



Along **THE** *Way*

A Guide for Parents
of Infants, Toddlers, and Children
with 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) and their families. The 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 this series to provide information and resources for individuals with I/DD, 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.

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.

Early Development - Infants & Toddlers

If you are reading this chapter, you most likely suspect your infant or toddler may have a developmental delay or special health care need. Or, your child may have already received a diagnosis. Whatever the case, it is extremely important to pay attention to your intuition and follow up with your medical provider for diagnosis and treatment as soon as possible. The earlier you begin to address your child's needs, the better the outcome. This chapter provides a roadmap for Nebraska's early intervention services.

1.1 Developmental Milestones

Your child's development throughout their early months and years provides important clues to share with your medical provider. Developmental milestones are things children can do by a certain age, including how they play, learn, speak, act, and move. If your child has a disability or you suspect that they do, developmental milestones will help you and your medical provider assess your child's condition. (See *FYI* Developmental Milestones.)

1.2 Early Intervention Services

Early Intervention Services are a collection of health and educational services families may need if their infant/toddler has a developmental delay and/or special health care need. Early Intervention Services are provided through a collaborative effort between the Nebraska Department of Health and Human Services and the Nebraska Department of Education.

 **Note:** In Nebraska, the statewide early intervention program is referred to as the Early Development Network and serves children from birth to age three and their families.

Early Development Network (EDN) Eligibility/Referrals: Anyone can make a referral to Nebraska's Early Development Network. An infant or toddler may receive early intervention services if:

- the family lives in Nebraska;
- the child is birth to three years of age; and
- the child meets the eligibility criteria for Nebraska early intervention services.

An infant or toddler should be referred if he or she is not developing typically or has been diagnosed with a health condition that will affect his or her development. Referrals and questions regarding services for infants and toddlers birth to three years old with disabilities should be made to the local Services Coordination agency. (See *FYI Nebraska Early Intervention services* for referral information.)

Early Development Network Multidisciplinary Evaluation Team (MDT):

Once a referral is made to the local Early Development Network Services Coordination agency, a Services Coordinator will contact you to talk about the program and process, as well as answer any questions you and your family may have. With your written consent, a multidisciplinary evaluation of your infant/toddler is conducted by your local school district to determine his or her unique needs and determine eligibility for the program. The following areas of development are considered:

- Cognitive - ability to learn and how the infant/toddler learns
- Physical - ability to move, see, and hear, as well as health development
- Communication - ability to understand language and express needs
- Social/emotional - ability to relate with others
- Adaptive skills - ability to dress, eat and take care of oneself

Note:

The MDT evaluation is provided at no cost and includes parent/caregiver input, observations, review of medical/other records, and evaluation of the infant/toddler's abilities.

Early Development Network Services Coordination: Upon referral, you will be assigned an Early Development Network Services Coordinator. The Services Coordinator acts as a central contact person to assist in coordinating and accessing services across multiple agencies to make sure your infant/toddler and your family receives the help you need. Families are entitled to help from a Services Coordinator up to the time of the evaluation, as well as after the evaluation if the infant/toddler is determined eligible for early intervention services. Year-round Services Coordination is provided at no cost to families.

Services Coordination helps families with special needs infants/toddlers below age three in the following ways:

- Find and link services to meet developmental, educational, financial, health care, child care, respite care, and other needs
- Work with multiple providers to make sure services are provided, as needed
- Coordinate services for the infant/toddler in the future

- Obtain access to needed early intervention services and other services identified in the Individualized Family Service Plan (IFSP)
- Make referrals to providers for needed services and schedule appointments
- Coordinate early intervention services and other services (such as educational, social, and medical services)
- Coordinate screenings (if applicable), evaluations, and assessments
- Facilitate and participate in the development, review, and evaluation of IFSPs
- Coordinate, facilitate, and monitor the delivery of services to ensure that the services are provided in a timely manner
- Inform families of their rights and procedural safeguards
- Facilitate the development of a transition plan to preschool or other services

Individualized Family Service Plan (IFSP): The Early Development Network Services Coordinator leads families and a team of professionals in the development of an IFSP. The IFSP is both a process and a document intended to assist you and professionals in combined efforts to meet the developmental needs of your infant/toddler. Early intervention services are selected in collaboration with your family to meet the individualized needs of your child/family.

