

A Guide for Parents of Infants, Toddlers, and Children with Disabilities



### **INSIDE FRONT COVER**

This guide was developed by:



# FRITZ & O'HARE ASSOCIATES

Lloya Fritz and Mary O'Hare

lloyafritz@gmail.com

<u>maryohare7@gmail.com</u>

Funding for this publication was provided by: Nebraska Council on Developmental Disabilities Department of Health and Human Services 301 Centennial Mall South

> PO Box 95026 Lincoln, Nebraska 68509-5026 Phone: 402-471-2330 Email: <u>dhhs.ddcouncil@nebraska.gov</u>

To view or print copies of this guide, visit the Nebraska Council on Developmental Disabilities website at: <u>Nebraska Council on Developmental Disabilities</u>

# Credits

Special thanks to all who provided valuable input and guidance in the development of the *Along the Way* series. Contributors are too numerous to mention, but include representatives from Nebraska state agencies, advocacy organizations, family members, self-advocates, and service providers. We couldn't have done it without the assistance of these dedicated people. Most importantly, we wish to thank the Nebraska Council on Developmental Disabilities for providing the opportunity to develop this series.

# **Table of Contents**

Introduction	4
Chapter 1. Early Development - Infants & Toddlers	5
1.1 Developmental Milestones	
1.2 Early Intervention Services	5
Tips Along the Way - Early Childhood Professionals	8
1.3 Transition to Pre-School	10
Tips Along the Way - Effective Communication with Early Childhood	
Professionals	10
FYI: Chapter 1. Early Development - Infants & Toddlers	11
Chapter 2. Special Education for School-Aged Children	12
2.1 Special Education Eligibility	12
Tips Along the Way - Prepare Your Child for Kindergarten	13
2.2 Special Education Multidisciplinary Evaluation	13
2.3 Individualized Education Program (IEP)	14
Tips Along the Way - Preparing for the IEP	16
2.4 Section 504	17
2.5. Parent/Family Participation	18
Tips Along the Way - Get Involved to Help Your Child Succeed	18
FYI: Chapter 2. Special Education for School-Aged Children	19
Chapter 3. Laws, Regulations, & Parental Rights	20
3.1 Laws	20
3.2 Regulations	20
3.3 Parental Rights in Early Intervention	21
3.4 Parental Rights in Special Education Services	21
FYI: Chapter 3. Laws, Regulations, & Parental Rights	23
Chapter 4. Benefits & Financial Planning	24
4.1 Social Security Administration (SSA)	
4.2 Department of Health & Human Services (DHHS) Assistance Program	
4.3 Financial Planning	
FYI: Chapter 4. Benefits & Financial Planning	
Chapter 5. Services & Supports	27
5.1 Department of Health and Human Services (DHHS) Programs	
5.2 Additional Programs & Services	
FYI: Chapter 5. Services & Supports	
Chapter 6. Advocacy	36
Tips Along the Way - Become an Effective Advocate	
FYI: Chapter 6. Advocacy	
Annondia	
Appendix	
Frequently Used Acronyms	
Index	

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

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

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

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 the Index lists topics, terms, and agencies discussed in this guide. *Tips Along the Way* sections offer helpful suggestions.



# 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.

### **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.



In Nebraska, the statewide early intervention program is referred to Note: 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 they are not developing typically or has been diagnosed with a health condition that will affect their 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.

**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 their 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



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 receive 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 to12-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 familycentered, individualized manner



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.<sup>1</sup>

### **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.

**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 connect with other parents who share your concerns, you will be on the road to becoming an effective advocate for your child.<sup>2</sup>

# FYI: Chapter 1. Early Development - Infants & Toddlers

### **Developmental Milestones**

- 1) Act Early. Learn the Signs <u>"Learn the Signs. Act Early." | CDC</u>
- 2) Milestone Moments <u>MilestoneMomentsEng508.pdf (cdc.gov)</u>
- Staying on Track as Your Child Grows and Learns <u>Staying on Track as Your Child Grows and Learns | Nebraska</u> <u>Early Development Network</u>

### Nebraska Early Intervention Services

- 1) A Family Guide to Early Intervention Services in Nebraska EDN-Family-Resource-Guide-April-2016.pdf (ne.gov)
- 2) Early Development Network Website Home | Nebraska Early Development Network
- 3) Social Emotional Tips for Providers Caring for Infants <u>CEMHC Tips Infants</u> <u>Providers 2.pdf</u>
- 4) What is Early Intervention? <u>What is Early Intervention? | Nebraska Early Development</u> <u>Network</u>



# Special Education for School-Aged Children

All parents want their child to do well in school and to get the most out of the experience. Students with disabilities may need additional supports to be successful, and that's where special education comes in. Special education is specially designed instruction, at no cost to the family, to meet the unique needs of a student with a verified disability. This chapter will assist you in understanding special education and advocating for your child and family along the way.

