# Along THE Way

## A Guide for Adults with Intellectual and Developmental Disabilities

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**This guide was developed by:**

FRITZ & O'HARE ASSOCIATES

Lloya Fritz and Mary O'Hare

lloyafritz@gmail.com

maryohare7@gmail.com

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Nebraska Council on Developmental Disabilities

Department of Health and Human Services

301 Centennial Mall South

PO Box 95026

Lincoln, Nebraska 68509-5026

Phone: 402-471-2330

Email: dhhs.ddcouncil@nebraska.gov

**To view or print copies of this guide, visit the Nebraska Council on Developmental Disabilities website at:**

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## Introduction

Welcome to *Along the Way*, a series of resource guides for persons with intellectual and developmental disabilities (I/DD) and those who support them. This series is based upon a goal of assisting people with I/DD in living and participating in their communities as independently as possible. This means supporting the person in:

- Living where and with whom they choose
- Working in real jobs of their choice and earning real wages
- Practicing the faith of their choice
- Being connected to an array of friends and family with whom they have deep personal and intimate relationships
- Growing and developing personally through opportunities for education and life-long learning
- Exploring areas of personal interest
- Experiencing physical and emotional well-being
- Having membership in community organizations
- Making choices, taking risks, and determining the course of their life
- Accepting the responsibilities of citizenship (such as paying taxes and voting)[1]

While there are many resources to assist in achieving this goal, it can be an overwhelming and difficult process to navigate the services and systems and to find needed answers. To help with the navigation, we have created a set of guides to provide information and resources for the person with I/DD, parents and family members, and others who may support the person.

Originally developed in 2018, the *Along the Way* guides were updated in 2021 to reflect information current at that time. The series contains three guides addressing the following life stages, along with a fourth publication that provides relevant resources and contact information.

- Parents of Infants, Toddlers, and Children with Disabilities
- Adolescents and Young Adults with Intellectual and Developmental Disabilities
- Adults with Intellectual and Developmental Disabilities

Note: Throughout this guide, you will see the terms "developmental disabilities" (DD) and "intellectual/developmental disabilities" (I/DD). For our purposes, these terms are interchangeable.

[1] Amy Hewitt (*2014*) Presidential Address, 2014—Embracing Complexity: Community Inclusion, Participation, and Citizenship. Intellectual and Developmental Disabilities: December 2014, Vol. 52, No. 6, pp. 475-495.

Relevant topics are discussed for each age group, along with resources and other tools that may be helpful. The purpose of this Adult guide is to provide a roadmap to the services and supports available for people with I/DD over age 21. We also address some of the issues that people with disabilities face as they age and resources to address those issues.

**FYI:** *Guide Format*

Each chapter covers a variety of topics and ends with a box titled *FYI* (For Your Information) that lists supporting documents and websites. The Appendix includes a list of frequently used acronyms and the Index lists topics, terms, and agencies discussed in this guide. *Tips Along the Way* sections offer helpful suggestions.

# Chapter 1.

## Benefits & Financial Planning

People with disabilities often qualify for medical and income support through benefits programs, such as Medicaid and Social Security. Benefits can be a key piece in assisting the person to live independently in the community, providing income and health care coverage. Eligibility requirements can be confusing and many fear that benefits will be lost if they become employed. This is a valid concern. These programs can be complicated and not everyone will qualify, so we'll begin with an overview to provide some background.

### 1.1 Supplemental Security Income (SSI)

The Social Security Administration provides SSI as a federal cash benefit program designed to guarantee a minimum monthly income to people who qualify. There is a two-step process for obtaining SSI benefits. First, the person must meet basic eligibility requirements. Then, a determination must be made that the person has a qualifying disability.

**SSI Basic Eligibility:** SSI benefits are based on need. Eligibility is not based on the amount the person paid into the program or number of quarters worked as it is in other Social Security programs. SSI benefits are paid to the eligible person only and not to family members or survivors. SSI is different than Social Security Disability Insurance (SSDI). SSDI pays benefits to the person and certain family members if the person worked long enough, recently enough, and paid Social Security taxes on their earnings. To qualify for SSI, a person must be:

- A U.S. citizen;
- Living in the U.S.; and
- Over 65, or blind, or disabled.

In addition to the above requirements, the person must pass income and resource tests. Income of the person applying and their spouse (if applicable) is considered. The person must show that resources or assets are limited. Resources include possessions such as real estate, personal belongings, household goods, money, stocks, and bonds.

**Disability Determinations:** Once Social Security determines that the person meets the basic eligibility requirements for Social Security disability benefit programs, the agency sends the applicant's file to Nebraska's Disability Determinations Section. Here, medical and psychological records are reviewed and a decision is made whether the person meets Social Security's definition of disability.

Persons age 18 or older may be considered disabled if they have a medically determinable physical or mental impairment (including an emotional or learning problem) which:

- Results in the inability to do any substantial gainful activity (see below); and
- Can be expected to result in death; or
- Has lasted or can be expected to last for a continuous period of not less than 12 months.

Note: In Nebraska, a person who is eligible for SSI also meets eligibility requirements for Medicaid. Medicaid doesn't automatically begin, however, as the person must apply and be approved for Medicaid (see Section 1.2).

**Substantial Gainful Activity (SGA):** An important part of determining if a person has a disability is the Social Security Administration's interpretation of substantial gainful activity. A person earning more than a certain monthly amount is considered to be engaging in substantial gainful activity. The amount considered for SGA depends on the nature of the disability. This amount is higher for persons who are blind. The amount typically changes every year. As a point of reference, the SGA amount for individuals who are blind is $2,260 per month for 2022, while the amount for persons who are not blind is $1,350 per month for 2022.

**Retirement/Survivorship/Disability:** To get the most out of Social Security, it's important to be aware of such things as who can get benefits on their Social Security record and how to obtain and use Social Security information in planning family financial security. Changes in status such as retirement, disability, or death of the person or, in some cases a spouse or parent, may result in a change in Social Security benefits.

Note: Before a person, parent, or spouse retires or if death or disability occurs, it is vitally important to determine how this change in status will impact benefits. Every situation is different, so it is recommended that the Social Security Administration be contacted to determine the impact.

**Appeals:** It may be necessary to appeal a decision made by the Social Security Administration. This can include decisions regarding eligibility, changes to the person's benefit amount, or overpayments. Filing an appeal will result in a review of the person's case and the entire determination, even those parts that are in the person's favor. Information regarding the appeals process may be found on the Social Security Administration's website.

### 1.2 Medicaid

Medicaid is a public health insurance program for certain people with limited income and resources, including those who are aged, blind, disabled, children, and others who meet eligibility requirements. Medicaid is a joint effort between the federal and state governments. There are varying income and resource guidelines for different Medicaid eligibility groups.

**Age/Disability**

To be eligible for Medicaid, a person must be:

- 65 years of age or older;
- Low income adult aged 19-64;
- Under 65 years of age with a disability, or visually impaired according to Social Security guidelines;
- 18 years of age or younger; or
- Dependent child who meets the eligibility requirements of the Aid to Dependent Children Program.

**Allowable Resources**

To be eligible for Medicaid, a person is allowed to possess the following resources:

- Home in which the person resides;
- One motor vehicle;
- Property used to operate a trade or business (for example, land, machinery and equipment); and
- Irrevocable burial trust.

**Financial Resources**

At the time of this publication, current guidelines for Medicaid eligibility require that the amount of financial resources cannot exceed the following guidelines:

- $4,000 for one-member family
- $6,000 for two-member family
- $25 for each additional family member

Children age 18 and younger and eligible pregnant women are not subject to a resource test.