The IFSP provides families:

- Predictable process for discussing and documenting the infant/toddler's and family's changing needs
- Family-centered services in which both the infant/toddler's needs and needs of the family are considered
- Focus on outcomes deemed most important to the family
- Living document that changes and grows as the needs of the infant/toddler and family change
- Written plan of who will do what, when, and where for a 6 to 12-month time period
- Family and professional input to the development and implementation of plans
- Access to available educational, medical, and social services in the community to help the family and the infant/toddler

- Expertise of early intervention professionals from many disciplines including: physical, occupational and speech therapy, social work, nursing, nutrition, audiology, psychology, child development, and education
- Coordination of services across agencies and professionals in a family-centered, individualized manner

Note:

Families must provide written consent to receive the early intervention services listed on the IFSP.

Services that may be provided to children and families include, but aren't limited to:

- Speech/language therapy
- Physical therapy
- Occupational therapy
- Psychological services
- Assistive technology devices & services
- Audiology and vision services
- Nutrition services
- Family training, counseling and home visits
- Health services
- Social work services
- Special instruction

TIPS ALONG THE WAY

Early Childhood Professionals

Based on your child's needs, you may work with many different types of professionals. The list below provides an overview of the functions of some of these professionals.

Infant/preschool teachers work with children from birth until they enroll in kindergarten. These Early Childhood Special Education teachers have a degree in special education as well as child development. They have specialized training to meet the needs of children and toddlers with learning or physical disabilities.

Psychologists administer intellectual and developmental tests and collect other assessment information; interpret test results; consult with other staff members in planning services to address the needs of the child; assist in developing positive behavioral intervention strategies; and help parents meet the child's needs.

Speech-language pathologists identify children with communication delays or impairments; diagnose and appraise specific speech or language impairments; make referrals for medical or other professional attention necessary for treating speech or language impairments; provide speech and language services for the treatment or prevention of communication impairments; and collaborate with parents and other team members about speech and language impairments.

Physical therapists provide services that generally address the development of a child's posture, muscle strength, mobility, and movement. Physical therapy may be provided to prevent the onset or progression of impairment, functional limitation, disability, or changes in physical function or health resulting from injury, disease, or other causes.

Occupational therapists develop the functional use of smaller muscles to improve ability to perform tasks for independent functioning and prevent, through early intervention, initial or further impairment or loss of function.

Vision specialists help a child explore their environment; use limited vision, if appropriate; develop functional skills with adaptations for vision disability; and help family members to understand and enhance the child's development. A vision specialist does not test visual acuity or make any kind of medical diagnosis.

Audiologists identify children with hearing loss; determine the range, nature, and degree of hearing loss, including referral for medical or other professional attention for the treatment of hearing loss; provide treatment activities, such as auditory rehabilitation and speech reading (lip-reading); and determine children's needs for amplification including selecting and fitting an appropriate hearing aid for infants and toddlers, evaluating the effectiveness of amplification and providing training and orientation for listening devices.¹

1.3 Transition to Pre-School

Families may remain in the Early Development Network and continue to receive Services Coordination until August 31 after their child's third birthday, or they may choose to move from an IFSP to an Individualized Education Program (IEP). At this point in time, if your child/family still needs other types of services, the Services Coordinator can connect you with other programs or community agencies before you leave the Early Development Network.

The Early Development Network Services Coordinator will schedule a transition meeting at least 90 days prior to your child's third birthday. Your IFSP team will review your child's program options for the remainder of the school year, describe how your family will be involved in the transition process, and develop the transition plan with you.

TIPS ALONG THE WAY

Effective Communication with Early Childhood Professionals

Children with disabilities also have a lot of abilities. By communicating your child's strengths and needs to early childhood professionals, you can help select the most appropriate services for your child. Your role is to help professionals understand your child. Here are some ideas that can help you do that effectively.

Know Your Child's Strengths and Needs: General guidelines show the skills and behaviors children typically have at certain ages. These guidelines, also referred to as milestones, can help you think about where your child is developing typically and where support might be helpful. (See *FYI* Developmental Milestones.)

Share Information: Once you've identified your child's strengths and needs, share them with early childhood professionals. Give examples to illustrate each one. It's also helpful to share your child's likes and dislikes. If you have strategies that have been successful, you might want to share them.