### 2.1 Special Education Eligibility

Schools are required to provide a free appropriate public education (also referred to as FAPE) for all students with identified 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. 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
- Deaf or Hard of Hearing
- Developmental Delay (applicable for age three to the end of the school year when a child turns eight)
- Emotional Disturbance
- Intellectual Disability
- Multiple Disabilities
- Orthopedic Impairment
- Other Health Impairment
- Specific Learning Disability
- Speech-Language Impairment
- Traumatic Brain Injury
- Visual Impairment



For purposes of this guide, we are assuming your child has already Note: 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 physician, 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.

### **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 0
  - "Off to School, Baby Duck!" by Amy Hest 0
  - "Vera's First Day of School" by Vera Rosenberry 0
  - "Look Out Kindergarten, Here I Come" 0 by Nancy Carlson.<sup>3</sup>

### 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 (Rtl) process for the same purpose. A parent may request a multidisciplinary evaluation at any time during this process.

<sup>3</sup>Adapted from: How to Prepare Your Child with Disabilities for Kindergarten: Tips for Parents How to Prepare Your Child with Disabilities for Kindergarten: Tips for Parents (pacer.org)

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



The MDT evaluation must be completed within 45 school days from Note: 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;
- 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; 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. School districts are required to provide free related services. 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?
- 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.<sup>4</sup>

### 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 the Individuals with Disabilities Education Act (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

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

Note: F

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.<sup>5</sup>

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

- 1) The Arc @ School Special Education Advocacy thearcatschool.org
- 2) Attending Meetings to Plan Your Child's Individualized Education Program Attending meetings to plan your child's IEP (pacer.org)
- 3) How Can My Child Be Involved in the IEP Process? How Can My Child Be Involved in the IEP Process? (pacer.org)
- 4) How to Prepare Your Child with Disabilities for Kindergarten: Tips for Parents <u>How to Prepare Your Child with Disabilities for Kindergarten: Tips</u> <u>for Parents (pacer.org)</u>
- 5) Law in Brief: Individual Education Program DRNE | Legal Resources (disabilityrightsnebraska.org)
- 6) Law in Brief: What is Section 504? DRNE | Legal Resources (disabilityrightsnebraska.org)
- 7) Nebraska Child Find <u>Referrals - Nebraska ChildFind</u>
- Nebraska Department of Education/PTI Nebraska's Family Guide to Special Education in Nebraska: <u>Family Guide to Special Education – Nebraska Department of</u> <u>Education</u>
- 9) Section 504 of the Rehabilitation Act of 1973 Section 504, Rehabilitation Act of 1973 | U.S. Department of Labor (dol.gov)
- 10) School Accommodations and Modifications: A Parent and Child Checklist School Accommodation Ideas for Students who Receive Section 504 or Special Education Services (pacer.org)
- 11) Want to Help Your Child Succeed in School? Be Involved! <u>Parents with High Expectations: Want to Help Your Child Succeed in</u> <u>School? Be Involved! (pacer.org)</u>



# Laws, Regulations, & Parental Rights

As a parent of a student with a disability, you have certain rights guaranteed by federal and state laws. To be an effective advocate, you must know your rights and those of your student. An understanding of the laws is an important first step. Exercising these rights and fulfilling your responsibilities are important steps in supporting your student on their educational journey.

### **3.1 Laws**

Individuals with Disabilities Education Act (IDEA): The cornerstone for special education services lies within the Individuals with Disabilities Education Act. 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 state 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 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.

