

Along **THE** *Way*

A Guide for Adolescents
and Young Adults
with Intellectual and
Developmental Disabilities

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INSIDE FRONT COVER

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Introduction

Welcome to *Along the Way*, a series of resource guides for persons with intellectual and developmental disabilities (I/DD). 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 people with I/DD. They may require the support of family members and others as they move through the stages of life. While there are many resources to assist, 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 individuals with developmental disabilities, their parents, and other family members. The 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.

Relevant topics are discussed for each age group, along with resources and other tools that may be helpful. While it’s impossible to cover everything, it is our hope that this information can help people with I/DD and those who support them in living the life they choose.

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.

Chapter 1.

Special Education Eligibility, Laws, Regulations, & Rights

1.1 Special Education Eligibility

Special education means specially designed instruction, at no cost to the parent, to meet the unique needs of a student with a verified disability. A student with a disability may also receive related services. Related services include transportation and developmental, corrective, and other supportive services as required to assist the student to benefit from special education.

Schools are required to provide a free appropriate public education (also referred to as FAPE) for all students with verified disabilities from birth through the school year in which the student reaches age 21. The exception to this is students who have graduated with a regular high school diploma. We will discuss that further in Chapter 2.

To be eligible for special education and related services, students must be verified as having an eligible disability and need services to benefit from their education. Verification categories include:

- Autism
- Deaf-Blindness
- Developmental Delay
- Emotional Disturbance
- Hearing Impairment
- Intellectual Disability
- Multiple Impairments
- Orthopedic Impairment
- Other Health Impairment
- Specific Learning Disability
- Speech-Language Impairment
- Traumatic Brain Injury
- Visual Impairment including Blindness

 **Note:**

For purposes of this guide, we are assuming your child has already been determined eligible for special education or related services. If not or if you don't know, stop here. You may wish to have a conversation with your child's teacher, counselor, or other school personnel to see if your child should be evaluated.

We won't elaborate on the entire process of verifying eligibility for special education services, but we will mention a few things to give you an overview.

Nebraska Child Find: Each Nebraska school district is responsible for implementing a Child Find system to locate, identify, and evaluate students suspected of having a disability who need special education services. School districts also accept referrals for evaluation directly from parents, other agencies, or school districts.

Student Assistance Team: Upon receiving a referral, the school district holds a Student Assistance Team (SAT) meeting to assist the teacher in the provision of general education. If the Assistance Team is unable to properly educate the student, a multidisciplinary evaluation team is utilized to determine if the student needs special education. Some school districts use a Multitiered System of Supports (MTSS) or Response to Intervention (RtI) process for the same purpose. A parent may request a multidisciplinary evaluation at any time during this process.

Multidisciplinary Team (MDT) Evaluation: A multidisciplinary team conducts evaluations or assessments, in the student's primary language, in all areas of suspected disability. This may include assessment of:

- Health
- Vision
- Hearing
- Social and Emotional Status
- General Intelligence
- Academic Performance
- Communicative Status
- Motor Abilities

Parents are entitled to a copy of the Multidisciplinary Team report at no cost. If the parent disagrees with the findings or recommendations, the parent may request an independent education evaluation, which must be provided at no cost and considered by the student's Individualized Education Program (IEP) team. Further information about the IEP is provided in Chapter 2. A re-evaluation of the student may not occur more than once a year, but must take place at least once every three years. These timelines may be altered if the parent and school agree otherwise.

1.2 Laws, Regulations, and Rights

There are many laws, regulations, and rights that impact adolescents and young adults with disabilities. We will highlight a few of those.

Individuals with Disabilities Education Act (IDEA): The cornerstone for special education services lies within IDEA. This important federal law addresses the many educational requirements for students with disabilities. IDEA is a law ensuring services to children with disabilities throughout the nation. IDEA governs how states and public agencies provide early intervention, special education, and related services to eligible infants, toddlers, children and youth with disabilities.

Section 504 of the Rehabilitation Act of 1973 (Section 504): Section 504 is a federal law that applies to those students who do not qualify for special education services under IDEA, but have needs related to a disability. This law is designed to protect the rights of individuals with disabilities in all programs and activities that receive federal financial assistance. This includes public school districts, institutions of higher education, and other state and local education agencies.

Nebraska Department of Education's Rule 51, Regulations and Standards for Special Education Programs (Rule 51): On a state level, Rule 51 addresses requirements specific to Nebraska educational services. This includes defining the process for determining a student's eligibility for special education, as well as spelling out requirements for meeting the educational needs of students with disabilities.

Parents' Rights in Special Education Services: Parents' rights regarding Special Education services are protected under Procedural Safeguards, as spelled out in Section 009 of Nebraska's Rule 51. This includes requirements that parents must:

- Be notified in writing before any plans to change the identification, evaluation, or educational placement of the student, or changes to plans for providing a free appropriate public education (FAPE).
- Provide consent for initial evaluation, services, or reevaluations of the student (including documentation of reasonable efforts to obtain consent).
- Have the right to obtain an independent educational evaluation of the student if you disagree with the school district's evaluation.
- Be ensured that information regarding the student is kept confidential.
- Have the right to inspect and review any educational records related to the student that are collected, maintained, or used by the school district.
- Have the right to complaints, hearings, mediation, and appeals.

Schools are required to establish:

- Procedures for disciplining students with disabilities, including change of educational placement because of disciplinary removals; and
- Requirements for unilateral placement of students by parents in private schools at public expense.

As a parent, you may file a written, signed, complaint directly with the Nebraska Department of Education, Special Education Office if you believe a school district has done one or more of the following:

- Failed to implement a valid IEP for your student;
- Failed to follow special education law; or
- Discriminated against a student or a group of students.

The complaint should:

- State the relevant problems.
- Include relevant facts.
- Include the student's name, residency, and school district.

You must also provide a copy of the complaint to the school district serving your student at the time the complaint is filed. Within sixty days of receiving the complaint, the Department of Education, Special Education Office, will review all the relevant information and provide a written notification of all findings of facts and conclusions to all persons involved.

FYI: Chapter 1: Laws, Regulations, and Rights

- 1) Nebraska Department of Education Rule 51, Regulations and Standards for Special Education Programs (Rule 51):
https://cdn.education.ne.gov/wp-content/uploads/2017/10/Rule51_2017.pdf
- 2) Individuals with Disabilities Education Act (IDEA):
<https://sites.ed.gov/idea/>
- 3) Section 504 of the Rehabilitation Act of 1973 (Section 504):
<https://www.dol.gov/oasam/regs/statutes/sec504.htm>
- 4) Know Your Parental Rights: The Meaning and Importance of Prior Written Notice and Parent Consent (Pacer Center):
<http://www.pacer.org/parent/php/php-c232.pdf>
- 5) Filing a Complaint with the Nebraska Department of Education:
http://www.disabilityrightsnebraska.org/resources/legal_resources.html
- 6) Parents' Rights in Special Education:
<https://cdn.education.ne.gov/wp-content/uploads/2018/07/Parent-Rights-for-Special-Education-3-21.pdf>

Chapter 2.