Ask Questions: Questions to consider asking early childhood professionals:

- How can you help me so that I can help my child?
- Have you worked with a child like mine?
- What community resources would be helpful to meet my child's needs?

Remember: You are the expert on your child. Early childhood professionals play an important role in developing goals for your child and should be able to address your concerns while being respectful of your family values, beliefs, culture, and priorities. As you practice communicating with your child's team and connecting with other parents who share your concerns, you will be on the road to becoming an effective advocate for your child.²

Developmental Milestones

- 1) Act Early. Learn the Signs
www.cdc.gov/ActEarly
- 2) Staying on Track as Your Child Grows and Learns
<https://edn.ne.gov/cms/resources/staying-on-track-as-your-child-grows-and-learns>
- 3) Milestone Moments
https://www.cdc.gov/ncbddd/actearly/pdf/parents_pdfs/MilestoneMomentsEng508.pdf

Nebraska Early Intervention Services

- 1) Early Development Network Website
<http://edn.ne.gov>
- 2) What is Early Intervention?
<https://edn.ne.gov/cms/what-is-early-intervention>
- 3) A Family Guide to Early Intervention Services in Nebraska
<https://edn.ne.gov/cms/sites/default/files/u1/brochures/EDN-Family-Resource-Guide-April-2016.pdf>
- 4) Social Emotional Tips for Providers Caring for Infants
https://www.ecmhc.org/documents/CEMHC_Tips_Infants_Providers_2.pdf

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.

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. (See *FYI* for link to Nebraska Child Find.)

TIPS ALONG THE WAY

Prepare Your Child for Kindergarten

Once enrolled in kindergarten, you can make your child's transition easier by doing the following:

- Have your child visit the classroom and meet the teacher before the school year begins.
- Take pictures of the school and classroom and use the pictures to talk with your child about starting kindergarten.
- Arrange summer play times with other students who will be in your child's classroom.
- Read books with your child about kindergarten, such as:
 - "David Goes to School" by David Shannon
 - "Off to School, Baby Duck!" by Amy Hest
 - "Vera's First Day of School" by Vera Rosenberry
 - "Look Out Kindergarten, Here I Come" by Nancy Carlson.³

2.2 Special Education Multidisciplinary Evaluation

Student Assistance Team (SAT): Upon receiving a referral, the school district holds a Student Assistance Team meeting to assist the teacher in providing general education for the student. If the SAT is unable to develop a plan to properly educate the student, a multidisciplinary evaluation team (MDT) is utilized to determine if the student needs special education. Some school districts use a Multi-tiered 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.

³Adapted from: How to Prepare Your Child with Disabilities for Kindergarten: Tips for Parents
<http://www.pacer.org/parent/php/PHP-c179.pdf>

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

Note:

The MDT evaluation must be completed within 45 school days from the date that the school district receives the signed 'Consent to Test' form from the parent.

Parents are entitled to a copy of the Multidisciplinary Team report at no cost. If you disagree with the findings or recommendations, you may request an independent educational evaluation, which must be provided at no cost and considered by the student's Individualized Education Program (IEP) team. 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.

2.3 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. The IEP outlines, in writing, the educational program 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
- Regular education teacher (if the child is, or may be, participating in the regular education environment)
- District representative who is qualified to provide or supervise the provision of specially designed education

- Other participants, including any individuals who have knowledge or special expertise regarding the child, including related service personnel
- The child with a disability, when appropriate

IEP Content: The IEP must include the following:

- Present levels of academic achievement;
- Measurable annual goals;
- 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 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; and
- Anticipated location and duration of those services.

Related Services: A child who has been identified with a disability may require related services to meet their educational needs. These related services should be considered by the IEP team and included in the IEP, as appropriate. 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

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 convenient time.
- 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.

Note:

The IEP must be developed within 30 days of determining that the child 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.

TIPS ALONG THE WAY

Preparing for the IEP

- Remember that special education decisions are based on data rather than personal opinion. School records provide important information that is used when making decisions. You may ask for copies of any records you wish to review or keep.
- At a minimum, read the IEP and evaluation report before the IEP meeting.
- Be sure to review the meeting notice. Who is invited? What is the purpose of the meeting? Will the student attend all or part of the meeting? Does the student need any preparation for his or her participation?
- Make a list of your priorities and concerns before the meeting. You may want to share your list with the student's IEP case manager and ask that your items be included on the agenda.