Special Education Act: The Special Education Act defines special education in Nebraska and requires that: "The board of education of every school district shall provide or contract for special education programs and transportation for all resident children with disabilities who would benefit from such programs."1

Early Intervention Act: The Early Intervention Act defines an Individualized Family Service Plan (IFSP) as: "The process, periodically documented in writing, of determining appropriate early intervention services for an eligible infant or toddler with disabilities and his or her family."<sup>2</sup> It also entitles infants and toddlers who are referred because of possible disabilities to early identification, evaluation, and assessment in order to determine eligibility under the Special Education Act, and procedural safeguards, and services coordination and development of the IFSP.<sup>3</sup>

### 3.2 Regulations

Nebraska Department of Education Rule 51, Regulations and Standards for Special Education Programs: Rule 51 addresses requirements specific to Nebraska educational services. This includes defining the process for

<sup>1</sup> Nebraska Revised State Statute 79-1127 2

Nebraska Revised State Statute 43-2305(6)

<sup>3</sup> Nebraska Revised State Statute 43-2507.01

determining a student's eligibility for special education, as well as spelling out requirements for meeting the educational needs of students with disabilities.

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.

### 3.3 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.

### 3.4 Parental Rights in Special Education Services

Parents' rights regarding Special Education services are protected under Rule 51, Section 009. 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 their 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.

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) Individuals with Disabilities Education Act (IDEA)	
<ol> <li>Know Your Parental Rights: The Meaning and Importa Written Notice and Parental Consent <u>Meaning and Importance of Prior Written Notice and</u> <u>Consent (pacer.org)</u></li> </ol>	
<ol> <li>Law in Brief: Filing a Complaint with the Nebraska D Education (Disability Rights Nebraska) <u>DRNE   Legal Resources (disabilityrightsnebraska.org</u></li> </ol>	•
<ol> <li>Nebraska Department of Education Rule 51, Regulati Standards for Special Education Programs <u>Regulations/Policies – Nebraska Department of Educ</u></li> </ol>	
5) Nebraska Department of Education Rule 52: Regulati Standards for the Provision of Early Intervention Ser <u>State Regulations   Nebraska Early Development Net</u>	vices
6) Nebraska Department of Health and Human Services and Standards for the Provision of Early Intervention Coordination <u>State Regulations   Nebraska Early Development Net</u>	Services
7) Parents' Rights in Special Education Parent-Rights-for-Special-Education-3-21.pdf (ne.gov	)
8) Parental Rights in Early Intervention Parent Rights   Nebraska Early Development Networ	<u>k</u>



# **Benefits & Financial Planning**

Children with disabilities often qualify for medical and income support through benefits programs, such as those provided under Medicaid and Social Security. These benefits can provide valuable support for children and families. Eligibility requirements can be complicated and families often need help navigating the system. In addition to benefits programs, a financial planning program specifically for people with disabilities may be of interest to you. This chapter offers a broad overview of key programs and information on where you can get help.

### 4.1 Social Security Administration (SSA)

The Federal Social Security Administration (SSA) offers options for assisting persons with disabilities. Supplemental Security Income (SSI) and the Social Security Disability Insurance (SSDI) benefit known as the Childhood Disability Benefit (CBD) are important resources 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.

SSA defines disability and eligibility for Social Security benefits based upon the following for children under the age of 18:

- A medically determinable physical or mental impairment or impairment(s) 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, they meet the same definition of "blind" as applies for adults.

The SSA considers the income and resources of family members living in the child's household. If your family income and resources are more than the amount allowed, SSA will deny the child's application for SSI payments.

To get the most out of Social Security benefits, it's important to be aware of such things as who can get benefits on their Social Security record and how to obtain and use Social Security information in planning 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.



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 to determine the impact.
- 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 Nebraska Department of Health & Human Services (DHHS) Assistance Programs

**Medicaid**: Medicaid is a public health insurance program for certain lowincome 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. Low income adults aged 19-64 may also qualify for Medicaid.

**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 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 they are blind or disabled before the age of 26 and 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) Benefits for Children with Disabilities <u>Benefits For Children With Disabilities (ssa.gov)</u>
- 2) Benefits for People with Disabilities Benefits for People with Disabilities (ssa.gov)
- Children's Health Insurance Program (CHIP) <u>Nebraska Children's Health Insurance Program (CHIP) | Benefits.</u> gov
- 4) Disability Starter Kits Child Disability Starter Kit Fact Sheet (ssa.gov)
- 5) Nebraska Medicaid <u>Medicaid Eligibility (ne.gov)</u>
- 6) Nebraska Enable Savings Plan Enable Savings Plans - Enable Savings
- 7) Social Security Administration Child Disability Benefits Application Apply For A Child (Under Age 18) | Disability Benefits | SSA



# **Services & Supports**

There are many services and supports that may assist children with disabilities and their families. Following is a brief description of some of those available in Nebraska.