Individualized Education Program & Section 504 Plan

2.1 Individualized Education Program (IEP)

Individualized Education Program (IEP): Every student who receives special education services must have an Individualized Education Program. This is commonly referred to as an IEP. The IEP is a written plan that defines the educational services the student will receive. It outlines in writing the educational program created especially for the student.

IEP Team: The IEP is developed at a meeting by a team coordinated by a lead staff member of the district, also known as the IEP case manager. The team includes the following representatives:

- Parent(s)
- Special education teacher
- Student, when appropriate
- Regular education teacher, (if child is, or may be, participating in a regular education environment)
- District representative who is qualified to provide or supervise the provision of specially designed education
- Other participants, which may include any individuals who have knowledge or special expertise regarding the student, including related service personnel

IEP Content: The IEP must include the following:

- Present levels of academic achievement
- Measurable annual goals
- Benchmarks or short-term objectives
- How progress will be measured and when periodic reports of progress will be provided
- Special education and related services to be provided to the student
- Extent to which the student will or will not participate with nondisabled students in the regular class
- Individual appropriate accommodations that are necessary to measure the functional performance of the student
- Beginning date of services
- Anticipated location and duration of those services


Other IEP Requirements:

- The school is responsible for holding an IEP meeting at least once every 12 months and for revising the IEP as necessary. Additional meetings may be scheduled, as needed, by any member of the IEP team.
- The parent(s) and the school must agree on where and when to have the IEP meeting. Often, meetings are held at school during regular staff time. However, meetings can happen before, during, or after the regular school day. Parents have the right to ask that the meeting be scheduled at a time convenient for them.
- The school must notify the parent/guardian in writing regarding:
 - The purpose of the meeting;
 - The time and place for the meeting;
 - Who will be there; and
 - The right to invite other people to the meeting who have knowledge or expertise about the student. Examples include a relative, friend, advocate, childcare provider, medical professional, or anyone else knowledgeable about the student.
- The IEP must be developed within 30 days of determining that the student needs special education services. It must be implemented as soon as possible after the IEP meeting and be in effect at the start of each school year.

Related Services: School districts are required to provide free related services. These related services should be considered by the IEP team and included in the IEP. Related services may include:

- Transportation
- Developmental services
- Corrective services
- Speech-language pathology and audiology services
- Interpreting services
- Psychological services
- Physical and occupational therapy
- Recreation, including therapeutic recreation
- Early identification and assessment of disabilities in children
- Counseling services, including rehabilitation counseling
- Orientation and mobility services
- Medical services for diagnostic or evaluation purposes

Transition and the IEP: For students with disabilities, the years between ages 14 and 21 are known as the transition years. The term “transition” is commonly used to refer to the bridge between school and adult life for students with disabilities. “Transition planning” refers to the process of preparing students for life after high school. This includes planning for post-secondary education or training, employment, and community living.

 **Note:** Both IDEA and Rule 51 state that transition planning must begin no later than the first IEP in effect when the student turns 16. Best practices suggest that transition planning should begin as early as possible – often at age 14 or even younger.

When the student reaches age 16, additional requirements for the IEP come into play. Federal and state regulations require that IEPs in effect at age 16 must:

- Be individualized and include the student and family as decision makers. This includes the requirement that the student be invited to the IEP meeting.
- Be coordinated by the school, involving a variety of school staff.
- Include a statement of the student’s transition needs and focus on their course of study.
- Include a statement of needed transition services for the student.
- Include a statement of connections between various agencies.
- Be a cooperative effort between the student, family, school, employers, and community agencies.

2.2 Section 504 Plan

Some students may not qualify for special education services, but will qualify for Section 504 of the Rehabilitation Act of 1973 (commonly referred to as Section 504). To be eligible for Section 504, a student must have a disability that limits a major life function. This includes things such as walking, seeing, hearing, speaking, breathing, learning, working, caring for oneself, performing manual tasks, eating, sleeping, standing, lifting, bending, reading, concentrating, thinking, communicating, and more.

There are many reasons a student may qualify for a 504 plan. Examples include a student with cancer who may exceed the usual number of allowable absences during a school year for health-related reasons or a student with attention deficit hyperactivity disorder (ADHD) who needs to be placed in a classroom with fewer distractions.

When a student is eligible under Section 504, the school must develop a plan to eliminate barriers that prevent the student from fully participating in school activities, including the general education curriculum. This plan is different

than an IEP. A 504 plan addresses accommodations or other services that the school will provide. Accommodations may include changes to the student's environment or provide equipment, supports, or services to help them learn.

Note:

Accommodations don't change the requirements a student must meet. Rather, they are supports to help them meet those requirements.

Examples of accommodations include:

- Testing in a quiet room
- Preferential seating
- Digital textbooks
- Tailored homework assignments
- Sign language interpreter for participation in activities in and out of the classroom

FYI: Chapter 2: IEP & Section 504

- 1) Individual Education Plan (Disability Rights Nebraska):
http://www.disabilityrightsnebraska.org/resources/legal_resources.html
- 2) What is Section 504? (Disability Rights Nebraska):
http://www.disabilityrightsnebraska.org/resources/legal_resources.html
- 3) Accommodations and Modifications: A Parent and Child Checklist (Pacer Center):
<http://www.pacer.org/parent/php/PHP-c49b.pdf>
- 4) National Technical Assistance Center on Transition:
<https://transitionta.org>

Self-Advocacy: It's important for you and the IEP team to know what your student's dreams are for life both during and after high school. Ongoing discussions are helpful to understand what the student is thinking and to make a plan to achieve those dreams. There are many good resources to assist you in guiding those discussions and some of those are listed in the *FYI* box at the end of this chapter.

A term you may hear as you work with the IEP team is "self-advocacy." This refers to the ability of a person to understand and explain his or her disability, strengths, and challenges. It is the ability to ask for help when it is needed. The self-advocacy movement was started by and for people with disabilities because they wanted to speak for themselves rather than having others speak for them. Strong self-advocacy skills are important for a person with a disability to be successful in school and in the adult world.

The transition years are a particularly important time for developing and practicing self-advocacy skills. Students should be provided opportunities to speak up for themselves, relying less on others to speak for them. This will become easier as they grow older and become more experienced in self-advocacy.

3.2 Making the Plan

Once the student has identified goals for the future, it's time to make a plan to achieve them. The IEP team must consider the student's interests, preferences, and needs. Formal and informal assessments may be used for this, but it's most important that the team considers the input and wishes of the student and those who know him or her best.

Students should be encouraged to advocate for themselves and be provided with opportunities to participate in every step of the process. Students who are involved in setting their own goals and monitoring their progress will be more invested in the outcome if they have played an active role in the process.