TIPS ALONG THE WAY

Preparing for the IEP *continued*

- If you plan to discuss a problem at the IEP meeting, define the issue clearly in your own mind. Bring ideas for solutions and be willing to listen to the ideas of others. Avoid blame and focus on ways to solve the problem.
- Finally, keep in mind that teamwork creates better outcomes. You are the expert on your child, and the school has expertise in education. Together, you can help your child succeed in school.⁴

2.4 Section 504

Section 504 of the Rehabilitation Act of 1973 (commonly referred to as Section 504) is a federal law that applies to students who do not qualify for special education services under IDEA, but have needs related to a disability. Some students may not qualify for special education services, but will qualify for a 504 plan.

Section 504 Eligibility: To be eligible for Section 504, a student must have a disability that limits a major life function. This includes such things 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. Examples of students who may qualify for a 504 plan include a child with cancer who may exceed the usual number of allowable absences during a school year for health-related reasons or a child with attention deficit hyperactivity disorder (ADHD) who needs to be placed in a classroom with fewer distractions.

Section 504 Plan: 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 the provision of equipment, supports, or services to help them learn. Examples of accommodations include:

- Testing in a quiet room
- Preferential seating
- Digital textbooks
- Tailored homework assignments

⁴Attending Meetings to Plan Your Child's Individualized Education Program:
<http://www.pacer.org/parent/php/php-c27.pdf>

- Sign language interpreter for participation in activities in and out of the classroom

Note:

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

2.5. Parent/Family Participation

It is critical that the student, family members, and others important to the student's life are involved in the development of the IEP or 504 plan. As a parent, you know your child in a way no one else can and you have important information to share about their educational planning. Parents can take action to make changes when they are needed.

TIPS ALONG THE WAY

Get Involved to Help Your Child Succeed

All parents want their children to do well in school. One way to help children succeed is to be involved in their education. Try these tips!

Encourage

- Let your child know you believe education is important.
- Volunteer at your child's school, if possible.

Model

- Let your child see you learn.
- Stick with and complete your own difficult tasks.

Reinforce

- Praise your child for learning and working hard.
- Ask your child how school is every day. Talk about any positive examples or concerns.
- Work with your child on homework.
- Model life lessons, such as completing a tough job, learning from mistakes, and meeting requirements.

Celebrate your child's success

- Serve your child's favorite food for dinner.
- Let your child choose a special movie for the family to watch.
- Share your child's success with friends and family. Let your child hear you do this.
- Display schoolwork on the refrigerator or bulletin board at home.

When parents participate, children achieve. Students learn more, have higher grades, and have better school attendance.⁵

FYI: Chapter 2. Special Education for School-Aged Children

- 1) Nebraska Child Find
<http://childfind.ne.gov/content/referrals.html>
- 2) How to Prepare Your Child with Disabilities for Kindergarten:
Tips for Parents
<http://www.pacer.org/parent/php/PHP-c179.pdf>
- 3) Law in Brief: Individual Education Plan
http://www.disabilityrightsnebraska.org/resources/legal_resources.html
- 4) Section 504 of the Rehabilitation Act of 1973
<https://www.dol.gov/oasam/regs/statutes/sec504.htm>
- 5) Law in Brief: What is Section 504?
http://www.disabilityrightsnebraska.org/resources/legal_resources.html
- 6) School Accommodations and Modifications:
A Parent and Child Checklist
<http://www.pacer.org/parent/php/PHP-c49b.pdf>
- 7) Attending Meetings to Plan Your Child's Individualized
Education Program
<http://www.pacer.org/parent/php/php-c27.pdf>
- 8) How Can My Child Be Involved in the IEP Process?
<http://www.pacer.org/parent/php/PHP-c77.pdf>
- 9) Want to Help Your Child Succeed in School? Be Involved!
<http://www.pacer.org/pdf/ge/GE-2.pdf>

Nebraska Department of Education Rule 52, Regulations and Standards for the Provision of Early Intervention Services: Rule 52 refers to the specific regulations for determining eligibility and implementing Nebraska’s early intervention services.

Nebraska Department of Health and Human Services Title 480 of the Nebraska Administrative Code (NAC), Chapter 3: These state regulations and standards govern the implementation of Early Intervention Services Coordination.

