



Along **THE** *Way*

A Guide for Adults
with Intellectual and
Developmental Disabilities

December 2018

INSIDE FRONT COVER

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Funding for this publication was provided by:

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Nebraska Planning Council on Developmental Disabilities website at:

http://dhhs.ne.gov/developmental_disabilities/pages/ddplanning_index.aspx

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Table of Contents

Introduction	5
	
Chapter 1. Benefits & Financial Planning	7
1.1 Supplemental Security Income (SSI).....	7
1.2 Medicaid	9
1.3 Benefits Services	11
1.4 ABLE Savings Plan (Enable)	12
	
Chapter 2. Community Living	14
2.1 Nebraska Assistive Technology Partnership (ATP)	14
2.2 Nebraska Commission for the Blind and Visually Impaired (NCBVI)	15
2.3 Nebraska Commission for the Deaf and Hard of Hearing (NCDHH)	16
2.4 Nebraska Department of Health and Human Services (DHHS)	16
Division of Behavioral Health	16
Aged and Disabled (AD) Home and Community-Based Services Waiver	16
Traumatic Brain Injury (TBI) Waiver.....	17
Division of Developmental Disabilities (DHHS-DD)	18
Nebraska Lifespan Respite.....	23
	
Chapter 3. Employment	26
3.1 Nebraska VR	26
3.2 Ticket to Work.....	28
	
Chapter 4. Postsecondary Education and Training	30
4.1 Postsecondary Disability Services.....	31
4.2 Nebraska VR Certificate Programs.....	31
	
Chapter 5. Nebraska Public Assistance Programs	33
5.1 Commodity Supplemental Food Program.....	33
5.2 Community Action Agencies	33
5.3 Energy Assistance.....	34
5.4 Nebraska Housing Authorities.....	34
5.5 Supplemental Nutrition Assistance Program (SNAP).....	34
	
Chapter 6. Aging with I/DD	36
6.1 Community-Based Support	36
6.2 Aging and Disability Resource Centers.....	36
6.3 Medicaid-Medicare Dual Eligibility	37
6.4 Supplemental Security Income and Retirement	37



Chapter 7. Legal and Advocacy	38
7.1 Adult Protective Services (APS)	38
7.2 Appeals & Complaints.....	38
7.3 Conservatorship/Guardianship/Representative Payee.....	39
7.4 Office of Public Guardian	39
7.5 Advocacy	40



Appendix	44
Frequently Used Acronyms.....	44
Index	45

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 core belief that all people should be given the opportunity to live, love, work, play and pursue their chosen life. We know this is often difficult for a person with I/DD and support may be needed throughout the stages of life.

We believe in a goal of assisting people in living and participating in their communities as independently as possible. If you are a person with I/DD, this means:

- Living where and with whom you choose
- Working in real jobs of your choice and earning real wages
- Practicing the faith of your choice
- Being connected to an array of friends and family with whom you 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 your 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. The *Along the Way* series contains three guides addressing the following life stages, along with a fourth publication that provides relevant resources and contact information.

- Infants, Toddlers, and Children
- Adolescents and Young Adults
- Adults

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: *Resources*

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 an index that lists topics, terms, and agencies discussed in this guide.

- Other papers which list resources
- Pay stubs
- Medical records relating to disability

Disability Determinations: Once Social Security determines that the person meets the basic eligibility requirements for SSI, 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; 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: An important part of determining if a person has a disability is the Social Security Administration's interpretation of substantial gainful activity (SGA). 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. As a point of reference, the SGA amount for individuals who are blind is \$1970 for 2018, while the amount for persons who are not blind is \$1180.

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 (see *FYI*).

1.2 Medicaid

Medicaid is a public health insurance program for certain low-income persons, 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. The following information provides an overview of Nebraska Medicaid eligibility requirements.