### 5.1 Nebraska Department of Health and Human Services (DHHS) Programs

DHHS offers many programs that may be of benefit to you and your child. Due to the numerous programs and eligibility requirements, navigating DHHS can be extremely complex. To get you started, a brief description of certain DHHS programs is provided here. Further information about DHHS programs and how to apply is included in the *FYI* section.

### Aged and Disabled (AD) Medicaid Waiver

The Aged and Disabled Waiver is a Medicaid home and community-based services (HCBS) waiver, which offers an array of services to support people in their homes. Individuals of all ages may be eligible when they:

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

Aged and Disabled Level of Care is based on the level of care needed to live in a nursing facility. Persons who apply for the AD waiver are assessed to see if their needs are the same as those of people who live in a nursing facility. The assessment tool depends on the age of the participant. Nursing Facility Level of Care for children has criteria which may vary depending on the age of the child. It is documented in the Individualized Family Service Plan.

Some of the services provided include:

- Special equipment to make tasks easier to perform (assistive technology and supports)
- Home modifications to make it easier to get around
- Relief time for family caregivers (respite)
- Child care so the caregiver can maintain employment (extra child care for children with disabilities)

The AD waiver is one of several waiver programs in Nebraska. It is important to note that a person may only be on one Medicaid waiver at a time. For example, this means that a person cannot be on the AD waiver and a Developmental Disabilities (DD) waiver at the same time. However, since the AD waiver does not typically have a wait list, a person may be on the AD waiver while on the DD Registry (see next section for information on the DD wait list).

Aged and Disabled Waiver Application: Application for the AD waiver may be made to the Division of Developmental Disabilities (DDD) with a paper application at any DHHS office or by calling toll-free. The paper application may be used to apply for any or all of the HCBS waivers. Contact information is provided on the DDD website.

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

Aged and Disabled Service Coordination: A Service Coordinator is required for all persons on the AD waiver. The Service Coordinator is expected to make contact monthly with or on behalf of the person and may help them access other benefits and services. The Service Coordination provider is determined by the eligible person's age. Service Coordination for those birth to age three is provided by the Early Development Network and by DHHS local offices for those ages three through 17.

### **Developmental Disabilities (DD) Services**

The Nebraska Department of Health and Human Services Division of Developmental Disabilities (DDD) administers Medicaid home and community-based services (HCBS) waivers to help eligible people live, work, and access their community as independently as possible. The Comprehensive Developmental Disabilities Waiver is available for all ages. Medicaid DD waivers may be referred to as developmental disability (DD) services. DD services include 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.



The waiver services a child can receive (whether through the AD or Note:> DD waiver) are limited because they cannot replace services available through the school system. Services depend upon available funding.

**DD Service Eligibility:** Anyone who is potentially eligible for services through DDD 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. The online application includes consent to release information so that DDD can gather supporting documents. The DDD website has a document that walks through the online application with screenshots of every step. Or, you may request a paper application at any DHHS office or by calling toll-free. The paper application may be used to apply for any or all of the HCBS waivers. Contact information is provided on the DDD website and in the DD Services Eligibility brochure.

Once DDD 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 their 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 Multidisciplinary Team (MDT) reports
  - Most recent Individualized Education Program (IEP).

DDD has 90 days to decide on eligibility, but this decision is usually made within 14 days of receiving the application and all necessary supporting documents. 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 they may be eligible. One of these benefits is Medicaid, which is public health insurance. Medicaid provides a federal match to state funding, which allows DDD 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 services can appeal the decision. Instructions on how to appeal are sent with the written notice of decision. A person who is ineligible can reapply whenever new information becomes available.

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

**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, they 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
- Living at home with family.

The services available include:

- Respite care ("short break" for primary care givers)
- Mileage reimbursement for long distance or frequent medical trips
- Accessibility modifications

The Disabled Children's Program cannot duplicate services provided by other resources. In addition, supportive services for routine health care are not covered.