TIPS ALONG THE WAY

Questions to Consider for Transition Planning

- Where will the student live after high school?
- What will the student do for employment?
- Does the student want postsecondary education or training after high school?
- What are the student's transportation needs?
- How will the student be involved in social, recreational, or volunteer activities in the community?
- How will the student meet his or her medical needs, including health insurance?
- What benefits and financial support are available for the student?
- Are there legal issues to be addressed, such as full or partial guardianship?
- What agency supports or services may be needed and who can help the student apply for and connect with these?

Graduation: Another important consideration during transition planning is graduation. Schools are required to provide a free appropriate public education (FAPE) for all students with verified disabilities from birth through the school year in which the student reaches age 21. The exception to this is students who have graduated with a signed regular high school diploma. Once a student graduates with a regular high school diploma, they are no longer eligible to receive FAPE.

Note that the term "regular high school diploma" does not include an alternative degree such as a certificate or general educational developmental (GED) credential. A student may participate in a high school graduation ceremony with peers and receive a certificate of attendance and still continue to receive special education services. (Regulations regarding graduation from special education programs are located in Rule 51, Section 004.)

Note: Most adult services and supports are not available until age 21, so it is important that the student and IEP team carefully consider the best plan for graduation. Discussion about graduation plans should occur at every transition IEP. If the student graduates after four years of high school, there may be a gap in services until age 21.

All school districts are to offer 18-21 year old supports and services that focus on employment and life skills that go beyond a traditional academic curriculum. It is extremely important to determine what services and supports are needed to best fit the student.

Summary of Performance: Students leaving high school special education services with a regular signed diploma or at age 21 must be provided with a Summary of Performance (SOP). The SOP is to be a summary of the student's academic achievement and functional performance and include recommendations on how to assist him or her in meeting goals for life after high school. The intent of the SOP is to provide specific, meaningful, and understandable information that can be used as the student enters the adult world. (See Rule 51, 006.06E1.)

FYI: *Chapter 3: Transition Planning*

- 1) Attending Meetings to Plan Your Child's Individualized Education Program (IEP) (Pacer Center):
<http://www.pacer.org/parent/php/php-c27.pdf>
- 2) How Can My Child Be Involved in the IEP Process? (Pacer Center):
<http://www.pacer.org/parent/php/PHP-c77.pdf>
- 3) Want to Help Your Child Succeed in School? Be Involved! (Pacer Center):
<http://www.pacer.org/pdf/ge/GE-2.pdf>
- 4) It's All About the Plan:
 - The Parent and the Individual Education Program (IEP):
<http://itunes.southeast.edu/podcasts/CE/Choice/ParentIEP/story.html5.html>
 - The Student and the Individual Education Program (IEP):
<http://itunes.southeast.edu/podcasts/CE/Choice/StudentIEP/story.html5.html>
- 5) Talk to Your Child About Employment:
<http://www.pacer.org/transition/resource-library/publications/NPC-16.pdf>
- 6) Talk to Your Child About Postsecondary Education:
<http://www.pacer.org/transition/resource-library/publications/NPC-55.pdf>
- 7) Talk to Your Youth About Independent Living:
<http://www.pacer.org/transition/resource-library/publications/NPC-35.pdf>
- 8) Nebraska Department of Education Rule 51, Regulations and Standards for Special Education Programs (Rule 51):
<https://www.education.ne.gov/sped/regulationspolicies/>

Transition Timeline

This timeline provides a checklist of activities for students, parents, and school personnel to consider when planning for the student's transition from school to adult life. Activities and timeframes may vary, according to the needs and situation of each individual student. These are simply guidelines and may be started at any time before or after the suggested age.

By Age 16

- ✓ Identify student learning styles, interests & needs.
- ✓ Identify career interests and skills.
- ✓ Identify interests and options for future living arrangements.
- ✓ Provide opportunities to communicate wants and needs.
- ✓ Ensure student's understanding of his/her disability.
- ✓ Involve the student in the IEP process.
- ✓ Make plan for graduation. (Will student continue education until age 21?)
- ✓ Provide opportunities to learn and practice independent living skills.
- ✓ Provide opportunities for social and recreational activities.
- ✓ Acquire an identification card.
- ✓ Obtain Social Security card.
- ✓ Practice responding to emergency situations.
- ✓ Investigate options & acquire assistive technology devices.
- ✓ Learn about & apply for adult services.
- ✓ Encourage student to participate in IEP meetings (must invite at 16).
- ✓ Participate in VR Pre-Employment Transition Services.
- ✓ Invite VR Transition Specialist to IEP meetings.
- ✓ Consider transportation options (including a driver's license.)

By Age 18

- ✓ Continue to discuss and make plan for graduation.
- ✓ Consider need for partial or full guardianship or conservatorship.
- ✓ Register to vote.
- ✓ Register with Civil Service (for males.)
- ✓ Provide activities for career exploration.
- ✓ Continue participation in VR Pre-Employment Transition Services.
- ✓ Apply for or re-evaluate Medicaid and Social Security (SSI) benefits. (Note: at age 18 youth's financial resources are considered, not parents, when determining eligibility for these benefits.)

Prior to Graduation (Age 21 or Before)

- ✓ Implement plan for graduation.
- ✓ Visit colleges or vocational programs.
- ✓ If attending college, work with Disability Services Office for accommodations.
- ✓ If eligible for DD services and approved for funding, work with Service Coordinator to select service(s) and provider(s).
- ✓ Ensure health care needs (including insurance) are covered.

Chapter 4.

Partners and Resources


There are many things to consider when making plans for the student's future. For purposes of this chapter, we have grouped information according to the following topics. We'll discuss and provide an overview of the partners and resources that can assist for each topic.

1. Employment
2. Postsecondary Education or Training
3. Community Living
4. Health
5. Benefits & Financial Planning
6. Legal/Advocacy

4.1 Employment

It is important that students be given opportunities to develop awareness about employment options both during and after high school. These opportunities can be provided in a variety of ways by the school, family, and other outside sources. Career exploration activities during high school may include activities such as taking career interest tests and participating in career fairs and business tours.

Nebraska VR: VR, also known as Vocational Rehabilitation or Voc Rehab, works closely with schools to help students prepare for employment. This is an employment program for people of all ages with disabilities. Services and eligibility vary by age. The program is voluntary and there is no charge for VR services.

 **Note:** VR works in partnership with schools for transition age (14-21) students who are eligible for and receiving special education or related services or who are covered under Section 504.

These pre-employment transition services give students with disabilities an early start on career exploration and identifying career interests. You can request VR services through your school, at any Nebraska VR office, or online (see *FYI* for links).

After the student and parent or guardian completes a Pre-Employment Transition Consent and Release form, VR determines the student's eligibility for services. Eligible students meet individually and/or in groups with a VR Pre-Employment Transition Services Coordinator throughout the school year. VR transition staff may also attend IEP meetings, if invited by student or the student's parent or guardian.