Age/Disability

To be eligible for Medicaid, a person must be:

- 65 years of age or older;
- 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

Currently, to be eligible for Medicaid, the amount of financial resources cannot exceed the following guidelines:

- \$2,000 for one-member family, if SSI eligible
- \$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. 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 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) or online through ACCESS Nebraska (see FYI).

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

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 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.)

Agencies providing benefits planning services are:

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

These benefits planning services are provided by Community Work Incentives Counselors (CWICs). Counselors have extensive training in how work incentives may be used by Social Security beneficiaries to maximize earning potential and minimize negative impact to benefits.

Benefits Services may provide:

- Answers to questions about current benefits
- An outline of work incentive options to assist in understanding how earning income will affect benefits
- A projection of financial outcomes for each work incentive option
- An opportunity to make an informed decision about the work incentive strategies that will work best for the person

People may have a choice of agencies to work with depending on where they live. Contact information for agencies that currently offer benefits planning services is provided in the *FYI* box at the end of this chapter.

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 he or she:

- Is blind or disabled before the age of 26 and is entitled to Supplemental Security Income or Social Security Disability Insurance benefits; or
- Has a certification from a physician indicating that he/she has 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

Supplemental Security Income

- 1) Best Eligibility Screening Tool
<https://ssabest.benefits.gov/>
- 2) Supplemental Security Income
<https://www.ssa.gov/pubs/EN-05-11000.pdf>
- 3) Social Security Benefits
<https://www.ssa.gov/benefits/ssi/>
- 4) Understanding Supplemental Security Income
<https://www.ssa.gov/ssi/text-understanding-ssi.htm>
- 5) Understanding Supplemental Security Income: Appeals Process
<https://www.ssa.gov/ssi/text-appeals-ussi.htm>
- 6) Social Security Office Locator
<https://secure.ssa.gov/ICON/main.jsp>

Medicaid

- 1) Nebraska Medicaid
http://dhhs.ne.gov/children_family_services/AccessNebraska/Documents/MedicaidBrochure.pdf
- 2) What do I need to know about Medicaid?
http://dhhs.ne.gov/developmental_disabilities/Documents/WhatisMedicaid.pdf
- 3) Medicaid
<https://www.ssa.gov/disabilityresearch/wi/medicaid.htm>
- 4) ACCESSNebraska
www.ACCESSNebraska.ne.gov
- 5) Nebraska DHHS Local Offices
<http://dhhs.ne.gov/Pages/localoffices.aspx>

Benefits & Financial Planning

- 1) Benefits Planning Services
http://www.vr.nebraska.gov/partners/#benefit_services
- 2) Easterseals Nebraska
<http://www.easterseals.com/ne/>
- 3) Goodwill Industries of Greater Nebraska
<https://www.goodwillne.org/>
- 4) Region V Services
<https://regionvservices.presencehost.net>
- 5) Enable Savings Plan
<https://www.enableavings.com/home.html>

- 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, classrooms 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 (see *FYI*) 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 the blind. NCBVI works to help Nebraskans who are blind and visually impaired achieve full and rewarding lives by teaching independent living skills and assisting with finding employment.

NCBVI provides the training, counseling, and resources needed for a positive understanding of blindness and visual impairment. Expectations include employment and fulfillment in all aspects of the person's life. Their website provides information about the Commission and about blindness in general for people who are blind and visually impaired, their families, and businesses seeking job candidates to fulfill Nebraska employment needs.

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 aspects impacting the daily lives of people who are deaf or hard of hearing; and 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, links to resources, and interpreter referrals.

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 (see *FYI*). 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 Home and Community-Based Services (HCBS) waiver is offered through a state and federal partnership under Medicaid and is administered by DHHS. The AD waiver 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.

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

- Eligible for Medicaid;
- 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 his or her home.

Nursing facility level of care means the person requires services such as those provided to people who live in a nursing facility. For example, a person may need assistance with everyday tasks such as getting dressed, taking a bath or shower, eating, or walking safely. Other areas considered include the need for assistance in taking medications, issues related to memory problems, or need for assistance in managing health conditions. Persons 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.