3.2 Parental Rights in Early Intervention

Parents’ rights regarding Early Intervention services are protected under Rule 52 and 480 NAC, Chapter 3. This includes requirements that parents must:

- Have the right to apply and receive timely response per federal Medicaid provisions;
- Receive prior written notice before the infant or toddler is screened or evaluated for eligibility;
- Provide consent for screening, evaluation, and services for the infant or toddler;
- Be assured that information regarding the infant or toddler is kept confidential;
- Have the right to inspect and review any early intervention records related to the infant or toddler that are collected maintained or used by the services coordination agency and school district; and
- Have the right to complaints, hearings, mediation, and appeals.

3.3 Parental Rights in Special Education Services

Parents’ rights regarding Special Education services are protected under 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) for the student;
- Provide consent for initial evaluation, services, or reevaluations of the student including documentation of reasonable efforts to obtain your consent;
- Have the right to obtain an independent educational evaluation of the student if they 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; and
- Have the right to complaints, hearings, mediation, and appeals.

Note:

If you believe the school district has failed to implement a valid IEP for your student, has failed to follow special education law, or is discriminating against your student or a group of students, you may file a written, signed, complaint directly with the Nebraska Department of Education, Special Education Office.

The complaint should:

- State the relevant problems;
- Include relevant facts; and
- Include the child'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 3. Laws, Regulations, & Parental Rights

- 1) Individuals with Disabilities Education Act (IDEA)
<https://sites.ed.gov/idea/>
- 2) Nebraska Department of Education Rule 51, Regulations and Standards for Special Education Programs
<https://www.education.ne.gov/sped/regulationspolicies/>
- 3) Nebraska Department of Education Rule 52: Regulations and Standards for the Provision of Early Intervention Services
<https://www.education.ne.gov/nderule/provision-of-early-intervention/>
- 4) Nebraska Department of Health and Human Services Regulations and Standards for the Provision of Early Intervention Services Coordination
<https://edn.ne.gov/cms/edn-services-coordination-regulations-480-nac-3>
- 5) Know Your Parental Rights: The Meaning and Importance of Prior Written Notice and Parent Consent
<http://www.pacer.org/parent/php/php-c232.pdf>
- 6) Law in Brief: Filing a Complaint with the Nebraska Department of Education (Disability Rights Nebraska)
http://www.disabilityrightsnebraska.org/resources/legal_resources.html
- 7) Parents' Rights in Special Education
<https://cdn.education.ne.gov/wp-content/uploads/2018/07/Parent-Rights-for-Special-Education-3-21.pdf>
- 8) Parental Rights in Early Intervention
<http://edn.ne.gov/cms/parent-rights>



Note:

Important information regarding benefits:

- Before a parent retires or if death or disability occurs, it is vitally important to check with the Social Security Administration to determine how this change in status may impact the child's benefits. Because every situation is different, it is important to contact the Social Security Administration.
- Once a person turns 18, they will need to re-establish eligibility for Social Security benefits under the definition of disability for adults.

4.2 Department of Health & Human Services (DHHS) Assistance Programs

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. Children 18 years of age or younger may qualify, as well as dependent children who meet the eligibility requirements of the Aid to Dependent Children (ADC) program.

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.

4.3 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. 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 benefits services.

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

4.4 Financial Planning

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. In Nebraska, this is known as 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 the age of 26 and is entitled to Supplemental Security Income (SSI) or Supplemental Security Disability Income (SSDI). Or, the person 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 4. Benefits & Financial Planning

- 1) Nebraska Medicaid
http://dhhs.ne.gov/medicaid/Pages/med_medindex.aspx
- 2) Children's Health Insurance Program (CHIP)
http://dhhs.ne.gov/medicaid/Pages/med_CHIP.aspx
- 3) Disability Starter Kits
https://www.ssa.gov/disability/disability_starter_kits_child_factsheet.htm
- 4) Benefits for Children with Disabilities
<https://www.ssa.gov/pubs/EN-05-10026.pdf>
- 5) Benefits for People with Disabilities
<https://www.ssa.gov/disability/index.htm>
- 6) Nebraska Enable Savings Plan
www.enablesavings.com

Developmental Disabilities (DD) Services

The Nebraska Department of Health and Human Services 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 also 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 may be provided by agency providers or independent providers, or a combination of the two types.

Note:

The DD services a child can receive are limited because they cannot replace services available through the school system. 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. Application can be submitted as soon as a disability is diagnosed. For those determined eligible at a young age, their eligibility will be re-determined at ages 9 and 18.