To learn about the world of work, students may participate in activities for:

- Exploring careers
- Identifying work accommodations
- Planning for postsecondary education
- Training for workplace readiness, including social and independent living skills
- Building job search skills
- Developing self-advocacy skills, including peer mentoring
- Participating in work-based learning experiences, such as:
 - Job fairs
 - Informational interviews
 - Job shadows
 - Business tours
 - Work experiences
 - Project SEARCH

Nebraska VR also provides services to adults with disabilities to help them get and keep a job, as well as develop a plan for postsecondary education and training to prepare for a job or career. The VR Transition Services Coordinator will help guide the student through the process of applying for adult services. If determined eligible and if funding is available, the young adult may continue to receive VR services beyond high school. Further information about VR services for adults is located in the Adult guide of this series.

Nebraska Commission for the Blind and Visually Impaired: The Commission for the Blind and Visually Impaired is Nebraska's vocational rehabilitation agency for people who are blind or visually impaired. Transition services are provided to help students make a smooth transition from high school to adult life. Additional information about the Commission is provided in this guide under Section 4.3 Community Living.

Project SEARCH: Project SEARCH is a partnership between Nebraska VR, businesses, area school systems, Educational Service Units, the Commission for the Blind and Visually Impaired, and the Assistive Technology Partnership. This one-year school-to-work program is business led and takes place entirely in the workplace.

The program includes a combination of classroom instruction, career exploration, and hands-on training through worksite rotations consisting of three 10-week internships. Students who have completed their academic requirements may apply if they are in their last year of high school. Project SEARCH is located in a number of sites across the state. View the website (see *FYI* below) or ask at your school to see if it's available in your area.

FYI: Chapter 4.1: Employment

- 1) Nebraska VR Services for Students:
<http://www.vr.nebraska.gov/students/index.html>
- 2) Nebraska VR office locations:
www.vr.nebraska.gov/offices
- 3) Project SEARCH:
http://www.vr.nebraska.gov/partners/project_search.html

4.2 Postsecondary Education or Training

Some students may wish to continue their education or training after high school. 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 upon the program and circumstances of the student. A high school guidance counselor or other IEP team member may be able to assist in locating financial aid options.

There are many differences between high school and postsecondary programs that impact students with disabilities. Three major differences are:

1. Different laws apply in college than in the public school system.
2. The goals and responsibilities of the public school system are different from those in the college setting.
3. Students must become self-advocates. Others will no longer make sure their needs are addressed.

Students with disabilities have the right to receive educational services until age 21 or graduation from high school, but this same right doesn't apply to postsecondary education.

Note:

A college applicant cannot be denied admission simply because he or she has a disability. However, all applicants (disabled or not) must meet all essential technical or academic standards for admission.

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. This is to ensure that the academic requirements don't discriminate on the basis of disability. Examples of academic adjustments 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 a program. Academic adjustments or accommodations do not guarantee passing grades. They provide a fair chance for the student with a disability – not an unfair advantage.

Office of 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 the postsecondary institution's Office of Disability Services to help as the student transitions to college life and to provide support throughout the college years. It is the student's responsibility to take the first step and 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 Office of Disability Services 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 affects the student's academic performance
- Suggestions for educational accommodations appropriate for the college setting

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 tutoring 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 is expected to be responsible for their education the same as any other college student.

Differences Between High School and College²	
High School	College
Legal Differences	
Individuals with Disabilities Education Act (IDEA)	Americans with Disabilities Act (ADA)
Section 504, Rehabilitation Act of 1973	Section 504, Rehabilitation Act of 1973
IDEA is about facilitating SUCCESS	ADA is about facilitating ACCESS
Documentation	
IEP and/or Section 504 Plan	Documentation guidelines vary by postsecondary institution and specify information required for each category of disability; available upon request from the postsecondary institution
Evaluation provided at school's expense	Student is responsible for providing necessary documentation (i.e., testing)
Documentation to determine eligibility for services based on specific categories in IDEA	Documentation must include information on specific functional limitations and demonstrate the need for specific accommodations
Self-Advocacy	
Student – identified by the school; supported by parents and teachers	Student must self-identify (disclose) to the Office of Disability Services if they wish to receive accommodations
School is responsible for arranging accommodations	Student is responsible for self-advocacy; arranging accommodations is student's responsibility
Teachers may approach the student if they feel they need help	Professors typically wait for the student to initiate contact if help is needed
Parental Role	
Parent has access to the student's records	Students must provide written consent for parent to access student records
Attends IEP or Section 504 meetings	Students attend meetings on their own (unless they provide consent for parents to attend)
Parents may advocate for their child	Student must advocate for him or herself

² Adapted from: National Technical Assistance Center on Transition (NTACT): *Differences Between Secondary and Postsecondary Education*

Instructional Differences	
Teachers may modify curriculum or assignments	Professors are not required to make modifications to curriculum, nor to assignments (including deadlines)
Content is supported differently (i.e., material for homework may be discussed in class or re-taught)	Many classes require large amounts of reading and writing which may or may not be reviewed in class
Content material is typically less dense and intense and in-depth review may not be as necessary	Content material is often dense and may require greater review and active reading/note-taking; review is essential
Student Responsibilities	
Tutoring and academic support may be a part of a student's IEP or 504 plan	Tutoring and academic support are not a part of the Office of Disability Services; student must use the tutoring/academic support services offered to all students
The student's time is structured by others (i.e., in school approx. 8 hours a day)	The student structures his or her own time and must complete assignments independently (i.e., no progress checks)
Study time outside of class may be minimal	Average of 2-3 hours per credit hour is usually required in college-level classes (i.e., a 3-credit class requires between 8-10 additional hours)

Western Iowa & Nebraska Association on Higher Education and Disability is made up of representatives from two- and four-year colleges and universities who work directly with students with disabilities to ensure equal access to higher education. WINAHEAD provides resources and information for students, families, and educators, including transition presentations upon request to schools and organizations.

FYI: Chapter 4.2: Postsecondary Education or Training

- 1) National Technical Assistance Center on Transition (NTACT) - Differences Between Secondary and Postsecondary Education: [https://transitionta.org/system/files/resources/Highschool vs College list.pdf?file=1&type=node&id=1236&force=](https://transitionta.org/system/files/resources/Highschool_vs_College_list.pdf?file=1&type=node&id=1236&force=)
- 2) Transition of Students with Disabilities to Postsecondary Education - A Guide for High School Educators: <https://www2.ed.gov/about/offices/list/ocr/transitionguide.html>
- 3) Western Iowa & Nebraska Association on Higher Education and Disability (WINAHEAD): <https://winahead.wordpress.com>
- 4) WINAHEAD Transitions publication: https://winahead.files.wordpress.com/2016/09/winahead_transitions_oct2016_web.pdf

4.3 Community Living

An important part of transition planning is identifying the student's goals for community living after high school. There are many possibilities and questions to be answered! Does the student 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 will the young adult need for life after high school?

What can be done now and, in the future, to help the student acquire these skills? Some of the life skills needed to live independently include the following:

- 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 you might want 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 a student takes 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 student and provide assistance (natural support) as needed.