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:

- Services 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
- Training to increase independence in activities of daily living at home
- Community supports, such as adult day services and transportation for essential activities such as medical appointments
- Assisted Living services

Application: Application for the AD waiver may be made through ACCESSNebraska (see *FYI*).

Traumatic Brain Injury (TBI) Waiver

The Traumatic Brain Injury Home and Community Based Services waiver is also offered through a state and federal partnership under Medicaid. As with other waiver programs, 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. This waiver provides services that are available only at a designated assisted living facility in Omaha.

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: Specialized Assisted Living is provided in a specific Omaha facility. 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 (see *FYI*).

Division of Developmental Disabilities (DHHS-DD)

The Division of Developmental Disabilities oversees a system of services and supports to help eligible people live, work, and access their community as independently as possible. These services are also referred to as Developmental Disabilities (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 DHHS-DD 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 DHHS-DD can gather supporting documents. The DHHS-DD 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. Contact information is provided on the DHHS-DD website and in the DD Services Eligibility brochure (see *FYI*).

Once DHHS-DD 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 his/her 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 Multi-Disciplinary Team (MDT) reports
 - Most recent Individualized Education Program (IEP).

DHHS-DD 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 he/she is eligible for DD services.

In addition to applying for DD services, a person must also apply for and accept all benefits for which he/she may be eligible. One of these benefits is Medicaid. Medicaid provides a federal match to state funding, which allows DHHS-DD 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 & Wait List: 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, listing their date of need for services. A person's date of need may be as early as their date of application. Once their date of need has passed, they are considered to be waiting for services on the wait list. An adult on the wait list must have Medicaid.

 **Note:** It is possible that a person may qualify for more than one waiver. For example, a person may qualify for both a Developmental Disability waiver and the Aged and Disabled 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 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: Once a person is determined eligible and has been offered funding, DHHS-DD 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 a concept called person-centered planning. Person-centered planning 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

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

- What good things or achievements have happened in the past 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. Through the planning meeting process, goals are identified and services are arranged to teach the person the skills to be employed, live where they want, and access the community.

Once funding is available, the person will need to choose the DD services they want to receive and determine who will provide them. Service options include the following:

- 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 finding employment. This includes an array of options, ranging from prevocational services, supported employment, habilitative workshop, and habilitative community inclusion. In order to receive day services, a participant must also apply for VR (Vocational Rehabilitation) services. VR will determine if the person is ready for employment.
- Residential services - services provided wherever the person lives, whether with family, on his/her own, with friends, or in a provider-operated setting.
- Assistive technology and modifications - devices or modifications to the home or vehicle to increase the person's independence and safety.

A full description of services may be found in the DHHS-DD publication, "DD Waiver Services Quick Guide" (see *FYI*).

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: DHHS-DD 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 DHHS-DD. 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, or situations in which there is a high risk of abuse or neglect for the person with special needs. Exceptional circumstances, including Crisis Respite is available.

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 (see *FYI*).

Assistive Technology

- 1) Assistive Technology Partnership
<https://atp.nebraska.gov>
- 2) AT4ALL
<https://www.at4all.com>

Nebraska Commission for the Blind and Visually Impaired

- 1) Nebraska Commission for the Blind and Visually Impaired
<https://ncbvi.nebraska.gov>

Nebraska Commission for the Deaf and Hard of Hearing

- 1) Nebraska Commission for the Deaf and Hard of Hearing
<https://ncdhh.nebraska.gov/about-ncdhh>

Nebraska Division of Behavioral Health

- 1) Division of Behavioral Health Network of Care
http://dhhs.ne.gov/behavioral_health/Pages/networkofcare_index.aspx