To be eligible for DD services, 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."

A child from birth through the age of nine years who has a substantial developmental delay or specific congenital or acquired condition may be considered to have a developmental disability without meeting three or more of the major life activities described in #4 of the above section if the child, without services and support, has a high probability of meeting those criteria later in life.

DD Services Application: Application for DD services may be made online at ACCESSNebraska (see link in *FYI*). 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 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 within a few days 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 affect 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 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.

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 Registry. 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 on the "wait list."

DD Service Coordination: A Service Coordinator (SC) is available for all persons on the DD Registry. Medicaid pays for service coordination for those who are Medicaid eligible. If the person does not have Medicaid, he/she will be assessed an Ability to Pay if they wish to receive this service. When a person is actively receiving DD services, they are required to have an SC. The SC is expected to make contact monthly with or on behalf of the person and may help them access other benefits and services even before DD services begin.

Disabled Children's Program (DCP)

The Disabled Children's 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 Supplemental 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. Children 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
- Need for 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

Medically Handicapped Children's Program (MHCP)

MHCP provides specialized medical services for children and youth with special health care needs. 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
- Meet financial eligibility based on current regulations.

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. 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.

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

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

5.2 Additional Programs & Services

Assistive Technology Partnership (ATP)

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

- Electronic communication aids
- Computer software
- Voice recognition systems
- Touch-sensitive computer screens or tablets
- Switches or battery-operated devices

The Nebraska Assistive Technology Partnership 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

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.

Additionally, a loan pool of devices and equipment 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.)

Munroe-Meyer Institute for Genetics and Rehabilitation

Munroe-Meyer Institute provides interdisciplinary, family-centered services for persons with disabilities and complex healthcare needs across the lifespan at more than 40 provider locations across the state. 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

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. A child's eligibility for services is determined through the IEP process.

Nebraska Commission for the Deaf and Hard of Hearing

The Commission promotes and advocates for children and adults who are deaf, deaf-blind, or hard of hearing. They educate parents of deaf, deaf-blind, and hard of hearing children about opportunities available to their children. In addition, the Commission advocates with parents to assure equal access to quality education for children who are deaf, deaf-blind, and/or hard of hearing. Other services include hearing aid banks, a media center, assistive devices loan program, trainings and presentations, links to resources, and interpreter referrals.

FYI: Chapter 5. Services & Supports

- 1) DHHS Programs
http://dhhs.ne.gov/children_family_services/Pages/fia_fiaindex.aspx
- 2) ACCESSNebraska
<https://dhhs-access-neb-menu.ne.gov/start/%3Ft%3Den>
- 3) Aged & Disabled Waiver
http://dhhs.ne.gov/Pages/hcs_programs_ad-waiver.aspx
- 4) DD Services Eligibility
http://dhhs.ne.gov/developmental_disabilities/Documents/EligibilityDDServices.pdf
- 5) Disabled Children's Program
http://dhhs.ne.gov/Pages/hcs_programs_dcp.aspx
- 6) Katie Beckett Program
http://dhhs.ne.gov/Pages/hcs_programs_katie-beckett.aspx
- 7) Medically Handicapped Children's Program
http://dhhs.ne.gov/pages/hcs_programs_mhcp.aspx
- 8) Nebraska Lifespan Respite
<https://nrrs.ne.gov/respite/>
- 9) Nebraska Assistive Technology Partnership
<https://atp.nebraska.gov>
- 10) AT4All
<https://www.at4all.com>
- 11) Munroe-Meyer Institute for Genetics and Rehabilitation
<https://www.unmc.edu/mmi/>
- 12) Nebraska Center for Education of Children who are Blind or Visually Impaired
<http://www.ncecbvi.org>
- 13) Nebraska Commission for the Deaf and Hard of Hearing
<https://ncdhh.nebraska.gov>

Chapter 6.

Advocacy

You're not alone! Many organizations and people are available to help people with disabilities and their family members in advocating for their rights and getting 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. We will highlight here a few of the state organizations that serve as valuable resources in Nebraska. A full listing of organizations may be found in the *"Along the Way: Resources for Individuals with Intellectual and Developmental Disabilities"* publication that is a part of this series.

