

2010

State and Local Resources for Care Coordinators within the Medical Home for Children with Special Health Care Needs

Module 5 in a series of 5



North Dakota Center for Persons with Disabilities
Minot State University

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State and Local Resources for Care Coordinators within the Medical Home for Children with Special Health Care Needs

This training manual was developed by the North Dakota Center for Persons with Disabilities at Minot State University to be used by providers of coordinated medical care services for children and youth with developmental disabilities and special healthcare needs. Requests for use of this publication for any other purpose should be submitted to Minot State University, NDCPD, Attn: Executive Management, 500 University Avenue West, Minot, ND 58707.

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INTRODUCTION

State and Local Resources is the second module in a series of eight modules. Thank you to the Medical Home Grant Project for funding this curriculum. In addition, thank you to North Dakota Department of Health-Children's Special Health Services, Early Childhood Comprehensive System Program, North Dakota Department of Human Services-Medical Services Division and Family Voices of North Dakota. A special thanks to Kora Dockter, Program Director for her assistance with organizing and developing this module.



MODULE OBJECTIVES

1. Participant will be able to describe the role of the Department of Health as it relates to CYSHCN/DD within the Medical Home setting.
2. Participant will be able to identify programs and services within the Department of Health relevant to care coordination for CYSHCN/DD within the Medical Home setting.
3. Participant will be able to articulate terms specific to state and local resources for CYSHCN/DD within the Medical Home setting.
4. Participant will be able to identify programs and services within the Department of Human Services relevant to care coordination for CYSHCN/DD within the Medical Home setting.
5. Participant will be able to verbalize community resources relevant to CYSHCN/DD.
6. Participant will be able to recognize age specific state and local resources that would be beneficial for CYSHCN/DD.
7. Participant will be able to understand the importance of advocacy for CYSHCN/DD

STATE AND LOCAL RESOURCES OVERVIEW

State and local resources for CYSHCN/DD can be complicated and confusing. Families that have children or youth with special health care needs or developmental disabilities (CYSHCN/DD) spend many hours providing direct patient care. In addition to direct patient care, the duties of care coordination can be very time consuming and lead to a dead end. The question of “who do I ask?” or “who can help me?” can be made easier if the child is part of a Medical Home. In North Dakota, families rely on the care coordinators or clinic staff for assistance, guidance and support for problem solving. The purpose of this Module **State and Local Resources** is to teach care coordinators ways to assist families with navigating the system which will help families and patients in meeting their care outcomes. Before we learn about what resources are available, getting organized is a key.

LET’S GET ORGANIZED

Below is a list of things to help you get organized.

1. Keep a, log, journal, communication notebook or electronic medical record updated with pertinent information on the patient. Make sure that medication changes, treatment changes and follow up visit information is current. The family should also be encouraged to have a record keeping system with accurate medical information. For examples, refer to www.fvnd.org
2. Develop a communication plan for the days that the care coordinator is not in the clinic so if a family calls, the fill in person knows what is happening with the patient.
3. Familiarize yourself with the basic differences of some of the state and local resources such as the Department of Health (DoH) which is where Children’s Special Health Services located and Department of Human Services which is the division for Medicaid and county social services offices. The details about programs and such can be found by going to www.nd.gov and selecting from the alphabetical list found in the lower left hand corner.
4. Know your area and region. Urban and rural settings can have different resources available because of population and funding. Keep in mind that advocacy groups, churches, United Way and other parent groups focus on improving the well-being of families and could assist with meeting the needs of families.
5. Know the system you work in and how best to collaborate and communicate with other community organizations. The benefit of knowing how your organization works as well as the other community organizations is that you will be more able to “make things happen.”
6. Think outside the box. Consider non-profit organizations, church groups, civic groups or other volunteer organizations. Taking a few quick minutes to look in the yellow pages of the phone book, ask a co-worker or Google a specific topic may be very beneficial. For example, some non-



profits have funds to assist with expenses such as transportation, glasses, food etc. and the eligibility criteria is more flexible. Churches and other religious entities may also have a small budget to assist with unmet needs.