Lifespan Respite

- 1) Lifespan Respite
https://nrrs.ne.gov/respite/cfs-pam-12_rev_092016.pdf

ACCESSNebraska

- 1) ACCESSNebraska
www.ACCESSNebraska.ne.gov

Aged and Disabled Waiver

- 1) Aged & Disabled Waiver
http://dhhs.ne.gov/Pages/hcs_programs_ad-waiver.aspx

Traumatic Brain Injury Waiver

- 1) Traumatic Brain Injury Waiver
http://dhhs.ne.gov/Pages/hcs_programs_tbi-waiver.aspx

Developmental Disability Services

General Information:

- 1) DHHS-DD Participant and Family Page
http://dhhs.ne.gov/developmental_disabilities/Pages/aDDIF.aspx
- 2) Staff Directory/Office Locations DHHS-DD
http://dhhs.ne.gov/developmental_disabilities/Documents/DDMainDirectory.pdf

Application & Eligibility:

- 3) Applying for Developmental Disability Services
http://dhhs.ne.gov/developmental_disabilities/Documents/ApplyingforDDServices.pdf
- 4) DD Services Eligibility
http://dhhs.ne.gov/developmental_disabilities/Documents/EligibilityDDServices.pdf

Waivers & Services:

- 5) HCBS Waivers Available for People with Developmental Disabilities
http://dhhs.ne.gov/developmental_disabilities/Documents/InfoSheet-HCBSWaivers.pdf
- 6) Nebraska Medicaid HCBS Waivers Participant Handbook
http://dhhs.ne.gov/developmental_disabilities/Documents/DD-PUB-8.pdf
- 7) DHHS-DD Directory-Comprehensive Directory of DD Services
http://dhhs.ne.gov/developmental_disabilities/Documents/DD-ServiceDirectory.pdf
- 8) Nebraska Medicaid HCBS DD Waivers Services Quick Guide
http://dhhs.ne.gov/developmental_disabilities/Documents/DD-PUB-9spreads.pdf
- 9) DHHS-DD Assessment and Budgeting
http://dhhs.ne.gov/developmental_disabilities/Documents/AssessmentBudget.pdf
- 10) Participant Guide for Self-Direction
http://dhhs.ne.gov/developmental_disabilities/Documents/ParticipantGuideSelf-Direction.pdf

Service Providers:

- 11) Provider Agencies for Home and Community Based Services (DHHS-DD):
http://dhhs.ne.gov/developmental_disabilities/Documents/ProviderAgencyList.pdf
- 12) Providers of Waiver Services: Understanding Who Can Provide What Services
http://dhhs.ne.gov/developmental_disabilities/Documents/ProviderTypes.pdf

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 are still 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 (see *FYI*).

Application: There are many ways to apply for VR services. Many people start the process by calling or visiting one of VR's eleven services office locations across the state. Nebraska VR has partner relationships with many state agencies, community action agencies, schools, and employers that may also begin the referral process. 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.

People interested in VR services are encouraged to watch the VR orientation video online or attend an individual orientation meeting with a VR

employment specialist. The next step is a meeting with a VR counselor to determine eligibility. Information needed to determine eligibility includes:

- Medical records, listing doctors or therapists, and dates of service
- List of current medications
- Correspondence from the Social Security Administration, if receiving benefits due to disability

Services: Once eligibility has been determined, a VR counselor will meet with the person to begin the process. The counselor will ask questions to help determine if the person is ready for employment. Work will begin to help the person set an appropriate job goal and a plan to reach that goal. Together, the person and Counselor will explore work interests, work values, work preferences, work considerations, training, job skills, work history, and support network. 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
- Identification of who will pay (person may 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. 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 in contract with the Social Security Administration as an Employment Network to administer the Nebraska Ticket to Work program. 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
<http://www.vr.nebraska.gov/>
- 2) Nebraska VR Order of Selection Fact Sheet
http://www.vr.nebraska.gov/resources/pdfs/OOS_Fact_Sheet.pdf
- 3) Welcome Job Seekers-Nebraska VR
http://www.vr.nebraska.gov/job_seekers/index.html
- 4) Nebraska VR Office Locations/Contacts
<http://www.vr.nebraska.gov/offices/>
- 5) Ticket to Work
<https://choosework.ssa.gov/findhelp/>

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 modifications, 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 (see *FYI*).