Assistive Technology: 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. Consider how assistive technology can assist the student – whether at home, in school, in the community, or in their place of employment. 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

Assistive technology must be addressed within the IEP process for every student. The IEP team must consider whether assistive technology is necessary for the student to:

- Achieve education or social goals
- Gain meaningful benefit from the education
- Make reasonable progress in the least restrictive environment

Nebraska Assistive Technology Partnership (ATP): ATP is an agency that helps people of all ages with disabilities locate and use assistive technology. This includes people with a disability or those who are recovering from an injury or illness. They also assist with home and vehicle modification projects to make the home or vehicle more accessible for the person with a disability.

ATP Technology Specialists visit schools and homes at no cost and can provide:

- Training to individuals and groups on equipment and how it works
- Guidance to the IEP team on assessing and selecting appropriate assistive technology
- Technical support (troubleshooting and setting up equipment)
- Demonstrations to individuals and groups on the features and use of assistive technology

A loan pool of devices is available to allow people to try before buying or to help fill a short-term need. The AT4All website has a listing of available devices and equipment (see FYI for link).

ATP provides Resource Coordination to assist in obtaining needed assistive technology and home/vehicle accessibility modifications. To apply for services, an application must be completed to see what resources, programs, and funding may be available.

Nebraska Center for the Education of Children who are Blind or Visually Impaired: The Center serves children from infancy to age 21. This program offers the expertise and specialized skills of their staff for students who are blind, visually impaired, and multi-handicapped in residential, day, and outreach settings. Services are provided for local school districts, students, families, teachers, and other support staff upon request. Supports also include training for a smooth transition to adult life. A student's eligibility for services is determined through the IEP process.

Nebraska Commission for the Blind and Visually Impaired: This Commission is the state vocational rehabilitation agency for the blind. The agency works to help Nebraskans who are blind and visually impaired achieve full and rewarding lives through independent living skills and assists with finding employment.

The coordination of services between the Commission and schools ensures that students who are blind and visually impaired make a smooth transition from high school to adult life. The Commission offers several programs for blind and visually impaired students, including:

- **College Prep:** an intense workshop for high school seniors and college students. Focus is on information about the Americans with Disabilities Act, accessing textbooks, hiring readers, and providing opportunities to speak with other students with disabilities.
- **Work and Gain Experience in the Summer (WAGES):** practical experience for teens in career areas of their choice during a summer employment program. Participants live at the University of Nebraska-Lincoln during the program.
- **Winnerfest:** a semi-annual retreat for teens focusing on personal achievement, goal setting, communication, and other life skills.
- **Round Tuit:** a three-day summer program for students that provides practical information regarding what it takes to get and keep a job.

Nebraska Commission for the Deaf and Hard of Hearing: This Commission 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, and training and presentations, links to resources, and interpreter referrals.

Nebraska Department of Health and Human Services Division of Developmental Disabilities (DHHS-DD): The Nebraska Department of Health and Human Services (DHHS) Division of Developmental Disabilities (DHHS-DD) oversees a system of services and supports to help eligible people live, work, and access their community as independently as possible. These services are referred to as developmental disability (DD) services. DD services include employment, residential, and other services designed to help the person live independently and access their community. Services can be provided by agency providers or independent providers.

Note:

While still in high school, if a student is determined eligible, a DD Service Coordinator (SC) can attend IEP meetings and assist in identifying and applying for services that benefit the student.

The DD services a youth can receive are limited because they cannot replace services available through the school system. Once a student graduates and reaches age 21, day services may be available to help the young adult find a job, volunteer, or increase skills needed to join the workforce. Other DD services, such as residential, depend upon available funding.

DD Service Eligibility: Anyone who is potentially eligible for services through DHHS-DD is encouraged to apply early. Age 14 is not too early! For those determined eligible before specific ages, redetermination is done at ages 9 and 18. This should not discourage a person from applying at a younger age. Application can be submitted as soon as a disability is diagnosed.

To be eligible, a person must be a US citizen or legal resident, a resident of Nebraska, and 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."

DD Services Application: Application for DD services may be made online at ACCESSNebraska (see link in FYI). The online application is easy to complete and 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 can request a paper application:

- At any DHHS office in Nebraska.
- By calling toll-free 877-667-6266.

Once you have submitted an application, a DHHS-DD employee will call you within a few days of receiving it. They will work to gather appropriate documents. Required documentation may include, but is not limited to:

- Current developmental disability diagnoses, 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; and
- 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. You will receive a Notice of Decision that will state that the applicant is either eligible or not 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, which is public health insurance. Medicaid provides a federal match to state funding, which allows DHHS-DD to fund more eligible people. Application for Medicaid can be made at any age, but parental income may disqualify some people. At age 19, parental income is no longer counted, and the Medicaid applicant is a "household of one" even if they live with their parents. For more information about Medicaid, see Chapter 5 of this guide.

Determination of Ineligibility for DD Services: Persons found to be not eligible, or "ineligible," for DD can appeal the decision. Instructions on how to appeal are sent with the written notice of decision.

DD Registry of Need: 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 Registry of Needs. 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."

DD Funding for Graduates: Historically, eligible new graduates were entitled to DD services when they graduated from high school and reached age 21. On May 24, 2017 changes were made in Nebraska State Statute that impacted services for high school graduates. An eligible 21-year-old graduate will not automatically receive funding if there is someone with a higher priority need. Graduates are offered funding for day services under the state's fourth funding priority as a person transitioning from the educational system. It is anticipated that, based on historical data, the state has reserved enough funding to serve all new graduates.

TIPS ALONG THE WAY

More About Graduates and Funding

- Since the educational system is responsible until a person graduates, the person cannot use DD funding to purchase day services until after graduation.
- A person who drops out on their 21st birthday would not be considered a graduate until the school year concludes.
- Certain services, such as Respite, Personal Emergency Response System (PERS) or Home Modifications, are available before graduation.
- Service Coordination is given names of eligible persons 60 to 90 days before their 21st birthday. At that time:
 - A DHHS-DD worker contacts the person/guardian;
 - DHHS-DD completes an objective assessment to determine the person's annual budget amount; and
 - Service planning can start after the budget is determined.

DD Service Coordination: A Service Coordinator (SC) is available for all persons on the wait list for DD funding. When a person has Medicaid, it will pay for DD Service Coordination as targeted case management. If the person does not have Medicaid, he/she will be assessed an Ability to Pay for this service.

The Service Coordinator 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 DD services begin. The SC may attend IEP meetings if the parent or guardian grants permission to invite them. This assists the SC in forming relationships and to start learning about the student's interests and goals. The SC will work with the school system and Nebraska VR to help with a smooth transition to adult services.

Choosing DD Services and Providers: Once funding is available, the young adult will need to choose DD services and providers.

- Respite can be provided when the person lives with a non-paid caregiver, such as family.
- Day services include an array of options, ranging from prevocational services, supported employment, habilitative workshop, and habilitative community inclusion.
- Residential services include a variety of options and can be provided wherever the person lives, whether with family, on his/her own, with friends, or in a provider-operated setting.