**Other Requirements**

To be eligible for Medicaid, the person must:

- Complete an application;
- Have US citizenship or qualifying alien status;

- Be a Nebraska resident;
- Have a Social Security Number;
- Provide information for any relative with responsibility;
- Have income and resources within established limits for certain eligibility categories;
- Show cooperation with child support;
- Have a qualifying living arrangement; and
- Accept assignment of third-party medical payments.

**Assistance to the Aged, Blind, or Disabled (AABD):** There are different Medicaid categories based on the person's needs. Most people with I/DD are eligible for Medicaid under AABD. Current eligibility requirements for this program are as follows:

- Age 65 or older;
- Blind or disabled, age 64 and younger, and determined disabled by the Social Security Administration or by the State Review Team;
- Receiving either Supplemental Security Income (SSI) and/or Social Security Disability Insurance (SSDI) payments; and
- Meet income and resource limits:
    - Income limit = 100% of the federal poverty level
    - Resource limits = If SSI eligible: $2,000 for one person. If not SSI eligible: $4,000 for one person and $6,000 for two people

Note that private health insurance expenses are an allowable income deduction with some restrictions.

Note: Application for Medicaid may be made at the nearest Department of Health and Human Services (DHHS) office or online through ACCESS Nebraska.

**Appeals:** There may be a time when it's necessary to file an appeal if the person doesn't agree with a decision made by DHHS. See Section 7.2 of this guide for information regarding appeals.

## TIPS ALONG THE WAY

**Applying for Benefits**

The process of applying for benefits can be time consuming. Documents will need to be gathered and many forms must be completed. To help with the process:

- Call periodically and ask about the status of the application.
- Do not be afraid to ask questions.
- Keep records and copies of applications, as well as notes of phone conversations and meetings.
- Remember that there may be a need to appeal a decision if denied for a program.
- Be patient and persistent!

### 1.3 Benefits Planning Services

By now you can see that applying for and receiving benefits can be complicated. Fortunately, benefits services are available in Nebraska to assist in navigating the system. Under agreement with Nebraska VR (previously known as Vocational Rehabilitation or Voc Rehab), three agencies may assist in providing benefits planning services for persons who receive Social Security and other benefits and who are served by VR. (Information regarding VR and how to contact them is provided later in this guide.) People may have a choice of agencies to work with depending on where they live.

Agencies providing benefits planning services are:

- Easterseals Nebraska
- Goodwill Industries of Greater Nebraska
- Region V Services

Benefits planning services are provided by Benefits Counselors who have extensive training and can offer expert guidance based on the person's circumstances.

Benefits Planning Services may provide:

- Answers to questions about current benefits
- An outline of available work incentive options
- A projection of how levels of earnings and number of hours worked will affect benefits
- An opportunity to make an informed decision about the work incentive strategies that will work best for the person

Beginning at age 14, Work Incentives Planning and Assistance (WIPA) projects provide information and benefits counseling to help in understanding how work and earnings can affect benefts. The WIPA Project for the state of Nebraska is operated by Easterseals Nebraska. Contact the Ticket to Work Help Line to begin the intake process.

Note: Nebraska's Aging and Disability Resource Center (ADRC) assists people in understanding and/or applying for public benefits. See Chapter 7 for more information about the ADRC.

### 1.4 ABLE Savings Plan (Enable)

In addition to understanding and applying for benefits programs, it may be helpful to know about a special financial planning program designed for persons with disabilities. In 2014, Congress passed the Achieving a Better Life Experience Act (ABLE) as a financial tool for people with disabilities. As a result of the federal law, Nebraska passed the Enable Savings Plan in 2015.

Enable allows Nebraskans with certain disabilities to create tax-advantaged ABLE savings accounts to pay for qualified disability-related expenses. Qualified disability-related expenses include basic living expenses and expenses that enhance a person's quality of life. This allows people to keep their public benefits and provides income tax and estate tax benefits. Assets up to and including $100,000 in an Enable account are not counted for purposes of determining eligibility for Supplemental Security Income (SSI). There is no limit for Medicaid eligibility.

A person is eligible for Enable if they:

- Are blind or disabled before the age of 26 and entitled to Supplemental Security Income or Social Security Disability Insurance benefits; or
- Have a certification from a physician indicating that they have a marked or severe functional limitation that was diagnosed before the age of 26, which is expected to result in death or has lasted or can be expected to last for a continuous period of not less than 12 months.

**FYI:** *Chapter 1. Benefits & Financial Planning*

**Social Security Benefits**

1) Best Eligibility Screening Tool
   Welcome to SSA BEST | SSABEST (benefits.gov)
2) Social Security Benefits
   Supplemental Security Income Payments | SSA
3) Social Security Office Locator
   Social Security Office Locator, SSA Office Locator Social Security Office Locator, Social Security

4) Supplemental Security Income
   Supplemental Security Income (SSI) (ssa.gov)

5) Understanding SSI Eligibility Requirements
   UnderstandingSSI-SSIEligibility(ssa.gov)

6) Understanding Supplemental Security Income
   Understanding Supplemental Security Income (SSI) -- Home Page (ssa.gov)

7) Understanding Supplemental Security Income: Appeals Process
   Understanding SSI - Appeals Process (ssa.gov)

**Medicaid**

1) ACCESSNebraska
   ACCESSNebraska

2) Nebraska DHHS Local Offices
   Public Assistance Offices (ne.gov)

3) Nebraska Medicaid
   Medicaid Brochure (ne.gov)

4) What do I need to know about Medicaid?
   Eligibility for DD Services (ne.gov)

**Benefits & Financial Planning**

1) Benefits Planning Services
   Nebraska VR I Partners

2) Easterseals Nebraska
   Easterseals Nebraska | Homepage

3) Enable Savings Plan
   Enable Savings Plans - Enable Savings

4) Goodwill Industries of Greater Nebraska
   Home - Goodwill Industries of Greater Nebraska (goodwillne.org)

5) Nebraska Ticket to Work
   Work and Disability Benefits | Nebraska Ticket to Work Program

6) Region V Services
   Region V Services : Home

# Chapter 2.

## Community Living

There are many things to consider when thinking about the goal of living and participating in the community as independently as possible. This chapter discusses some of the partners and resources available to assist in the area of Community Living.

There are many questions to be answered when it comes to making a plan for community living. Does the person want to live alone, with a roommate, with support from others, with family or relatives, or in a group home or other agency-operated setting? What supports does the person need to live safely? Does the person have the skills needed to live independently? This includes skills for:

- Daily living (cooking, laundry, household maintenance, etc.)
- Health/physical care (personal cleanliness, medication management, medical appointments, etc.)
- Leisure activities (connections with friends, access to social and recreational activities, etc.)
- Mobility (transportation skills to access the community)
- Money management (shopping, bill paying, budgeting, etc.)

**Natural Supports:** A concept to think about is "natural supports." A natural support is the support and assistance that naturally flows from relationships and associations formed in natural settings, such as within the family or community. Natural supports are not based on being eligible for a program or having money to pay for a service. A natural support is not paid. An example of a natural support is when the person attends a swim class at a local YMCA with others who may or may not have a disability. A trusted friend, family member, or peer may take the class alongside the person and provide transportation to the class and assistance (natural support) as needed.

### 2.1 Nebraska Assistive Technology Partnership (ATP)

An important support for people with disabilities is assistive technology. Assistive technology is any item, piece of equipment, or system used to improve or maintain the skills of a person with a disability. Examples of assistive technology devices include:

- Electronic communication aids
- Computer software

- Voice recognition system
- Touch-sensitive computer screens or tablets
- Switches or battery-operated devices

The Nebraska Assistive Technology Partnership (ATP) is an agency that helps people of all ages with disabilities locate and use assistive technology to help them live, learn, and work in their communities. This includes people with a disability or those who are recovering from an injury or illness and need temporary solutions. ATP also may assist with home and vehicle modification projects to make a home or vehicle more accessible for the person with a disability.