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 business partners, community colleges, and local schools. Students take classes, tour business, 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 (see *FYI*).

FYI: Chapter 4. Postsecondary Education and Training

- 1) Western Iowa & Nebraska Association on Higher Education and Disability (WINAHEAD)
<https://winahead.wordpress.com>
- 2) Nebraska VR Certificate Programs
http://www.vr.nebraska.gov/partners/certificate_programs.html

- 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. Currently, the resource limit is \$25,000. 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 LIHEAP webpage. Application for Energy Assistance may be made online through ACCESSNebraska (see *FYI*).

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 (see *FYI*).

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 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 (see *FYI*).

FYI: *Chapter 5. Nebraska Public Assistance Programs*

- 1) DHHS Children & Families Programs
http://dhhs.ne.gov/children_family_services/Pages/children_families.aspx
- 2) DHHS Financial Assistance Programs
http://dhhs.ne.gov/children_family_services/Pages/fia_fiaindex.aspx
- 3) Commodity Supplemental Food Program
http://dhhs.ne.gov/publichealth/Pages/nutrition_csfp.aspx
- 4) Community Action Agencies
<https://canhelp.org/get-help/>
- 5) Nebraska Housing Authorities
<https://www.hud.gov/states/nebraska/renting/hawebsites>
- 6) Nebraska Low Income Home Energy Assistance Program (LIHEAP)
http://dhhs.ne.gov/children_family_services/Pages/fia_energy.aspx
- 7) Supplemental Nutrition Assistance Program (SNAP)
http://dhhs.ne.gov/children_family_services/Pages/fia_fstamps.aspx
- 8) ACCESSNebraska
www.ACCESSNebraska.ne.gov

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 and Disability Resource Center (ADRC)
<http://adrcnebraska.org>
- 2) Dementia Among Individuals with Intellectual and Developmental Disabilities
<https://aadmd.org/sites/default/files/Gorden-%20ID-Article-2.pdf>
- 3) Down Syndrome & Alzheimer's Disease
<https://www.alz.org/dementia/down-syndrome-alzheimers-symptoms.asp>
- 4) Alzheimer's Disease and People with Down Syndrome
<https://www.nia.nih.gov/health/alzheimers-disease-people-down-syndrome>
- 5) New Caregiver Initiative for Individuals with Down Syndrome
<https://aadmd.org/sites/default/files/P46%20from%20Exceptional%20Parent.pdf>
- 6) Aging with I/DD (Training)
https://shriver.umassmed.edu/cdder/aging_idd_education/general-aging
- 7) Dual Eligible Beneficiaries under Medicare & Medicaid
https://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/downloads/Medicare_Beneficiaries_Dual_Eligibles_At_a_Glance.pdf
- 8) Social Security Administration
<https://www.ssa.gov>
- 9) Understanding Supplemental Security Income
<https://www.ssa.gov/ssi/text-understanding-ssi.htm>

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 the 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. For information about appeals, see *FYI*.

7.3 Conservatorship/Guardianship/Representative Payee

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:

- Health care power of attorney
- Representative payee
- Power of attorney
- Durable 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. Additionally, the Office of Public Guardian provides education, training, and support for volunteer and family guardians and conservators and recruits 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 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 the DD waiting list. Local Arc chapters are located throughout the state.

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.

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: Vocational Rehabilitation; 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)
- Fair Housing
- Social Security
- Substituted Judgment
- Voting
- Financial Planning for Adults with Disabilities: Special Needs Trusts
- Medical Assistance Programs
- Service Animals in Business
- Transportation

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.