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. A directory is available on the DHHS-DD website.

For more information about DD services and providers, see the Adult Guide in this Along the Way series.

Process for Graduates: DD Funding for Day Services

DHHS-DD Service Coordinator explains service options at IEP meetings during the person's last year in the educational program.

60 to 90 days before an eligible person turns 21, DHHS-DD staff contacts him/her and offers funding for DD services, including day services, after graduation.

The person must accept DD services and agree to be on a waiver to receive funding under the fourth priority.

DHHS-DD completes an objective assessment to determine the funding amount the person will receive to meet his/her needs.

The eligible person chooses DD services and provider(s).

Service Coordinator completes referral for agency providers and/or helps independent providers with enrollment.

Service Coordinator holds intake Individual Support Plan (ISP) meeting to identify DD services and supports and assign responsibility.

Service Coordinator completes service authorization(s) assigning funding to provider(s).

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. 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 DHHS. A person may only receive respite from one source; for example, one cannot have both Lifespan Respite and respite through DHHS-DD.

FYI: Chapter 4.3: Community Living

Assistive Technology

- 1) Nebraska Assistive Technology Partnership (ATP):
<https://atp.nebraska.gov>
- 2) AT4All (Nebraska Assistive Technology Partnership):
<https://www.at4all.com>

Services for Blind and Visually Impaired

- 1) Nebraska Center for the Education of Children who are Blind or Visually Impaired:
<http://www.ncecbvi.org>
- 2) Nebraska Commission for the Blind and Visually Impaired:
<http://ncbvi.nebraska.gov>

Services for Deaf and Hard of Hearing

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

FYI: Chapter 4.3: Community Living

Division of Developmental Disabilities (DHHS-DD)

- 1) Nebraska Department of Health and Human Services (DHHS) Division of Developmental Disabilities (DHHS-DD):
http://dhhs.ne.gov/developmental_disabilities/Pages/developmental_disabilities_index.aspx
- 2) DD Services Eligibility (Brochure):
http://dhhs.ne.gov/developmental_disabilities/Documents/EligibilityDDServices.pdf
- 3) DHHS-DD Eligibility for Developmental Disabilities (Webpage):
http://dhhs.ne.gov/developmental_disabilities/Pages/aDDIF-Eligibility.aspx
- 4) ACCESSNebraska:
www.ACCESSNebraska.ne.gov
- 5) Applying for Developmental Disabilities Services (screenshots of online application):
http://dhhs.ne.gov/developmental_disabilities/Documents/ApplyingforDDServices.pdf
- 6) Transitioning from High School at 21 Years Old:
http://dhhs.ne.gov/developmental_disabilities/Pages/aDDIF-Transitioning.aspx
- 7) Available Services for Teens & Young Adults with Developmental Disabilities:
http://dhhs.ne.gov/developmental_disabilities/Documents/DD-PUB-7.pdf
- 8) Ready, Set, Go!: Service Options for Individuals with Developmental Disabilities:
http://dhhs.ne.gov/developmental_disabilities/Pages/RSG-HOME.aspx
- 9) DD Agency Provider Directory:
http://dhhs.ne.gov/developmental_disabilities/Documents/ProviderAgencyList.pdf

Nebraska Lifespan Respite

- 1) Lifespan Respite Program:
http://dhhs.ne.gov/Pages/hcs_services_respite.aspx

4.4 Health

Like everyone else, people with disabilities deserve a happy, healthy life. Whether attending school, enjoying community events, living with their families, or worshiping with friends and neighbors, everyone deserves the opportunity to become healthy, productive adults. In addition to the need for routine healthcare, people with disabilities may also have challenging health conditions – physical, mental, or emotional – that require more planning and attention. Assistance may be needed to navigate the complex healthcare system. Following is a brief description of health-related programs and services available in Nebraska.

Aged & Disabled Medicaid Waiver: The Aged and Disabled Medicaid Waiver is a program that offers an array of services to support people in their homes. Individuals of all ages are eligible who meet the following criteria:

- Eligible for Medicaid or under age 19 and only denied due to parental income;
- Needs are at nursing facility level of care;
- Desire to live at home rather than a nursing facility; and
- Can be served safely at home.

Some of the services provided include: in-home help; relief time for family caregivers (respite); and childcare so the caregiver can maintain employment (for children with disabilities).

A person may only be on one Medicaid Waiver. This means that one cannot have both Aged & Disabled Medicaid Waiver and a DD Waiver through DHHS-DD. The Aged & Disabled Medicaid Waiver does not have a wait list and a person can be on that waiver while on the DD wait list.

Children's Health Insurance Program (CHIP): CHIP is part of Nebraska Medicaid and provides medical assistance to children age 18 and younger who are without other health insurance and who do not qualify for Medicaid. CHIP provides the same services covered under Medicaid.

Disabled Children's Program: This program serves children with disabilities by assisting with payments of non-medical services and supports. Services are determined based on an assessment of needs and shown in a jointly developed plan with the family. Eligibility includes children who meet the following criteria:

- Birth through 15 years of age;
- Receiving monthly Social Security Income (SSI) payments;

- Nebraska resident; and
- Has an identified disability-related need.

The services available include:

- Respite care (“temporary break” for caregivers)
- Mileage reimbursement for medical care
- Pre-approved travel reimbursement for long distance medical trips
- Accessibility modifications

Katie Beckett: The Katie Beckett program provides home health nursing and other medical services to children who otherwise would be hospitalized because of their high level of health care needs. Youth on the Katie Beckett program are eligible for Medicaid. Eligibility includes families with a child or children under 18 years old who have one or more of the following:

- A ventilator to breathe
- A tracheostomy
- Need for complex nursing services to be provided at home
- Use excessive amounts of medical supplies, equipment, and/or therapies

Services available through the Katie Beckett program include all Medicaid services based on medical need, including, but not limited to:

- Nursing care in the home
- Hospital stays
- Medicine, medical supplies, and equipment
- Physician fees

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. The following are the age and disability requirements for Medicaid:

- 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.

Medically Handicapped Children's Program: The Medically Handicapped Children's Program provides specialized medical services for children and youth with special health care needs. Services may include service coordination/case management, specialty medical team evaluations, access to specialty physicians, and payment of authorized medical services. The program does NOT provide or cover general medical care. Eligibility criteria includes:

- Birth through 20 years of age;
- Nebraska resident;
- Diagnosed with an eligible chronic medical condition and an active individual medical treatment plan; and
- Must meet financial eligibility based on current regulations.

Other funded services *may* include:

- **Diagnostic and Consultative Services:** These services may include assistance with locating offices of participating specialists, hospitals, or specialty clinics.
- **Treatment Services:** Funds are used to pay for costs of prior authorized specialized medical treatment related to the eligible diagnosis(es). Treatment must be in accordance with the individual treatment plan.