ATP provides Resource Coordination to assist in obtaining needed assistive technology and home/vehicle accessibility modifications. To receive services, an application must be completed to see what resources, programs, and funding may be available. ATP has partnerships with organizations that might help cover costs for all or part of what's needed. They help connect people with potential funding sources, financial loans, or used and donated items.

Assistive Technology Specialists help identify equipment options, features, and modifications for use at home, school, or work. ATP is experienced with building codes and specifications for ramps, showers, classrooms, workplace requirements, and modified tools. On-site assessments in homes and worksites may be available, along with training on equipment use.

ATP also helps service coordinators, employers, educators, and agency personnel learn about the benefits of assistive technology. The AT4ALL website lists equipment that is available for demonstration or loan. This helps with the evaluation process or to assist someone with finding the right assistive technology by trying it out before purchasing. Through this site, recycled and donated items are often available for free to use at home, school, and work.

## 2.2 Nebraska Commission for the Blind and Visually Impaired (NCBVI)

This Commission is the state vocational rehabilitation agency for Nebraskans who are blind or have low vision. NCBVI strives to empower people with vision loss with the tools, training, mentorship, and resources they need to succeed in high school, college, and beyond to find and maintain employment, and participate actively in their communities. NCBVI services include, but are not limited to:

- Training in non-visual (or low vision) skills that allow full participation in life
- Assistance in securing or maintaining employment

- Fulfilling employment needs in Nebraska
- Career counseling and guidance resulting in employment
- Job-related equipment, tools, and supplies
- Educational assistance such as tuition, books, equipment, and readers
- Peer support and counseling
- Consultation services for agencies and community organizations which come into contact with blind persons

## 2.3 Nebraska Commission for the Deaf and Hard of Hearing (NCDHH)

NCDHH promotes and advocates for Nebraskans who are deaf, deaf-blind, or hard of hearing. The Commission works to achieve equality and opportunity in social, educational, vocational, and legal settings to impact the daily lives of people who are deaf or hard of hearing. The Commission also works to enhance and monitor access to effective communication and telecommunication technology. Services offered include hearing aid banks, media center, assistive devices loan program, training and presentations, and links to resources.

## 2.4 Nebraska Department of Health and Human Services (DHHS)

There are many programs offered through the Nebraska Department of Health and Human Services that may benefit people with I/DD. Some of those are discussed here.

### Division of Behavioral Health

This Division of DHHS works with six regions throughout the state in the delivery of mental health and substance use disorder services.These services are offered on a sliding fee scale. Behavioral health service providers can be located on the Division's Network of Care website. This website is for people with mental illness, their caregivers, and service providers and lets people access information about issues such as treatments, resources and diagnoses, and wellness recovery action plans.

### Aged and Disabled (AD) Home and Community-Based Services Waiver

The Aged and Disabled (AD) Waiver is a Medicaid Home and Community-Based Services (HCBS) waiver which provides services and supports to people who choose to live in the community rather than in a nursing facility. The AD Waiver provides an array of services that help people live at home or in the community.

The AD Waiver is one of several waivers in Nebraska. A person may only be on one Medicaid waiver at a time. This means, for example, that a person cannot have both AD Waiver and a Developmental Disabilities (DD) Waiver.

**Eligibility:** The AD waiver is available to aged persons and persons of all ages with disabilities who meet the following criteria:

- Eligible for Medicaid;
- Have physical and health needs that require nursing facility level of care;
- Desire to live at home rather than a nursing facility; and
- Have an individualized plan of services and supports to keep the person safe in their home.

Aged and Disabled Level of Care is based on the level of care needed to live in a nursing facility. The Level of Care assessment tool depends on the age of the participant. Nursing Facility Level of Care for adults (age 18+) looks at activities of daily living, risk factors, medical treatment, and cognition factors. The assessment categories are: social support, health status, medications and medical equipment, nutrition, instrumental activities of daily living, and housing. People who apply for the AD waiver are assessed to see if their needs are the same as those of people who live in a nursing facility.

**Service Coordination:** A Service Coordinator is required for all persons on the AD waiver. The Service Coordinator is expected to make contact monthly with or on behalf of the person and may help them access other benefits and services. The Service Coordination provider for adults (ages 18 and older) is either through an Area Agency on Aging or the League of Human Dignity.

**Services:** Because AD waiver participants have medical needs, services focus on supporting them by doing things for them that they cannot do themselves. Services under the AD waiver include:

- Service Coordination provided by specially trained staff who help match needs with services and providers, based on preferences
- In-home assistance, such as: home delivered meals, cleaning, laundry, grocery shopping, nutrition services, personal emergency response system, special equipment to make tasks easier to perform, or modifications to make the person's home accessible
- Relief time (respite) for family caregivers
- Community supports, such as adult day services and non-medical transportation
- Assisted Living services

**Application:** Application for the AD waiver may be made to the Division of Developmental Disabilities (DDD) with a paper application at any DHHS office or by calling toll-free. The paper application may be used to apply

for any or all of the HCBS waivers. Contact information is provided on the DDD website.

In addition to applying for the AD waiver, a person must also apply for and accept all benefits for which they may be eligible. One of these benefits is Medicaid, which is public health insurance. Medicaid provides a federal match to state funding, which allows the program to fund more eligible people. Application for Medicaid can be made at any age, but parental income may disqualify some people.

### Traumatic Brain Injury (TBI) Waiver

The Traumatic Brain Injury (TBI) Waiver is a Medicaid Home and Community-Based Services (HCBS) waiver. As with other Medicaid waivers, the TBI Waiver provides services and supports to people who choose to live in the community rather than in an institution or nursing facility. The TBI Waiver is available to people ages 18 to 64 with traumatic brain injury who meet nursing facility level of care.

**Eligibility:** Eligibility requirements for the Traumatic Brain Injury Waiver include the following:

- Live in Nebraska;
- Eligible for Medicaid;
- Ages 18 through 64;
- Have a diagnosis of traumatic brain injury* (such as a blow to the head);
- Meet nursing facility level of care; and
- Have a need for specialized assisted living.

*This program is not for acquired brain injury caused by strokes, tumors, and other non-traumatic causes.

Nursing facility level of care means the person requires services such as those provided to people who live in a nursing facility. Persons who apply for the TBI Waiver are assessed to see if their needs are the same as those of people who live in a nursing facility.

**Services:** This waiver provides Specialized Assisted Living services. Currently, this service is offered by one provider in the Omaha area. Services include assistance with personal care activities and activities of daily living.

**Application:** Application for the Traumatic Brain Injury Waiver may be made through ACCESSNebraska. Application may also be made with a paper application at any DHHS office, or by calling toll-free. The paper application allows the person to apply for any or all of the HCBS waivers. Contact information is provided on the DDD website.

**Developmental Disabilities Waivers**

The Division of Developmental Disabilities (DDD) administers Medicaid home and community-based services (HCBS) waivers to help eligible people live, work, and access their community as independently as possible. The developmental disabilities (DD) waivers may be referred to as DD services. DD services include employment, residential, and other services designed to help the person live independently and access their community. Services may be provided by agency providers or independent providers, or by a combination of the two types.