7. Continue to be the change agent and advocate for your patient and family. Be persistent.

Now that we have a system for organization, we are ready to begin working with patients and families. How a child with special health care needs gets connected with programs and services varies throughout the state. Clinics and hospitals have their own formats and methods for referring to different agencies. The first encounter the health care professional has with child is often times during the screening process or suspicion of a potential healthcare concern. Once a diagnosis is confirmed the needs of the patient and family maybe clearer. It's important for the care coordinator to have a system or standardized method for referring patients or at least asking about the potential needs. The following list of questions would be beneficial in determining what resources to refer the patient and family to.

IMPORTANT QUESTIONS TO ASK

1. What do you know about your infant/child's diagnosis?
2. Do you have Health Insurance or have you applied for Medicaid?
3. Do you know who to contact and how to apply for Medicaid?
4. Do you have a social worker, care coordinator or parent partner
5. Do you know how to contact Family Voices of North Dakota and what role they could play in the management of your child's health condition?
6. Who can provide child care if parents are working? Respite care, Day care etc.
7. Does your child qualify for a waiver and why would a waiver be beneficial?
8. What is Children's Special Health Services (CSHS)? How do you contact them and what can they do?
9. What is Early Intervention and Infant Development?
10. What is an IEP (Individual Education Plan)?
11. What is a transition IEP?
12. What concerns you as a parent the most?

DEFINITION OF TERMS UNDER INDIVIDUALS WITH DISABILITIES EDUCATION ACT

Retrieved from www.wrightslaw.com

There are 14 specific primary terms included in IDEA under the lead definition of child with a disability. These federal terms and definitions guide how States define disability and who is eligible for a

free appropriate public education under special education law. The definitions of these specific terms from the IDEA regulations are shown beneath each term listed below. Note, in order to fully meet the definition and eligibility for special education and related services as a "child with a disability," a child's educational performance *must be adversely affected* due to the disability.

1. **Autism** means a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age 3 that adversely affects a child's educational performance. Other characteristics often associated with autism are engaging in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences. The term *autism* does not apply if the child's educational performance is adversely affected primarily because the child has an emotional disturbance, as defined in #5 below. A child who shows the characteristics of autism after age 3 could be diagnosed as having autism if the criteria above are satisfied.
2. **Deaf-Blindness** means concomitant hearing and visual impairments, the combination of which causes such severe communication and other developmental and educational needs that they cannot be accommodated in special education programs solely for children with deafness or children with blindness.
3. **Deafness** means a hearing impairment so severe that a child is impaired in processing linguistic information through hearing with or without amplification that adversely affects a child's educational performance.
4. **Developmental Delay** for children from birth to age three under IDEA Part C and children from ages three through nine under IDEA Part B. The term developmental delay as defined by each state means a delay in one or more of the following areas: physical development; cognitive development, communication, social or emotional development or behavioral development.
5. **Emotional Disturbance** means a condition exhibiting one or more of the following characteristics over a long period of time and to a marked degree that adversely affects a child's educational performance: (a) An inability to learn that cannot be explained by intellectual, sensory, or health factors. (b) An inability to build or maintain satisfactory interpersonal relationships with peers and teachers. (c) Inappropriate types of behavior or feelings under normal circumstances. (d) A general pervasive mood of unhappiness or depression. (e) A tendency to develop physical symptoms or fears associated with personal or school problems. The term includes schizophrenia. The term does not apply to children who are socially maladjusted, unless it is determined that they have an emotional disturbance.
6. **Hearing Impairment** means impairment in hearing, permanent or fluctuating, that adversely affects a child's educational performance but is not included under the definition of deafness.
7. **Mental Retardation** means significantly sub average general intellectual functioning, existing concurrently at the same time with deficits in adaptive behavior and manifested during the developmental period that adversely affects a child's educational performance.

One in five households has a child with a special health care need!