### 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 19 years old who have one or more of the following:

- A ventilator to breathe
- A tracheostomy
- A need for intravenous therapy involving central lines for daily fluids or nutrition
- A need for frequent and complex medical care that requires use of equipment to prevent life-threatening situations

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. 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 DDD. The person must live with an unpaid caregiver in a non-institutional setting and meet financial eligibility requirements. Special needs include, but are not limited to:

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

32

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. Families who think their child could benefit from assistive technology should speak with their IFSP/IEP team.

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.

### Munroe-Meyer Institute (MMI)

Munroe-Meyer Institute (MMI) provides interdisciplinary, family-centered services for persons with disabilities and complex healthcare needs across the lifespan at more than 40 provider locations across the state. Munroe-Meyer also provides leadership training for persons with disabilities, family members, and other stakeholders, as well as working in the areas of policy and advocacy related to disability-focused concerns.

The types 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 and individual resources, including family navigation
- 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 (NCECBVI)

The Center serves children from infancy to age 21. NCECBVI offers the expertise and specialized skills of their staff for students who are blind, visually impaired, and have multiple disabilites 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 IFSP/IEP process.
#### Nebraska Commission for the Deaf and Hard of Hearing (NCDHH)

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 and resources available to their children. In addition, NCDHH 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, and links to resources.

### FYI: Chapter 5. Services & Supports

- 1) ACCESSNebraska ACCESSNebraska
- 2) Aged & Disabled Waiver <u>Eligibility for Medicaid HCBS Waiver Services (ne.gov)</u>
- 3) AT4AII <u>AT4AII</u>
- 4) DHHS Programs <u>Department of Health and Human Services (ne.gov)</u>
- 5) Developmental Disabilities (DD) Services Eligibility Eligibility for DD Services (ne.gov)
- 6) Disabled Children's Program (DCP) Disabled Children's Program (ne.gov)
- 7) Katie Beckett Program <u>Home and Community-Based Services (ne.gov)</u>
- 8) Medically Handicapped Children's Program (MHCP) <u>Medically Handicapped Children's Program (ne.gov)</u>
- 9) Munroe-Meyer Institute Home | Munroe-Meyer Institute (unmc.edu)
- 10) Nebraska Assistive Technology Partnership <u>Welcome | Assistive Technology Partnership (nebraska.gov)</u>
- 11) Nebraska Center for Education of Children who are Blind or Visually Impaired <u>NCECBVI: Nebraska Center for the Education of Children who are</u> <u>Blind or Visually Impaired</u>
- 12)Nebraska Commission for the Deaf and Hard of Hearing Welcome | Deaf and Hard of Hearing (nebraska.gov)
- 13)Nebraska Lifespan Respite Home | Nebraska Lifespan Respite Network



### Advocacy

You're not alone! Many organizations and advocates 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. Additionally, 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 is a support and information connection for families and professionals seeking assistance. Answers4Families provides information, opportunities for dialogue, education, and support to Nebraskans with disabilities, 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 waiting lists. Local Arc chapters are located throughout the state and provide a variety of programs and services specific to their area.

#### **Autism Family Network (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. PTI focuses on providing training, information, and referrals through a variety of services, including one-on-one support and assistance, small and large group workshops, publications, and websites.



You may also find it necessary to connect with state and local officials Note: 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 child.

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.<sup>6</sup>

#### FYI: Chapter 6. Advocacy

- 1) Aging and Disability Resource Center Aging and Disability Resource Center (ne.gov)
- 2) Answers4Families Answers4Families home page
- 3) Arc of Nebraska <u>Chapters - The Arc of Nebraska (arc-nebraska.org)</u>
- 4) Autism Family Network Autism Family Network - AFN
- Autism Society of Nebraska
  <u>Home Autism Society (autismnebraska.org)</u>
- 6) Disability Rights Nebraska Disability Rights Nebraska | Reform | Lincoln
- 7) Family Resources Family Resources | Nebraska Early Development Network
- 8) How to Advocate for Your Child with Special Health Care Needs How to Advocate for Your Child With Special Health Care Needs (pacer.org)
- 9) Nebraska Child Find <u>Nebraska ChildFind</u>
- 10) PTI Nebraska <u>About PTI Nebraska (Parent, Training and Information) | PTI</u> <u>Nebraska (pti-nebraska.org)</u>
- 11) Tips for Working with Doctors <u>Tips for Working with Doctors (pacer.org)</u>
- 12) Top 10 Topics: Parents Concerns & Resources (Centers for Disease Control & Prevention) <u>Top 10 Topics: Parents Concerns and Matching Resources - PACER</u> <u>Center</u>