**Eligibility:** To be eligible for DD services, a person must meet the definition of developmental disability as defined in Nebraska Revised Statute 83-1205: "Developmental disability shall mean a severe, chronic disability, including an intellectual disability, other than mental illness which:

1) Is attributable to a mental or physical impairment unless the impairment is solely attributable to a severe emotional disturbance or persistent mental illness;

2) Is manifested before the age of twenty-two years;

3) Is likely to continue indefinitely;

4) Results in substantial functional limitations in one of each of the following areas of adaptive functioning:

    a) Conceptual skills, including language, literacy, money, time, number concepts, and self-direction;

    b) Social skills, including interpersonal skills, social responsibility, self-esteem, gullibility, wariness, social problem solving, and the ability to follow laws and rules and to avoid being victimized; and

    c) Practical skills, including activities of daily living, personal care, occupational skills, healthcare, mobility, and the capacity for independent living; and

5) Reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated."

Note: Anyone who is potentially eligible for services through DDD is encouraged to apply. Due to limited funding for these services, people are encouraged to apply early!

**DD Services Application:** Application for DD services may be made online at ACCESSNebraska. The online application includes consent to release information so that DDD can gather supporting documents. The DDD website has a document that walks through the online application with screenshots of every step. Or, you may request a paper application in

person at any DHHS office or by calling toll-free. The paper application can be used to apply for any or all of the Medicaid HCBS waivers. Contact information is provided on the DDD website and in the DD Services Eligibility brochure.

Once DDD receives an application, an employee will call to begin the process of gathering appropriate documents. Required documentation may include, but is not limited to:

- Current developmental disability diagnosis, with onset prior to age 22, completed by a licensed psychologist or medical doctor operating in the scope of their practice.
- Assessments for intellectual or adaptive behavioral functioning which affected the applicant's ability to carry out activities of daily living skills.
- School reports:
    - All Multidisciplinary Team (MDT) reports
    - Most recent Individualized Education Program (IEP).

DDD has 90 days to decide on eligibility, but this decision is usually made within 14 days of receiving the application and all necessary supporting documents. A Notice of Decision will be sent to the applicant, stating whether they are eligible for DD services.

In addition to applying for DD services, a person must also apply for and accept all benefits for which they may be eligible. One of these benefits is Medicaid. Medicaid provides a federal match to state funding, which allows DDD to fund more eligible people. For adults (age 19 and over), parental income is not counted. An adult Medicaid applicant is considered a "household of one" even if they live with their parents. For more information about Medicaid, see Chapter 1 of this guide.

**Determination of Ineligibility for DD Services:** Persons found to be ineligible for DD can appeal the decision. Instructions on how to appeal are sent with the written notice of decision. A person who is ineligible can reapply whenever new information becomes available.

**DD Registry:** Being determined eligible does not mean the person will immediately receive services. DD services are not an entitlement and there is limited funding available, as allocated by the Nebraska State Legislature. Funding for DD services is based upon funding priorities, as defined in Nebraska Rev. State Statute 83-1216. If funding is not available, the person is placed on the DD Registry. An adult must have Medicaid to be on the DD Registry.

Note: It is possible that a person may qualify for more than one Medicaid HCBS waiver. For example, a person may qualify for both a Developmental Disability waiver and the Aged and Disabled (AD) waiver. Because there is often a wait for DD services, it may be possible for the person to utilize AD waiver services while waiting for DD services to become available.

**DD Service Coordination:** A Service Coordinator (SC) is available for all persons on the DD Registry. When a person is actively receiving DD services, they are required to have an SC. Medicaid pays for service coordination for those who are Medicaid eligible. Those who do not have Medicaid will be assessed a fee based upon Ability to Pay if they wish to receive this service.

The SC is expected to make contact monthly with or on behalf of the person. The SC may help the person access other benefits and services even before other DD services begin. A Service Coordinator will:

- Work directly with the person to develop a service plan based on their wants and needs.
- Complete referrals for DD agency providers and assist with visits and transition plans.
- Help DD independent providers enroll (if applicable).
- Help the person access services not funded by DD, such as Medicaid, SSI, and the Supplemental Nutrition Assistance Program.
- Help the person identify and access community resources.
- Hold meetings every six months, at a minimum, to help the person work toward goals.
- Complete monitoring of the plan to ensure it is being implemented and adequately addresses the person's needs.
- Follow up to ensure the person's needs are being met.
- Follow up with the person's legal representative (if applicable) and, as requested, family.
- Adjust plan and services when changes are necessary.
- Help advocate for what the person wants and needs from service providers, family, and community.
- Ensure services promote independence, productivity, and inclusion.

**Objective Assessment Process (OAP):** Once a person is determined eligible and has been offered funding, DDD staff complete an objective assessment. This assessment determines the person's needs and is used to determine the funding amount the person will receive on an annual basis. This funding is used to pay for DD services.

The objective assessment is completed with input from people who know the person best. This may include family members, teachers, and/or provider staff. Other documentation is reviewed such as program data, medical records, legal documents, and other assessments.

**Planning Meetings:** Planning meetings are held to determine the person's goals, as well as the services and supports needed to achieve the goals. These meetings are designed to utilize person-centered planning, which builds on the person's strengths and focuses on their choices and preferences. The person determines what services are desired, who will provide the services, and how the services will be provided.

### TIPS ALONG THE WAY

**Preparation for Planning Meetings**

Here are a few things for the person and those who support them to think about in preparation for planning meetings:

- What good things or achievements happened this year?
- What are the person's strengths?
- What are the person's preferences?
- What are the person's goals for the future?
- What supports does the person need to achieve these goals?
- What risks, if any, need to be addressed?
- What financial or medical issues need to be addressed?

**DD Services and Providers:** DD services help the person live the most independent life possible. Goals are identified and services arranged to teach the person the skills to be employed, live where they want, and access the community.

Once funding is available, the person chooses the DD services they want to receive and determines who will provide them. Service options include:

- Respite - a break or temporary relief for a non-paid caregiver with whom the person lives.
- Day services - services to increase the person's skills and assist in maintaining employment. This includes options ranging from prevocational services, supported employment, habilitative workshop, and habilitative community inclusion. To receive day services, a participant must apply for VR (Vocational Rehabilitation) services. VR will determine if the person is ready for employment and help them find a job.
- Residential services - services provided where the person lives, whether with family or friends, on their own, or in a provider-operated setting. Services increase independence in daily living, health maintenance, social and leisure skills, and community access.
- Assistive technology and modifications - devices or modifications to the home or vehicle to increase the person's independence and safety.

DD services may be delivered by independent providers or agency providers.

- Independent providers are people who do not work for an agency and may be someone the person already knows. An independent provider must meet requirements set by the state and cannot be parents of the person (if a minor child), spouse, or legal guardian. The person or their guardian is responsible for hiring, firing, scheduling, and training the independent provider.
- Agency providers are certified by the state and are responsible for hiring, firing, scheduling, and training staff who work with the person. There are many agency providers across the state. See *FYI* for a link to the directory of providers.

Note: DDD has developed numerous helpful documents explaining services and processes in more detail. Many of these documents are referenced in the *FYI* section of this chapter.

**Nebraska Lifespan Respite**

Respite care - planned or emergency - is short-term, temporary relief to unpaid family members caring for those with special needs. Even though many families take great joy in providing care for their loved ones so they can remain at home, the physical, emotional, and financial consequences for the family caregiver can be overwhelming.

People of any age with a special need may be eligible for the Nebraska Lifespan Respite program. A person may only receive respite from one source. For example, one cannot have both Lifespan Respite and respite through DDD. The person must live with an unpaid caregiver in a non-institutional setting and meet financial eligibility requirements.