8. **Multiple Disabilities** means concomitant simultaneous impairments (such as mental retardation-blindness, mental retardation-orthopedic impairment, etc.), the combination of which causes such severe educational needs that they cannot be accommodated in a special education program solely for one of the impairments. The term does not include deaf-blindness.
9. **Orthopedic Impairment** means a severe orthopedic impairment that adversely affects a child's educational performance. The term includes impairments caused by a congenital anomaly, impairments caused by disease (e.g., poliomyelitis, bone tuberculosis), and impairments from other causes (e.g., cerebral amputations, and fractures or burns that cause contractures).
10. **Other Health Impairment** means having limited strength, vitality, or alertness, including a heightened alertness to environmental stimuli, that results in limited alertness with respect to the educational environment, that— (a) is due to chronic or acute health problems such as asthma, attention deficit disorder or attention deficit hyperactivity disorder, diabetes, epilepsy, a heart condition, hemophilia, lead poisoning, leukemia, nephritis, rheumatic fever, sickle cell anemia, and Tourette syndrome; and (b) adversely affects a child's educational performance.
11. **Specific Learning Disability** means a disorder in one or more of the basic psychological processes involved in understanding or in using language, spoken or written, that may manifest itself in the imperfect ability to listen, think, speak, read, write, spell, or to do mathematical calculations. The term includes such conditions as perceptual disabilities, brain injury, minimal brain dysfunction, dyslexia, and developmental aphasia. The term does not include learning problems that are primarily the result of visual, hearing, or motor disabilities; of mental retardation; of emotional disturbance; or of environmental, cultural, or economic disadvantage.
12. **Speech or Language Impairment** means a communication disorder such as stuttering, impaired articulation, language impairment, or a voice impairment that adversely affects a child's educational performance.
13. **Traumatic Brain Injury** means an acquired injury to the brain caused by an external physical force, resulting in total or partial functional disability or psychosocial impairment, or both, that adversely affects a child's educational performance. The term applies to open or closed head injuries resulting in impairments in one or more areas, such as cognition; language; memory; attention; reasoning; abstract thinking; judgment; problem-solving; sensory, perceptual, and motor abilities; psychosocial behavior; physical functions; information processing; and speech.
14. **Visual Impairment Including Blindness** means impairment in vision that, even with correction, adversely affects a child's educational performance. The term includes both partial sight and blindness.

“Many families provide complicated health care for their children at home and need more support than they receive now. The impacts of a child with special health care needs on a parent's job, finances and time must be recognized and public policies must address these impacts. Children and youth with health conditions that are unstable and severe, have needs that are not well met by the present approaches of health plans, programs, and community agencies.”

According to a statistic noted on the Family Voices of ND website, 70% of all bankruptcies are a result of medical expenses.

EARLY INTERVENTION

Early Intervention (EI) or IDEA Part C is developmental services provided to children between birth and age 3 who have, or in states with broad eligibility are at risk of, developmental delay. State Early Intervention programs can receive federal education funds to subsidize these services. The care coordinator, MD or social worker can make the referral.

- 1. What if my child does not meet the developmental milestones?** Only when a baby or preschooler lags far behind, or fails altogether to reach the developmental milestones, or loses a previously acquired skill, is there reason to suspect a mental or physical problem serious enough to be considered a developmental disability (www.healthychildren.org)
- 2. Who can help me?** Many resources are available for parents with CYSHCN/DD. Beginning with your care coordinator within the medical home setting is a great start. The care coordinator is able to work collaboratively with the multidisciplinary team. The multidisciplinary team can include patient, family, health care providers, daycare, educators or other individuals that help provide care to the patient. Keep in mind that care coordination within the Medical Home setting is family focused. The family should be included in all decision making to assure that the recommendations are something the family can implement.
- 3. How can I find childcare?** Child care can be a challenge for many families. The local social service office may have a listing of certified day providers, asking friends and family for referrals of individuals they know and trust. Once you find childcare, Temporary Assistance to Needy Families (TANF) provides cash assistance, pays for child care, conducts assessments for referrals to other providers for additional services and provides employment or training services and assists with vocational and secondary education.

