e., out of the country, progression of an illness). When choosing an Agent, the principal must ensure they can trust the individual delegated to the position. They will be giving extensive power to the Agent on their behalf.

- General Power of Attorney allows an agent to act on behalf of the principal in any matter allowed under state law regarding financial matters. Examples include buying or selling real estate, managing government benefits like social security, signing checks, filing taxes, etc. The POA will expire when the principal becomes incapacitated or incompetent.
- Special or Limited Power of Attorney allows an agent to act on behalf
 of the principal in limited capacity for a specific purpose or a specific
 amount of time. Limitations will be in writing at the time the POA was
 created (i.e., principal is out of town for the summer and the limited
 power authorization is only during the time they are gone).

- Durable Power of Attorney allows an agent to act on behalf of the principal in any matter allowed under state law for financial matters, like a general POA, but they can continue to act on behalf of the principal if they become incapacitated. Durable POA can prevent the need for a court appointed guardian or conservator. Durable POA can go into effect immediately or when certain criteria are met (i.e., principal is incapacitated in the hospital). Many states presume a power of attorney is durable unless stated otherwise in the POA documentation. It is important to seek legal counsel when creating your document.
- Medical or Health Care Power of Attorney allow an agent to make decisions on the course of health care treatment for the principal. You can name the same agent for all POA's, or you can name a different agent for each POA. For Medical Power of Attorney, you do have the option of naming alternative agents if your primary agent is unavailable, unwilling, or incapacitated to make decisions on your health care. When designating an agent, make sure they are clear on your wishes if you become incapacitated. Medical POA's are considered an Advanced Treatment Directive.

Representative Payee is a friend, relative or agency who manages an individual's benefit income received from the Social Security program. Individuals who receive Social Security Benefits are known as a beneficiary. If a beneficiary is unable to manage their finances or chooses to relinquish responsibility, the Social Security Administration can designate a representative payee to receive the benefits on behalf of the beneficiary. Representative payees are responsible for taking care of the beneficiary's current needs, future needs, and to save any money not spent taking care of those needs. A guardian is the first option for a representative payee, but if no guardian is available or wishes to be the payee, the Social Security Administration will choose a public or non-profit payee service. Payee organizations can charge a monthly fee for their payee services. If the guardian would like to be the representative payee; they will need to fill out a list of forms through the Social Security Administration to become appointed as a payee. For a list of payee services see the Finance section of this guide.

Special Needs Trust or Supplemental Needs Trust (SNT) is an account designed to provide supplemental funds for living expenses that cannot be covered by any public benefit programs for an individual diagnosed with a physical, mental, or intellectual disability defined by the Social Security Act. The individual does not need to receive Social Security Benefits to have an account. Having an SNT allows an individual to have a financial account with a balance that can go beyond set limits on certain public benefit programs (i.e., Section 8, Medicaid, SSI, etc.). Having funds in an SNT will not cause the individual to be disqualified from those needed benefits.

An individual with an SNT will not have direct access to their funds, but will have a designated trustee (i.e., family member, friend, 3rd party company). A trustee is decided at the time of the trust being opened. The trustee oversees the SNT and will be tasked with disbursing assets for the individual as needed and helping them with financial management of the account. For an individual to have access to the money, they will request money from the trust. The trustee is responsible for the amount of money in the trust, how the funds are being spent, ensure the money spent does not impact benefits, and to keep updated on the changes to SNT rules and regulations at the state and federal levels.

There are three types of Special Needs Trust:

- First-Party Special Needs Trust or Self-Settled or d4A is funded by the individual diagnosed with the disability. These funds could come from a lump sum settlement from a lawsuit or from an inheritance that was paid directly to the individual. This SNT can only be established by select individuals (i.e., the individual diagnosed with the disability, their parent, grandparent, legal guardian, or the court). There are several items to consider before choosing this SNT. If funds are still in the trust at the time of the account owner's death, the remaining balance must be paid to Medicaid, if the individual received any Medicaid funding during their lifetime. The trust cannot be changed once established. The trust must be established and funded before the account holder turns 65.
- Third-Party Special Needs Trust is funded by someone else's money and not the individual diagnosed with the disability (i.e., inheritance, gift from family member or friend). There are no age restrictions for this SNT and it can be established by anyone for the individual. At any time, the SNT can be revoked (i.e., funds are no longer needed, the funder needs access to the funds their child no longer needs). If funds are still in the trust at the time of the account owner's death, Medicaid does not have a payback provision like a First-Party Special Needs Trust. This SNT can be established and funded at the time of someone's death (i.e., at the time of a parent's death) or can be established and funded while all family members are living. If funded at the time of living, you allow anyone to put funds into the account or if other family members pass (i.e., grandparents), they can leave an inheritance into the trust for the individual.
- Pooled Special Needs Trust or Medical Assistance Pooled Trust or d4C is funded by the individual diagnosed with the disability money or by someone else's money (i.e., lump sum settlement, inheritance, gifts, etc.). Pooled SNT defers from other SNT's with the trustee being designated as a non-profit organization. Like other trustees, the

non-profit is responsible for following all federal and state rules and approves the use of funds from the account. There is usually a fee associated with having a Pooled SNT but can cost less than setting up an individual trust. Pooled SNT cannot be changed once established and the State of lowa is the residual beneficiary of the trust.

Things that can be purchased using SNT fund are items considered as wants for the individual and should benefit their daily life:

- Burial burial expenses, funeral arrangements
- Dental Services
- Electronics cable, computer, internet, phone, tablet, television
- Entertainment tickets to a concert or movie
- Hobbies crafts, books, art supplies
- Household & Personal Care clothing, furnishings, furniture, haircuts
- Medical Care not covered by Medicaid or Medicare
- Pet new fish
- School books, tuition
- Trips Family vacation, weekend trip with friends
- Vehicle gas, insurance, maintenance, purchase

Things that cannot be purchased from the SNT generally fall under food or housing. Talk with your trustee to decide if the need to use the trust outweighs the loss of some SSI benefits:

- Association Dues Homeowner or Condo Associations
- Groceries, food, or meals out at a restaurant
- Items for Others donations or gifts
- Mortgage or Rent
- Property taxes
- Utilities electricity, gas, water

To learn more about Special Needs Trusts and Pooled Trusts visit https://www.ablenrc.org/understanding-able-accounts-special-needs-trusts-and-pooled-trusts

Supported Decision Making is a plan to meet with a team of trusted people to assist an individual when making decisions. The individual has the final decision but has a team of people to help assist them in the process. Team members can include family, friends, medical providers, case managers, etc. When creating the plan, an individual can decide what areas of their life they may need extra help on when having to make decisions (i.e., housing, finance, etc.) and who they want to help talk through the decisions with (i.e., parents, aunt, sister, friend, etc.). The team members will talk through the pros and cons of decisions (i.e., voting in the next election, what college to attend, starting a relationship with someone, etc.).

Wills are a legal document expressing the preferences of an individual regarding the distribution of their assets after death. Items of distribution include belongings, money, and property. Anyone over the age of 18 should have a last will in place and updated regularly to ensure their wishes are met. Seek legal counsel when creating or updating your will.



680 2nd Street SE Cedar Rapids, IA 52401 319-365-0487 www.arceci.org