Special needs include, but are not limited to:

- Developmental disabilities
- Physical disabilities
- Chronic illness
- Physical, mental, or emotional conditions
- Special health care needs
- Cognitive impairments that require on-going supervision
- Situations in which there is a high risk of abuse or neglect for the person with special needs
- Exceptional circumstances, including Crisis Respite

This program pays (within established program dollar limits) for respite services to give the primary caregiver a temporary break from the care of the eligible person. Application for respite may be made at the Nebraska Department of Health and Human Services.

## **FYI:** *Chapter 2. Community Living*

1) ACCESSNebraska
   ACCESSNebraska

2) Assistive Technology Partnership
   Welcome | Assistive Technology Partnership (nebraska.gov)

3) AT4ALL
   AT4All

4) Nebraska Commission for the Blind and Visually Impaired
   Welcome | NCBVI (nebraska.gov)

5) Nebraska Commission for the Deaf and Hard of Hearing
   About NCDHH | Deaf and Hard of Hearing (nebraska.gov)

6) Nebraska Division of Behavioral Health
   Nebraska Network of Care for Behavioral Health - Network of Care

7) Nebraska Lifespan Respite
   Home | Nebraska Lifespan Respite Network

**Home & Community-Based Services (HCBS) Waivers & Services**

1) Aged & Disabled (AD) Waiver
   Services on the Aged and Disabled Waiver (ne.gov)

2) Aged & Disabled (AD) Waiver Services and Eligibility
   Eligibility for AD Services (ne.gov)

3) HCBS Waivers Participant and Family Page
   Waiver Participants and Families (ne.gov)

4) Participant Guide to Self-Direction
   Participant Guide to Self-Direction (ne.gov)

5) Traumatic Brain Injury Waiver
   Services On The Traumatic Brain Injury Waiver (ne.gov)

**Developmental Disabilities (DD) Services**

1) Applying for Developmental Disabilities Services
   How to Apply for DD Services Online

2) Developmental Disabilities (DD) Services Eligibility
   Eligibility for DD Services (ne.gov)

3) Division of Developmental Disabilities (DDD) Directory-Comprehensive Directory of DD Services
   Services on the Developmental Disabilities Waivers (ne.gov)

4) Division of Developmental Disabilities (DDD) Assessment and Budgeting
   DD Services Assessment and Budget (ne.gov)

**FYI:** *Chapter 2. Community Living*

5) Division of Developmental Disabilities (DDD) Policy Manual
DD Policy Manual (ne.gov)

6) Developmental Disabilities (DD) Agency Providers for Home and Community Based Services (DHHS-DD):
DD Agency Provider List (ne.gov)

7) HCBS Waivers Available for People with Developmental Disabilities
HCBS Waivers Available for Eligible Nebraskans

8) Staff Directory/Office Locations Division of Developmental Disabilities (DDD)
Contact DDD Staff (ne.gov)

# Chapter 3.

# Employment

Competitive, integrated employment is an important goal for people with disabilities. What does this mean? To state it simply, competitive employment is:

- Work performed on a full-time or part-time basis for which an individual is paid at a rate at or above minimum wage (including benefits, if available) and a wage comparable to what other employees without a disability are receiving for the same type of job;
- Work performed at a location where the employee with a disability interacts with other employees without disabilities in comparable positions; and
- Work that provides opportunities for advancement the same as other employees who do not have disabilities and work in similar positions.

The previous chapter discussed services provided through the Division of Developmental Disabilities (DDD). DDD works in cooperation with Nebraska VR to coordinate employment services for eligible individuals.

## 3.1 Nebraska VR

Nebraska VR (also referred to as Vocational Rehabilitation or Voc Rehab) is a state agency that helps people with disabilities identify their strengths and abilities in order to find success in the world of work. VR offers customized and individualized training and supports tailored to the person's specific needs and job goal.

VR's mission includes a dual-customer approach: to help people prepare for, find, and keep jobs and to help businesses recruit, train, and retain employees with disabilities. The services offered during each step in the process vary and depend upon the person's employment needs and interests. Services may include:

- Assessment of vocational needs to learn more about interests, skills, and needed services and supports
- Development of an Individualized Plan for Employment that outlines goals and services
- Coordination of services to reach the employment goal
- Post-employment services to help the person keep the job once employed

**Eligibility:** To qualify, a person must have the following:

- **Impairment:** This is a diagnosed impairment, also known as disability. This could be some type of physical, mental, emotional, or learning disability.
- **Impediment to employment:** Evidence is required to show that the impairment has caused problems in past employment, current employment, or would cause some problems preparing for and getting employment in the future.
- **Benefit:** Evidence is required to show that VR services would help the person obtain or keep successful employment.
- **Need for services:** Proof that VR services are necessary for the person to reach successful employment.

Note: Due to limited funds, Nebraska VR may be unable to serve everyone who is eligible. Therefore, eligible people are assigned a Priority Group based on how significantly their disability impacts their ability to work. This is called an Order of Selection. Individuals are encouraged to apply for services and may be placed on a waiting list.

There are three Priority Groups that determine the order in which people are served, as funding allows:

- Priority 1. Persons with the most significant disabilities
- Priority 2. Persons with significant disabilities
- Priority 3. All other eligible persons

It is important to note that, at the time of this publication, Priority Groups 1, 2, and 3 are closed. Individuals in Priority Group 1 are being served as they apply and are found eligible. Anyone is encouraged to apply for services. VR will serve eligible persons by Priority Group in order of their date of application if and when sufficient funds become available. Information about Priority Groups and Order of Selection are updated on the VR website.

**Application:** There are many ways to begin the VR process. Many people start the process by calling or visiting one of VR's twelve services office locations across the state. Nebraska VR has partner relationships with many state agencies, community action agencies, community rehabilitation programs, schools, and employers that may also make referrals to VR. In this case, the person is asked to fill out a short form with name, address, and basic information to be shared with VR.

People who are eligible for and receiving DD services are required to apply for and work with VR to meet their employment needs if they are also eligible for VR funding. The DD Service Coordinator may make a referral to VR on the person's behalf.

Following referral to VR, the person is contacted within 10 days to set up an orientation and initial meeting with a VR Specialist. People interested in VR services are encouraged to watch the VR orientation video online before the meeting (VR Orientation 2021 - YouTube).

At the initial meeting with a VR Specialist, orientation is completed, questions about VR services are answered, and the Specialist will ask questions to help determine if the person is ready for employment. The person's goals and objectives, history of employment, education, medical history, and other factors that may impact employment are discussed. The person may choose to apply for services if they have not already. Once the application is completed and signed, VR will collect additional records and information to make eligibility and priority determinations. This information may include:

- Medical records of other professionals who have provided services or supports related to the person's diagnoses
- Correspondence from the Social Security Administration, if receiving benefits due to disability
- Other educational and diagnostic information

**Eligibility and Priority Determinations:** A person determined eligible and in a priority group that is being served will meet with a VR Specialist to begin planning and goal development. Other eligible people will be provided information and referral to other resources and may choose to be placed on a waiting list.

**VR Services:** Work will begin to help the person set an appropriate job goal and a plan to reach that goal. Together, the person and VR Specialist will further explore work interests, work values, work preferences, working condition preferences, training, job skills, work history, and support network. A Benefits Orientation will be provided so that the person may make an informed choice about working, knowing how federal, state, and local benefits may be affected by earning income. An Individualized Plan for Employment (IPE) will be developed to include:

- Job goal
- Expected date to reach goal
- Services needed to reach goal and who will provide the services
- Additional benefits analysis services
- Identification of who will pay (person will be asked to participate in cost of services, if able)

## 3.2 Ticket to Work

Nebraska Ticket to Work is a free and voluntary program that assists people with disabilities in gaining financial independence. The program works with people between the ages of 18-64 who receive a Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI) cash benefit and want to move off these programs to employment and self-sufficiency. While working with Nebraska VR, the person assigns their Ticket to Work to VR. Following the completion of VR services, the person may re-assign their ticket to an Emploment Network, as noted below. Navigating disability and health care benefits can be complicated and Ticket experts are available to assist with that.