Munroe-Meyer Institute: Munroe-Meyer provides interdisciplinary, family-centered services for persons with disabilities and complex health care needs across the lifespan at more than 40 provider locations across Nebraska. The type of services provided include:

- Academic and educational interventions
- Applied Behavior Analysis (ABA)
- Augmentative and alternative communication (AAC)
- Autism Care for Toddlers Clinic
- Behavioral health services
- Autism spectrum disorders (ASD) treatment
- Community education
- Developmental medicine
- Early intervention
- Family resources
- Feeding and swallowing services
- Genetics evaluation/counseling/testing

- Motion analysis
- Neonatal intensive care follow-up
- Therapies (including Occupational, Physical, and Recreational)
- Rehabilitation services
- Severe behavior services
- Social skills services
- Speech language pathology

Parent Training and Information (PTI) Nebraska Family Voices: PTI Nebraska employs staff who are parent/professionals and are available to talk to parents and professionals about special education and disability specific information. The Family Voices program assists with issues related to the health care of a child or youth with a special need or disability.

FYI: Chapter 4.4: Health

- 1) Aged & Disabled Medicaid Waiver:
http://dhhs.ne.gov/Pages/hcs_programs_ad-waiver.aspx
- 2) Children's Health Insurance Program (CHIP):
http://dhhs.ne.gov/medicaid/Pages/med_CHIP.aspx
- 3) Disabled Children's Program:
http://dhhs.ne.gov/Pages/hcs_programs_dcp.aspx
- 4) Katie Beckett Program:
http://dhhs.ne.gov/Pages/hcs_programs_katie-beckett.aspx
- 5) Nebraska Medicaid:
http://dhhs.ne.gov/medicaid/Pages/med_medindex.aspx
- 6) Medically Handicapped Children's Program:
http://dhhs.ne.gov/pages/hcs_programs_mhcp.aspx
- 7) Munroe Meyer Institute:
<https://www.unmc.edu/mmi/>
- 8) PTI Nebraska Family Voices:
<http://pti-nebraska.org/family-voices/>
- 9) How to Advocate for Your Child with Special Health Care Needs:
<http://www.pacer.org/health/pdfs/HIAC-h28.pdf>
- 10) Tips for Working with Doctors (Pacer):
<http://www.pacer.org/health/pdfs/HIAC-h26.pdf>
- 11) Transition Health Plan for Youth with Disabilities and Their Families:
<http://www.pacer.org/transition/resource-library/publications/NPC-54.pdf>

Chapter 5.

Benefits & Financial Planning

People with disabilities often qualify for medical and income support through benefits programs, such as those provided under Medicaid and Social Security. Benefits programs are often a key piece for the person to live independently in the community, providing the needed income and health care coverage for the young adult leaving school. Eligibility requirements can be complicated and many fear that benefits will be lost if they become employed. This is a real fear. Families who understand the system, or who have help in navigating the system, can maximize benefits while the youth transitions to the adult world.

5.1 Benefits Services

Under agreement with Nebraska VR, three agencies may be authorized to provide benefits planning services for persons who receive Social Security and other benefits and are served by VR. These agencies are:

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

The agencies offer benefits planning services provided by Community Work Incentives Counselors (CWIC), who have extensive training in how work incentives may be used by Social Security beneficiaries to maximize earning potential and minimize negative impact to benefits. You may have a choice of agencies to work with depending on where you live.

The Benefits Services may provide:

- Answers to questions about current benefits.
- An outline of available work incentive options to assist in understanding how earning income will affect benefits so the person can make an informed choice about working.
- 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.

Nebraska VR also sponsors Benefits Workshops, offered by the same agencies. These workshops provide education and support for beneficiaries and their families in managing Social Security benefits, assisting them in gaining greater understanding in order to make the best-informed choices.

Benefits Workshops are provided regionally throughout the state (based on Educational Service Unit regions) and are offered in the spring and fall. Information regarding the workshops may be found by contacting the Educational Service Unit (ESU) in your area. ESU contact information is located in the Resource Guide of this series.

5.2 Department of Health and Human Services (DHHS) Financial Assistance Programs

In addition to the programs previously discussed, financial assistance may be available through other DHHS programs. Application for these programs may be made through ACCESSNebraska. DHHS financial programs include:

- Assistance to the Aged, Blind, or Disabled (AABD)
- Social Security Supplement
- Supplemental Nutritional Assistance Program (SNAP)
- Energy Assistance

5.3 Social Security Administration

The Social Security Administration offers several options for assisting persons with disabilities. Supplemental Security Income (SSI) is an important resource for children with disabilities. A “child” is defined as someone who is neither married nor head of a household and:

- Is under age 18; or
- Is under age 22 and is a student regularly attending school.

The Social Security Administration determines eligibility for SSI based upon the following for children under age 18:

- A medically determinable physical or mental impairment (including an emotional or learning problem) or impairments which result in marked and severe functional limitations; and
- The impairment(s) has lasted or can be expected to last for a continuous period of at least 12 months or be expected to result in death; or
- If the child is blind, he or she meets the same definition of “blind” as applies for adults.

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.

Substantial Gainful Activity: Of importance in 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 of Social Security's family protection features, 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 the parent's status such as retirement, disability, or death may result in a change in the child's Social Security benefits.

Note:

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

5.4 ABLE Savings Plan (Enable)

In addition to understanding and applying for benefits programs, it is important for people with disabilities and their families to participate in financial planning. In 2014, Congress passed the Achieving a Better Life Experience Act (ABLE) as a financial tool for people with disabilities. As a result, in 2015, Nebraska passed the Enable Savings Plan.

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 for those who contribute to the account.

A person is eligible for Enable if he or she is blind or disabled before age 26 and is entitled to Supplemental Security Income (SSI) or Supplemental

Security Disability Income (SSDI). Or, they must have a physician certification indicating that they have a marked or severe functional limitation diagnosed before age 26, which is expected to result in death or has lasted/may last for a continuous period of at least 12 months.

FYI: Chapter 5: Benefits & Financial Planning

- 1) Benefits 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:
<http://region5services.com>
- 5) DHHS Financial Assistance Programs:
http://dhhs.ne.gov/children_family_services/Pages/fia_fiaindex.aspx
- 6) Department of Health and Human Services Program Application:
www.ACCESSNebraska.ne.gov
- 7) What do I need to know about Medicaid?
http://dhhs.ne.gov/developmental_disabilities/Documents/Whatis-Medicaid.pdf
- 8) Social Security Administration:
<https://www.ssa.gov/benefits/disability/>
- 9) Benefits for Children with Disabilities (US Social Security Administration):
<https://www.ssa.gov/pubs/EN-05-10026.pdf>
- 10) Disability Starter Kits (US Social Security Administration):
https://www.ssa.gov/disability/disability_starter_kits_child_eng.htm
- 11) Nebraska Enable Savings Plan:
www.enablesavings.com

Chapter 6.