Parent Training and Information (PTI) Nebraska is a statewide resource for families of persons with disabilities and special health care needs. 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) Disability Rights Nebraska
http://www.disabilityrightsnebraska.org/about_us/
- 2) Disability Rights Nebraska Law-In-Brief Series
http://www.disabilityrightsnebraska.org/resources/legal_resources.html
- 3) Adult Protective Services
http://dhhs.ne.gov/children_family_services/Pages/nea_aps_apsindex.aspx
- 4) Nebraska Office of Public Guardian
<https://supremecourt.nebraska.gov/programs-services/office-public-guardian>

DHHS Appeals and Complaints

- 1) Nebraska Medicaid HCBS Waivers Participant Handbook
http://dhhs.ne.gov/developmental_disabilities/Documents/DD-PUB-8.pdf
- 2) Request for Fair Hearing Form
http://dhhs.ne.gov/developmental_disabilities/Documents/RequestForFairHearing.pdf
- 3) DHHS-DD Staff Directory and Office Locations
http://dhhs.ne.gov/developmental_disabilities/Documents/DDDMainDirectory.pdf
- 4) Complaint Form
http://dhhs.ne.gov/developmental_disabilities/Documents/ComplaintForm.pdf

Advocacy and Support Organizations

- 1) Aging and Disability Resource Center (ADRC)
<http://adrcnebraska.org>
- 2) Answers4Families
<http://www.answers4families.org/>
- 3) Arc of Nebraska
www.arc-nebraska.org
- 4) Area Agencies on Aging
<http://nebaaaa.org/default.html>
- 5) Autism Family Network
<http://autismfamilynetwork.org/>
- 6) Autism Society of Nebraska
<http://autismnebraska.org/>
- 7) Client Assistance Program
<http://www.cap.nebraska.gov/>
- 8) Disability Rights Nebraska
<http://www.disabilityrightsnebraska.org>
- 9) Legal Aid of Nebraska
<http://www.legalaidofnebraska.org/>
- 10) Parent Training and Information (PTI) Nebraska
<http://pti-nebraska.org/>
- 11) People First of Nebraska
<https://www.peoplefirstnebraska.com/>

Index

A

ACCESSNebraska, 10, 13, 24, 34, 35
Aging & Disability Resource Center, 36, 37, 40, 43
Answers4Families, 40, 43
Appeals & Complaints, 38, 42
Arc of Nebraska, 40, 43
Area Agencies on Aging, 40, 43
Assistive Technology, 14, 24
Autism Family Network, 40, 43
Autism Society of NE, 40, 43

B

Benefits Services, 11, 13

C

Client Assistance Program, 40, 43

D

Department of Health and Human Services (DHHS), 10, 16, 18, 35, 38
DHHS Local Offices, 13
Disability Rights Nebraska, 41, 42
Division of Behavioral Health, 16, 24
Division of Developmental Disabilities (DHHS-DD), 18-22, 24

E

Easterseals Nebraska, 11, 13
Enable Savings Plan, 12, 13

H

Home & Community-Based Services (HCBS)
Aged and Disabled Waiver (AD), 16, 24
Traumatic Brain Injury Waiver (TBI), 17, 24

L

Legal, 38, 42, 43

Adult Protective Service Act (APS), 38, 42

Conservatorship/Guardianship/Representative Payee, 39

Office of Public Guardianship, 29, 42

Legal Aid of Nebraska, 41, 43

Lifespan Respite, 23, 24

M

Medicaid, 9, 13, 16

Medicaid-Medicare Dual Eligibility, 37

N

Natural Supports, 14

Nebraska Commission for the Blind and Visually Impaired, 15, 24

Nebraska Commission for the Deaf and Hard of Hearing, 16, 24

Nebraska Public Assistance Programs, 33

Nebraska VR, 11, 26, 29, 32

O

Office of Public Guardian, 39, 42

P

Parent Training & Information (PTI), 41, 43

People First of Nebraska, 41, 43

Post-Secondary Education, 30

S

Service Coordination, 20

Supplemental Security Income (SSI), 7, 12, 37

T

Ticket to Work, 28, 29

W

Western Iowa & NE Association on Higher Education & Disability (WINAHEAD),
31, 32