Aging & Disability Resource Center (ADRC) Nebraska

The ADRC provides information, referral, and assistance for accessing community services and long-term care options for persons with disabilities of all ages, family members, caregivers, and advocates. While the ADRC does not provide direct services, this can be an important link to services and supports.

Answers4Families

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

Arc of Nebraska

The Arc 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 waiting list. Local Arc chapters are located throughout the state.

Autism Family Network (AFN)

AFN promotes a positive, respectful image of children with autism and their families through social opportunities, recreational experiences, and community inclusion.

Autism Society of Nebraska

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.

Disability Rights Nebraska (DRN)

DRN 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 Child Find

Child Find provides information for parents, school personnel, and service providers on child development and special education for children from birth (or date of diagnosis) to age 21. Child Find also helps parents access information on rights and resources to help them advocate for an appropriate education for their child.

Parent Training and Information (PTI) Nebraska

PTI is a statewide resource for families of children with disabilities and special health care needs. PTI staff members are parent/professionals who are available to assist parents and professionals with special education questions and issues and provide 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.

TIPS ALONG THE WAY

Become an Effective Advocate!

Advocating for your child with a disability is an ongoing process. It requires being informed, calm, and direct. You can learn to disagree respectfully and say “no” without feeling guilty or embarrassed. It is up to you to advocate for what your child needs and make decisions that ensure the well being of your son or daughter.

To be a good advocate, it is important to:

- Be persistent and focused
- Express your feelings with “I” phrases instead of “you”, which implies ownership of your own feelings
- Stay up to date on your child’s condition by reading newsletters or researching appropriate sites online
- Attend workshops and informational meetings
- Talk to other parents who have similar concerns
- Focus on one goal at a time
- Be willing to make some compromises to get started

You will become more confident with each success, but be realistic about what to expect. Change happens slowly over time. Be a good listener and understand the perspectives of other team members as well.⁶

FYI: *Chapter 6. Advocacy*

- 1) Aging and Disability Resource Center
<http://dhhs.ne.gov/medicaid/Aging/Pages/ADRC.aspx>
- 2) Answers4Families
<http://www.answers4families.org/>
- 3) Arc of Nebraska
<https://www.thearc.org/find-a-chapter/nebraska>
- 4) Autism Family Network
<https://www.autismfamilynetwork.org>
- 5) Autism Society of Nebraska
<http://autismnebraska.org/>
- 6) Disability Rights Nebraska
<http://www.disabilityrightsnebraska.org/>
- 7) Nebraska Child Find
<http://www.childfind.ne.gov/>
- 8) PTI Nebraska
<http://pti-nebraska.org/about/>
- 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
<http://www.pacer.org/health/pdfs/HIAC-h26.pdf>
- 11) Family Resources
<https://edn.ne.gov/cms/resources/family>
- 12) Top Ten Topics: Parents Concerns & Resources (Centers for Disease Control & Prevention)
<http://www.pacer.org/parent/top10-parent-concerns.asp>

Appendix

Frequently Used Acronyms

| | |
|-----------|---|
| AAC | Augmentative and Alternative Communication |
| ABA | Applied Behavior Analysis |
| ABLE | Achieving a Better Life Experience Act (Enable in Nebraska) |
| ADC | Aid to Dependent Children |
| ADRC | Aging & Disability Resource Center |
| AD Waiver | Aged & Disabled Medicaid Waiver |
| AFN | Autism Family Network |
| ASD | Autism Spectrum Disorders |
| ATP | Assistive Technology Partnership |
| CHIP | Children's Health Insurance Program |
| CDB | Childhood Disability Benefit |
| DCP | Disabled Children's Program |
| DD | Developmental Disabilities |
| DHHS | Nebraska Department of Health & Human Services |
| DHHS-DD | DHHS-Division of Developmental Disabilities |
| DRN | Disability Rights Nebraska |
| EDN | 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 |
| IFSP | Individualized Family Service Plan |
| MDT | Multidisciplinary Team |
| MHCP | Medically Handicapped Children's Program |
| MTSS | Multi-tiered System of Supports |
| NDE | Nebraska Department of Education |
| RtI | Response to Intervention |
| SAT | Student Assistance Team |
| SC | Service Coordinator |
| SSA | Social Security Administration |
| PTI | Nebraska Parent Training & Information |
| SSDI | Social Security Disability Insurance |
| SSI | Supplemental Security Income |

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