Easterseals Nebraska, Goodwill, and Community Options are currently under contract with the Social Security Administration as Employment Networks to administer the Ticket to Work program in Nebraska. The program has two areas of focus:

- **Employment Assistance/Support:** The program assists SSI and SSDI beneficiaries with obtaining and retaining employment. This may include assistance with resumes, cover letters, job searching techniques, applications, etc. Additionally, information on job and hiring fairs in the state and numerous weekly job listings are provided. Nebraska has numerous community resources available to residents. Experts help the person get in touch with resources that may be able to provide services. Experts are also able to assist with issues while on the job.

- **Benefits/Work Incentive Counseling:** Experts assist beneficiaries with understanding how their federal cash benefit (SSI or SSDI) will be affected by work and what work incentives are available to them. They also help navigate the Medicaid and Medicare programs. Many times, experts work directly with Social Security or Health and Human Services on the person's behalf to take away some of the burden and confusion, allowing the person to focus on work.

**FYI:** *Chapter 3. Employment*

1) Nebraska VR
   Nebraska VR | Welcome
2) Nebraska VR Order of Selection Fact Sheet
   OOS_Fact_Sheet (nebraska.gov)
3) Nebraska VR Office Locations/Contacts
   Nebraska VR | Find a Service Office
4) Ticket to Work
   Find Help - Ticket to Work - Social Security (ssa.gov)
5) Welcome Job Seekers-Nebraska VR
   Nebraska VR | Job Seekers

# Chapter 4.

## Postsecondary Education and Training

Education doesn't have to end with high school. Some people with I/DD may wish to receive additional education or training. Having a disability does not rule out the possibility of postsecondary education. In fact, there are many options for this. Postsecondary institutions include universities, community colleges, or vocational schools.

There are many factors to consider when determining the best option for postsecondary education. The first factor that often comes to mind is cost. Financial aid may be available, depending on the program and circumstances of the person. The second is finding the right fit for the person's interests, needs, and goals. A college degree may not be the person's goal. Rather, it may be more important to take classes to further develop skills in basic areas such as communication, writing, or math to make the person more employable. Sometimes, it's just about the opportunity for increasing social skills and connecting with others.

**Eligibility:** A person with a disability must meet the same requirements as those without a disability for admission to a postsecondary institution. It's important to note, however, that a person cannot be denied admission simply because they have a disability.

**Academic Adjustments & Accommodations:** A student with a disability may receive academic adjustments (also known as accommodations) to meet the essential academic and technical requirements of the program. Examples of accommodations include: reducing the student's course load, providing extended time for taking tests, or providing auxiliary aids and services. Examples of auxiliary aids and services include: note-takers, readers, recording devices, sign language interpreters, screen-readers, voice recognition devices, or other computer aids.

Postsecondary institutions are limited in the aids and services they can provide and are not required to provide personal devices such as eyeglasses or hearing aids or to pay for personal services such as attendants. Accommodations cannot alter the essential requirements of the course or the core curriculum of the program.

Note: Academic adjustments or accommodations do not guarantee passing grades. They provide a fair chance for the student with a disability – not an unfair advantage.

## 4.1 Postsecondary Disability Services

Students are not required to disclose their disability unless they wish to receive accommodations, be placed in accessible housing, or receive other disability-related services. If a student chooses, help is available from an office for disability services at the postsecondary institution. It is the student's responsibility to contact this office if they wish to receive assistance. Ideally, this contact should be made before enrolling to have the needed supports in place before beginning the program.

**Documentation:** To be eligible for accommodations, the student must provide the postsecondary institution's disability services office with current documentation of disability. Specific documentation required may vary by institution, but in general, evidence of disability includes:

- A diagnosis of a specific disability
- A statement of how the disability limits a major life activity
- An explanation of how the disability may affect academic performance
- Suggestions for educational accommodations appropriate for the college setting

**Services:** Once it's determined that the student qualifies as a person with a disability, a disability coordinator will work with that student to determine appropriate services, assist in arranging services or testing accommodations, and assist with problems as they arise. The disability coordinator does not provide direct educational services, such as testing or counseling, or help students manage their time or schedules. However, the coordinator may assist the student in arranging for services such as tutoring or counseling. The student with a disability is expected to be responsible for their education the same as any other college student.

The Western Iowa & Nebraska Association on Higher Education and Disability (WINAHEAD) organization is an excellent resource, providing information and contacts for support services available for students with disabilities in all of Nebraska and Western Iowa's postsecondary institutions.

## 4.2 Nebraska VR Certificate Programs

Hands-on training programs are available for adults with disabilities through Nebraska VR. Local VR offices partner with area businesses, community colleges, and local schools. Students take classes, tour businesses, and either work part-time or participate in an internship with employer partners.

The programs are business driven, short term, real life trainings that teach both technical hard skills and soft skills. Training on soft skills addresses the

basics such as being on time, being dependable, and communicating. These trainings give workers the opportunity to acquire the skills that they need to pursue in-demand jobs and careers.

Certificate Programs begin when Nebraska VR Employment Specialists from local area offices identify trends in client employment interest areas and job goals. Next, Nebraska VR evaluates the feasibility for the local area job market. The job field should be one that can provide future opportunities to grow or have an established career path. For information about this program, contact Nebraska VR.

**FYI:** *Chapter 4. Postsecondary Education and Training*

1) Nebraska VR Certificate Programs
   Nebraska VR | Certificate Programs
2) Western Iowa & Nebraska Association on Higher Education and Disability (WINAHEAD)
   Western Iowa and Nebraska AHEAD - AHEAD - Association on Higher Education And Disability

# Chapter 5.

## Nebraska Public Assistance Programs

Nebraska has a number of programs designed to support people with low incomes in the community. While not specific to people with disabilities, some of these may be of benefit to persons with I/DD. In this chapter we briefly describe a few of these, including financial assistance programs provided through the Nebraska Department of Health and Human Services (DHHS). For a more complete listing and descriptions of those programs, see the DHHS website.

### 5.1 Commodity Supplemental Food Program

This is a United States Department of Agriculture (USDA) program that provides food purchased and distributed by the USDA. Persons age 60 years and over may be eligible if they meet the federal and state guidelines for the program.

To determine eligibility, the person should contact a Community Action Agency in their area and provide:

- Proof of income (such as bank statement or Social Security letter);
- Birth certificate (or other document verifying age);
- Proof of residence - either a letter postmarked within the last 30 days, or a utility bill with date and address on it; and
- Proof of lawful immigration status (permanent resident card).

### 5.2 Community Action Agencies

Nebraska's nine Community Action Agencies provide services and programs designed to meet the local needs of the communities they serve. They are partners with DHHS in the provision of many DHHS sponsored programs. The goal of Community Action Agencies is to empower people living in poverty to reach economic stability. Services include:

- Housing
- Health
- Food & Nutrition
- Child Development (Head Start)
- Transportation

- Asset Development
- Employment Programs
- Disaster Relief

### 5.3 Energy Assistance

The Nebraska Low Income Home Energy Assistance Program (LIHEAP) helps people with limited incomes offset the cost of heating and cooling their homes. The program may partially pay the cost of electricity, fuel oil, gas, coal, wood, kerosene, propane, or other fuel source.