# 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
DDD	Division of Developmental Disabilities
DHHS	Nebraska Department of Health & Human Services
DRN	Disability Rights Nebraska
EDN	Early Development Network
ESU	Educational Service Unit
FAPE	Free Appropriate Public Education
FYI	For Your Information
HCBS	Home & Community-based Services
I/DD	Intellectual and Developmental Disabilities
IDEA	Individuals with Disabilities Education Act
IEP	Individualized Education Program
IFSP	Individualized Family Service Plan
MDT	MultidisciplinaryTeam
MHCP	Medically Handicapped Children's Program
MTSS	Multi-tiered System of Supports
NDE	Nebraska Department of Education
PTI	Nebraska Parent Training & Information
Rtl	Response to Intervention
SAT	Student Assistance Team
SC	Service Coordinator
SSA	Social Security Administration
SSDI	Social Security Disability Insurance
SSI	Supplemental Security Income

### Index

### Α

ABLE Savings Plan, 25, 26 ACCESSNebraska, 29, 35 Advocacy, 36 Aged & Disabled (AD) Waiver, 27, 35 Answers4Families, 36, 39 Arc of Nebraska, 36, 29 Assistive Technology Partnership (ATP), 33, 35 Autism Family Network (AFN), 36, 39 Autism Society of Nebraska, 37, 39

### В

Become an Effective Advocate!, 38 Benefits & Financial Planning, 24

### С

Children's Health Insurance Program (CHIP), 25, 26

### D

Department of Health & Human Services (DHHS) Assistance Programs, 25, 26 Developmental Disability (DD) Services, 28, 35 Developmental Milestones, 5, 11 Disability Rights Nebraska (DRN), 37, 39 Disabled Children's Program (DCP), 31, 35

### Е

Early Childhood Professionals, 8 Early Development Network (EDN), 5, 11 Early Intervention Act, 20 Early Intervention Services, 5, 11 Effective Communication with Early Childhood Professionals, 10 Enable Savings Plan, 25, 26

## F

Free Appropriate Public Education (FAPE), 12 Financial Planning, 25 FYI Chapter 1. Early Development-Infant & Toddlers, 11 FYI Chapter 2. Special Education for School-Aged Children, 19 FYI Chapter 3. Laws, Regulations, & Parental Rights, 23 FYI Chapter 4. Benefits & Financial Planning, 26 FYI Chapter 5. Services & Supports, 35 FYI Chapter 6. Advocacy, 38

### G

Get Involved to Help Your Child Succeed, 18

### 

Individualized Education (IEP) Program, 14, 19 Individualized Family Service Plan (IFSP), 7 Individuals with Disabilities Education Act (IDEA) 20, 23

### К

Katie Beckett, 31, 35

### L

Laws, 20, 23 Lifespan Respite, 32, 35

### Μ

Medicaid, 25, 26 Medically Handicapped Children's Program (MHCP), 32, 35 Munroe-Meyer Institute (MMI), 33, 35

#### Ν

Nebraska Center for Education of Children who are Blind or Visually Impaired, 34, 35 Nebraska Child Find, 13, 19, 37, 39 Nebraska Commission for Deaf & Hard of Hearing, 35 Nebraska Department of Education, 5, 11, 20, 21, 23 Nebraska Department of Health & Human Services (DHHS), 21, 27, 35

### Ρ

ParentTraining & Information (PTI) Nebraska, 37, 39 Parental Rights in Early Intervention, 21, 23 Parental Rights in Special Education Services, 21, 23 Prepare Your Child for Kindergarten, 13 Preparing for the IEP, 16

### R

Regulations, 20, 23 Related Services, 15 Rule 51 Regulations & Standards for Special Education Programs, 20, 23

Rule 52 Regulations & Standards for the Provision of Early Intervention Services, 21, 23

### S

Section 504 of the Rehabilitation Act of 1973 (Section 504), 17, 19 Special Education, 12, 19 Special Education Act, 20 Special Education Eligibility, 12 Special Education Multidisciplinary Evaluation, 13 Social Security Administration, 24, 26

### Т

Title 480 Early Intervention Services Coordination, 21, 23 Transition to Pre-School, 10

### **INSIDE BACK COVER**