Legal and Advocacy

6.1 Legal

Age of Majority: It is important that you and your child become familiar with the legal rights and responsibilities upon reaching the age of majority. In Nebraska, a person is considered an adult (age of majority) for most purposes at age 19. While there are many legal rights and responsibilities that go into effect at age 19, there are also some that occur at age 18. It's not possible to cover every area of the law related to this topic in this guide, but we'll highlight a few here.

Individual Rights:

What are some of the rights a person has at age 18?

- Applying for credit in your own name
- Filing a lawsuit
- Making a will
- Voting
- Making a contract (rent an apartment, buy a car, take out a loan) in your own name
- Becoming personally responsible for the obligations of contracts you make

What are some of the rights a person has at age 19?

- Making health care decisions
- Becoming eligible for jury duty
- Becoming legally independent from parental control (this naturally occurs unless steps are taken to legally prevent it, such as applying for guardianship)
- Becoming self-supporting (parents are no longer required to support the individual)

Conservatorship/Guardianship/Representative Payee: Parents are considered the legal guardian of their child until they reach the age of majority (19 in Nebraska), unless a legal determination has been made otherwise. It's important to consider the child's legal status prior to age 19. You may wish to visit with a lawyer and/or financial planner before deciding, as this is an important decision.

TIPS ALONG THE WAY

Questions to Consider in Legal Status Decisions

- Can the person take responsibility for his/her own personal safety?
- Can the person take responsibility for providing the necessities of food, clothing, and shelter on his or her own?
- Can the person manage his or her money independently?
- Is the person's decision-making ability and judgment impaired so that being completely independent would be a threat to his or her welfare?³

There are varying legal judgments (also referred to as substituted judgment) that can be made. It is important to consider the least restrictive alternative when considering options. Options, listed in order from least restrictive to most restrictive, include:

- Health care power of attorney
- Representative payee
- Power of attorney
- Durable power of attorney
- Conservatorship
- Guardianship (full or limited)

Note:

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 full guardianship.

Office of Public Guardian: The Office of Public Guardian is designed to serve as the guardian or conservator for an individual when no other alternative is available. In addition to providing the means of last resort as guardians or conservators for those situations where no family member or suitable individual is available, the Office of Public Guardian provides education, training, and support for volunteer and family guardians and conservators, and recruits individuals to serve as guardians and conservators for Nebraska's vulnerable individuals.

6.2 Advocacy

You're not alone! There are many organizations and people available to help people with disabilities and their family members to advocate for their rights

³ Pathways for Success: Preparing for Life After High School; Community Foundation of Northern Illinois

and get the services and supports they need. Other parents of children with disabilities are often your best source of information and support. Those who have “walked in your shoes” understand what you’re experiencing. There are several state and local organizations that serve as valuable resources and support and some of those are highlighted here.

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 wide 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 such as: voting, employment, special education, Medicaid, and the DD waiting list. Local Arc chapters are located throughout the state.

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

Disability Rights Nebraska uses a combination of legal advocacy, public policy advocacy, citizen advocacy, self-advocacy and advocacy education to protect vulnerable people with disabilities, especially those who learn, live, or work in isolated, segregated, or congregated settings.

Nebraska Youth Leadership Council is a group of young leaders from across the state who want to make a difference in the lives of other students with disabilities. Co-sponsored by Nebraska VR and the Nebraska Department of Special Education, Council members are leaders and advocates with a disability. They travel the state promoting disability awareness and educating peers on transitioning to college or work.

To be a member of the Nebraska Youth Leadership Council, a student must:

- Be between the ages of 14 and 24 years old
- Have a disability
- Have leadership skills OR want to learn these skills
- Represent youth with disabilities and speak on their behalf
- Be able to attend 4-5 Council meetings per year in their area

Parent Training and Information (PTI) Nebraska is a statewide resource for families of children with disabilities and special health care needs. PTI staff

are parent/professionals and are available to talk to parents and professionals about special education and disability specific information.

Note:

You may also find it necessary to connect with state and local officials for issues on a broader scale. And, of course, all citizens have a right to contact their Senator, Governor, or Congressional representative.

FYI: Chapter 6: Legal and Advocacy

Legal

- 1) Disability Rights Nebraska Law-in-Brief Series: Fact sheets to assist with understanding different aspects of the law. The following pertain to adolescents and young adults.
http://www.disabilityrightsnebraska.org/resources/legal_resources.html
 - Americans with Disabilities Act (ADA)
 - Conservatorship
 - Guardianship
 - Representative Payee
 - Special Education
 - Voting
- 2) Nebraska State Bar Foundation Reaching the Age of Majority - Legal Rights & Responsibilities of Adults:
<http://www.nebarfnd.org/age-of-majority.html>
- 3) Nebraska Office of Public Guardian:
<https://supremecourt.nebraska.gov/programs-services/office-public-guardian>

Advocacy

- 1) Answers for Families:
<http://www.answers4families.org/>
- 2) Arc of Nebraska:
www.arc-nebraska.org
- 3) Autism Family Network:
<http://autismfamilynetwork.org/>
- 4) Disability Rights Nebraska:
<http://www.disabilityrightsnebraska.org>
- 5) Nebraska Youth Leadership Council:
<http://nylc.nebraska.gov/NYLC/Welcome.html>
- 6) Parent Training and Information (PTI) Nebraska:
<http://pti-nebraska.org/>

Appendix

Frequently Used Acronyms

ABLE	Achieving a Better Life Experience Act (Enable, in Nebraska)
AD Waiver	Aged & Disabled Medicaid Waiver
ADA	Americans with Disabilities Act
ADC	Aid to Dependent Children Program
AT4All	Assistive Technology for All
ATP	Assistive Technology Partnership
CAP	Client Assistance Program
CHIP	Children's Health Insurance Program
CMS	Centers for Medicare & Medicaid Services
DCP	Disabled Children's Program
DHHS	Nebraska Department of Health & Human Services
DHHS-DD	DHHS - Division of Developmental Disabilities
EDN	Nebraska Early Development Network
ESU	Educational Service Unit
FAPE	Free Appropriate Public Education
FYI	For Your Information
I/DD	Intellectual and Developmental Disabilities
IDEA	Individuals with Disabilities Education Act
IEP	Individualized Education Program
ISP	Individual Support Plan
MHCP	Medically Handicapped Children's Program
MMI	Munroe-Meyer Institute
MDT	Multidisciplinary Team
NCBVI	Nebraska Commission for the Blind and Visually Impaired
NCDHH	Nebraska Commission for the Deaf and Hard of Hearing
NCECBVI	Nebraska Center for the Education of Children who are Blind or Visually Impaired
NDE	Nebraska Department of Education
NYLC	Nebraska Youth Leadership Council
PTI	Nebraska Parent Training & Information
SAT	Student Assistance Team
SC	Service Coordinator
SGA	Substantial Gainful Activity
SOP	Summary of Performance
SSDI	Social Security Disability Insurance
SSI	Supplemental Security Income
VR	Vocational Rehabilitation
WINA-HEAD	Western Iowa & Nebraska Association on Higher Education & Disability

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