In order to qualify for this benefit program, a person must be a resident of the state of Nebraska and need financial assistance for home energy costs. Eligibility is based on a household's resources and income. Some resources aren't counted, such as the person's home, one car, and personal belongings such as furniture and clothing. Resources that are counted include cash, checking and savings accounts, time certificates, CD's, stocks, bonds, and property other than the home.

Income guidelines are listed on the Nebraska LIHEAP webpage. Application for Energy Assistance may be made online through ACCESSNebraska.

### 5.4 Nebraska Housing Authorities

Nebraska Housing Authorities assist in providing affordable, safe, sanitary, and decent housing for qualifying individuals and families with financial needs. Information regarding local housing authorities and income limits for eligibility may be found on the Nebraska page of the US Department of Housing and Urban Development website.

### 5.5 Supplemental Nutrition Assistance Program (SNAP)

The federal Supplemental Nutrition Assistance Program (formerly known as food stamps) helps low-income people buy food. It's not necessary to be receiving other public assistance in order to be eligible. Households that meet the program guidelines for income and resources receive program benefits for free. A household can be one person or a group of people who purchase and prepare meals together. If groups live in the same house, but buy food separately, the groups may qualify as separate households.

SNAP benefits can only be used to buy food. Alcoholic beverages, pet food, tobacco, paper products, or other nonfood items can't be purchased with program benefits. The benefit amount is placed in an electronic account that

can be accessed with an Electronic Benefits Transfer (EBT) card. The cards are accepted by most supermarkets and grocery stores. Some "Meals on Wheels" services may accept them, and recipients over age 60 and their spouses may be able to use them to pay for congregate meals.

Application may be made online at ACCESSNebraska or by completing a paper application available on the DHHS website.

**FYI:** *Chapter 5. Nebraska Public Assistance Programs*

1) ACCESSNebraska
   ACCESSNebraska
2) Commodity Supplemental Food Program
   Commodity Supplemental Food Program (ne.gov)
3) Community Action Agencies
   Get Help : CAN (canhelp.org)
4) DHHS Children & Families Programs
   Economic Assistance (ne.gov)
5) DHHS Financial Assistance Programs
   Economic Assistance (ne.gov)
6) Nebraska Housing Authorities
   Housing Authorities on the Web: Nebraska | HUD.gov / U.S. Department of Housing and Urban Development (HUD)
7) Nebraska Low Income Home Energy Assistance Program (LIHEAP)
   Energy Assistance (LIHEAP)
8) Supplemental Nutrition Assistance Program (SNAP)
   Supplemental Nutrition Assistance Program (SNAP) (ne.gov)

# Chapter 6.

# Aging with Intellectual/Developmental Disabilities (I/DD)

Adults with I/DD are now routinely living into their 60's, 70's, and beyond. Often, health-related conditions associated with older adults are unrecognized or poorly managed in this population. Lack of accurate and timely identification and management of age-related disease and disability contributes to this group being one of the highest users of medical services. For example, estimates suggest that 50 percent or more of people with Down syndrome will develop dementia due to Alzheimer's disease as they age. Because people with Down syndrome live, on average, 55 to 60 years, they are more likely to develop younger-onset Alzheimer's (occurring before age 65) than older-onset Alzheimer's (occurring at age 65 or older).[1]

## 6.1 Community-Based Support

The need for enhanced community-based support for persons with I/DD and their caregivers will continue to expand as the overall population ages. The services and supports needed by the general population with dementia are the same as those needed by persons with I/DD with dementia. However, understanding the nature of the person's non–dementia-related, lifelong disability is necessary to provide person-centered services and supports.

The onset of dementia causes people with I/DD, their caregivers, and their primary providers to navigate between the aging and disability service systems. These systems must build greater capacity to provide services to an increasing number of aging persons with lifelong disabilities. They and their caregivers need access to dementia-capable home and community-based services. This can only be accomplished by improving the dementia-capability at the system, policy, and practice levels. Nationwide, models are emerging for developing dementia-capable and culturally competent care across agencies and organizations.[2]

## 6.2 Area Agencies on Aging

Area Agencies on Aging offer a wide range of services for older adults located all across the state. Services typically include congregate and home-delivered meals; family care support services; homemaker services; legal services; information and assistance; Medicaid waiver services; senior centers; transportation; and volunteer opportunities.

[1] "Down Syndrome and Alzheimer's Disease." Alzheimer's Association. What is Dementia? Symptoms, Causes & Treatment | alz.org

[2] Gordon, K. Dementia Among Individuals with Intellectual and Developmental Disabilities: Policies and Practices. Journal of the American Society on Aging; Fall 2017, pg. 30-36.

### 6.3 Medicaid-Medicare Dual Eligibility

Medicare-Medicaid enrollees (often called dual eligibles) are low-income seniors and people with disabilities. For those who have Medicare and full Medicaid coverage, most health care costs are likely covered. Medicare coverage may be through Original Medicare or a Medicare Advantage Plan (Part C).

Note: Medicaid never pays first for services covered by Medicare. It only pays after Medicare, employer group health plans, and/or Medicare Supplement (Medigap) Insurance have paid.

### 6.4 Supplemental Security Income and Retirement

To get the most of Social Security benefits, it's important to be aware of such things as who can get benefits on their Social Security record and how to obtain and use Social Security information in planning financial security. Changes in status such as retirement, disability, or death of family members may result in a change in benefits. It is important to check with the Social Security Administration to determine what impact these changes may have on benefits.

**FYI:** *Chapter 6. Aging with I/DD*

1) Aging with I/DD (Training)
   Aging with Intellectual and Developmental Disability Trainings – Eunice Kennedy Shriver Center (umassmed.edu)
2) Alzheimer's Disease in People with Down Syndrome
   Alzheimer's Disease in People With Down Syndrome | National Institute on Aging (nih.gov)
3) Area Agencies on Aging
   State Unit on Aging (ne.gov)
4) Dementia Among Individuals with Intellectual and Developmental Disabilities
   Dementia Among Individuals with Intellectual and Developmental Disabilities | RTI
5) Down Syndrome & Alzheimer's Disease
   Down Syndrome and Alzheimer's | Symptoms & Treatments | alz.org
6) Dually Eligible Beneficiaries under Medicare & Medicaid
   Dually Eligible Beneficiaries Under Medicare and Medicaid (cms.gov)
7) New Caregiver Initiative for Individuals with Down Syndrome
   Caregiver Initiative For Individuals With Down Syndrome - Special Needs Resource (eparent.com)
8) Social Security Administration
   The United States Social Security Administration (ssa.gov)
9) Understanding Supplemental Security Income
   Understanding Supplemental Security Income (SSI) -- Home Page (ssa.gov)

# Chapter 7.

# Legal and Advocacy

There are many things to consider when it comes to legal issues and rights for people with disabilities. While we can't cover all of that information, we will highlight some important resources to assist.

## 7.1 Adult Protective Services (APS)

The Adult Protective Services Act established a program designed to meet the needs of vulnerable adults and to assure the availability of the program to all eligible persons. It places authority and responsibility for investigations and interventions in situations of abuse or neglect of vulnerable adults with Nebraska Department of Health and Human Services (DHHS) and local law enforcement agencies. APS investigates reports of vulnerable adult abuse/neglect/exploitation, including self-neglect, and intervenes when maltreatment is confirmed.

Adult protective services are to be provided with as little disruption to the person's life as possible. Whenever possible, the person is helped to live in the environment of their choice. DHHS acknowledges that as long as adults can recognize the consequences of decisions they have made about their lives, the right to make those decisions must be respected, provided they are capable of making that choice.

## 7.2 Appeals & Complaints

Most, if not all, programs and services provide some type of mechanism to appeal decisions and services provided. It is recommended that people exercise the right to appeal when necessary.

Many of the programs discussed in this guide are administered by DHHS. There may be a time when it's necessary to file an appeal or register a complaint regarding these programs. This may happen when a person doesn't agree with a decision made by DHHS or they may think that the services provided through a program are not meeting their needs.

Anyone may fill out a Request for Fair Hearing form (DA-6). This form may be requested either from a DHHS office, through a DHHS staff member, or by going online. The completed form can be emailed, mailed, or brought into any local DHHS office. An appeal hearing is a formal proceeding where the case is reviewed by a DHHS hearing officer. The appeal will be conducted according to the Administrative Procedure Act in a manner similar to a court proceeding.

People filing an appeal may represent themselves or choose someone else to represent them. At the hearing, both sides will present evidence for the hearing officer to consider. All witnesses who testify may be asked questions by the other side and/or the hearing officer. When the appeal hearing is over, the hearing officer will make a recommendation to the DHHS division director, who will make the final decision.

### 7.3 Assistance with Decision Making

There are varying legal judgments (also referred to as substituted judgment) that can be made for a person with a disability. It is important to consider the least restrictive alternative when considering what is right for the person. Options, listed in order from allowing the most independence to the least independence, include:

- Supported decision making
- Health care power of attorney
- Representative payee
- Power of attorney
- Conservatorship
- Guardianship

Because guardianship is a serious step and a restriction of the person's freedom, it is important to consider other, less restrictive alternatives before pursuing this.

### 7.4 Office of Public Guardian

Nebraska's Office of Public Guardian is designed to serve as the guardian or conservator for a person when no other alternative is available. The office may be the last resort as guardians or conservators for those situations where no family member or suitable person is available. The Office of Public Guardian provides education, training, and support for volunteer and family guardians and conservators. Additionally, they recruit people to serve as guardians and conservators for Nebraska's vulnerable population.

## 7.5 Advocacy

There are many organizations and people available to help people with disabilities and their family members in advocating for their rights and getting the services and supports they need. A few are highlighted here.

**Aging and Disability Resource Centers (ADRC)** assist older Nebraskans (age 60 and older), people with disabilities of all ages, family members, caregivers and advocates. Local ADRCs provide information, referral, and assistance for accessing community services and long-term care options.

**Answers4Families** is a support and information connection for families and professionals seeking assistance. Answers4Families provides information, opportunities for dialogue, education, and support to Nebraskans with special needs and their families by developing and providing web-based resources.

**Arc of Nebraska** offers a range of programs and services to meet the needs of those with intellectual and developmental disabilities. They help families by providing programs, information, and resources. The Arc focuses on issues including: voting, employment, special education, Medicaid, and waiting lists. Local Arc chapters are located throughout the state and provide a variety of programs and services specific to their area.

**Autism Family Network** promotes a positive, respectful image of children with autism and their families by offering social opportunities, recreational experiences, and community inclusion.

**Autism Society of Nebraska** provides information, referral, support, awareness, and special events related to individuals on the autism spectrum and their families in a number of Nebraska communities.

**Client Assistance Program (CAP)** is a free service to help find solutions for those having problems with any of the following programs: Nebraska VR; Nebraska Commission for the Blind and Visually Impaired, and Centers for Independent Living.

**Disability Rights Nebraska (DRN)** uses a combination of legal advocacy, public policy advocacy, citizen advocacy, self-advocacy, and advocacy education to protect vulnerable people with disabilities. In addition, they have the Law-in-Brief series of publications to addresses legal topics, including the following:

- Americans with Disabilities Act (ADA)
- Assistive Technology

- Fair Housing
- Special Education
- Substituted Judgment
- Voting

**Legal Aid of Nebraska** is a statewide non-profit law firm serving Nebraska counties. Legal Aid offers free legal help to low-income and senior citizens (60+) clients in a full range of civil matters.

**Munroe-Meyer Institute (MMI)** provides interdisciplinary, family-centered services for persons with disabilities and complex healthcare needs across the lifespan at more than 40 provider locations across the state. MMI also provides leadership training for persons with disabilities, family members, and other stakeholders, as well as working in policy and advocacy related to disability-focused concerns. MMI operates as an educational institute of the University of Nebraska Medical Center, engaging in research, teaching, and technical assistance, as well as providing services.

**Parent Training and Information (PTI) Nebraska** is a statewide resource for families of persons with disabilities and special health care needs, birth through age 26. PTI staff members are parent/professionals who are available to assist with disability issues.

**People First of Nebraska** is a statewide advocacy organization run by and for people with disabilities. People First trains and supports people with disabilities to become stronger, more effective advocates for themselves and each other. Local chapters are located in communities across the state.

## FYI: *Chapter 7. Legal and Advocacy*

**Legal**

1) Adult Protective Services
   Adult Protective Services (ne.gov)
2) Disability Rights Nebraska
   DRNE | Who We Are (disabilityrightsnebraska.org)
3) Disability Rights Nebraska Law-In-Brief Series
   DRNE | Legal Resources (disabilityrightsnebraska.org)
4) Nebraska Office of Public Guardian
   Office of the Public Guardian | Nebraska Judicial Branch
5) Power of Attorney
   Power of Attorney - Financial | Nebraska Judicial Branch

**Advocacy and Support Organizations**

1) Aging and Disability Resurce Center (ADRC)
   Aging and Disability Resource Center (ne.gov)
2) Answers4Families
   Answers4Families home page
3) Arc of Nebraska
   Chapters - The Arc of Nebraska (arc-nebraska.org)
4) Autism Family Network
   Autism Family Network - AFN
5) Autism Society of Nebraska
   Home - Autism Society (autismnebraska.org)
6) Client Assistance Program
   NE Client Assistance Program (CAP) (nebraska.gov)
7) Disability Rights Nebraska
   Disability Rights Nebraska | Reform | Lincoln
8) Legal Aid of Nebraska
   Legal Aid of Nebraska | We Make Equal Justice Happen
9) Parent Training and Information (PTI) Nebraska
   PTI Nebraska | (pti-nebraska.org)
10) People First of Nebraska
    peoplefirstnebraska.com

# Appendix

## Frequently Used Acronyms

| | |
|---|---|
| ABLE | Achieving a Better Life Experience Act (Enable in Nebraska) |
| ADA | Americans with Disabilities Act |
| ADRC | Aging and Disability Resource Center |
| AD Waiver | Aged & Disabled Medicaid Waiver |
| APS | Adult Protective Services |
| AT4All | Assistive Technology for All |
| ATP | Assistive Technology Partnership |
| CAP | Client Assistance Program |
| DD | Developmental Disabilities |
| DHHS | Nebraska Department of Health & Human Services |
| DDD | Division of Developmental Disabilities |
| DRN | Disability Rights Nebraska |
| FYI | For Your Information |
| HCBS | Home & Community-Based Services |
| I/DD | Intellectual and Developmental Disabilities |
| ICF | Intermediate Care Facility |
| NCBVI | Nebraska Commission for the Blind and Visually Impaired |
| NCDHH | Nebraska Commission for the Deaf and Hard of Hearing |
| OAP | Objective Assessment Process |
| PTI | Nebraska Parent Training and Information |
| SC | Service Coordinator |
| SGA | Substantial Gainful Activity |
| SNAP | Supplemental Nutrition Assistance Program |
| SSDI | Social Security Disability Insurance |
| SSI | Supplemental Security Income |
| VR | Vocational Rehabilitation or Voc Rehab |
| WINA-HEAD | Western Iowa & Nebraska Association on Higher Education & Disability |

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