Right Track is a free program for children birth through age 2 that provides developmental screenings, ideas for stimulating your child's development, information and referrals to locate state and national organizations.

DEPARTMENT OF HEALTH

The mission of the North Dakota Department of Health is to protect and enhance the health and safety of all North Dakotans and the environment in which we live. To accomplish the mission, the North Dakota Department of Health is committed to improving the health status of the people of North Dakota, improving access to and delivery of quality health care, preserving and improving the quality of the environment, promoting a state of emergency readiness and response, and achieving strategic outcomes within available resources. Retrieved from [http://www.ndhealth.gov/DoH/Overview/#Department Overview](http://www.ndhealth.gov/DoH/Overview/#Department%20Overview)

The Division of Children's Special Health Services (CSHS) within the North Dakota Department of Health provides services for children with special healthcare needs and their families and promotes family-centered, community-based, coordinated services and systems of health care. Programs and services within the division include:

- **Specialty Care Diagnostic and Treatment Program** – CSHS helps families pay for medical services for eligible children, including health-care visits and tests to diagnose chronic health conditions early and specialty care needed for treatment.
- **Multidisciplinary Clinics** – CSHS funds and administers clinics that support coordinated management of 10 different types of chronic health conditions. Clinics provide access to pediatric specialty care and enable families to see many different medical providers and health-care professionals in one place at one time.
- **Care Coordination** – CSHS supports community-based programs to help families who have children with special health-care needs access services and resources. Partners include county social services and local public health.
- **Metabolic Food** – CSHS provides medical food and low-protein modified food products to individuals with phenylketonuria and maple syrup urine disease.
- **Russell-Silver Syndrome Program** – CSHS pays for growth hormone treatment and medical food for individuals with Russell-Silver syndrome.
- **Information Resource Center** – CSHS provides health-care resource information to families and service providers.
- **Data Systems** – CSHS provides data about the population of children with special health-care needs and their families through the State Systems Development Initiative.
- **Children with Special Health Care Needs Service System** – CSHS supports initiatives that lead to a community-based system of services for all children, youth and families with special health-care needs.



The Office for the Elimination of Health Disparities is this part of the Department of Health. The department works to address inequalities in health status, utilization or access due to structural, financial, personal or cultural barriers. Population categories affected include, but are not limited to, those identified by gender, gender identity, age, race or ethnicity, education or income, disability, geographic location, or sexual orientation. The office's goals are the following:

- To improve statewide and territory-wide planning, coordination, collaboration and linkages among public and private entities that address minority health and health disparities.
- To improve coordination and collaboration among state and territorial public health offices that benefits minority health and contribute to eliminating health disparities.
- To support planning and coordination, to promote and implement evidence-based approaches and programs that address priority minority health problems(s); to monitor and evaluate state

and territorial efforts; and to disseminate information focused on improving minority health and eliminating health disparities.

- To establish or enhance multicultural partnerships to build efforts within communities to collaboratively address health issues that affect minority communities.

Cancer Prevention and Control is to improve the quality life for North Dakota citizens by reducing illness and death from cancer. Programs and services included are Comprehensive Cancer Control, Women’s Way and Cancer Registry.

Chronic Disease works to improve the health and quality of life for behaviors, North Dakotans who have chronic diseases by promoting healthy behaviors, supporting health-care improvement measures, developing community policies and practices, and increasing disease risk awareness. Programs within the division are Behavioral Risk Factor Surveillance System, Healthy People 2010, Heart Disease and Stroke Prevention and State Asthma Work Group.

Family Health administers state and federal programs designed to improve the health of North Dakota Families. Programs and supervises provided by these divisions that are very beneficial resources for CYSHCN/DD include:

- **Coordinated School Health Program** provides consultation and technical assistances for schools and school nurses to use in organizing and managing school health and wellness initiatives.
- **Cribs for Kids Program** provides infant safe portable cribs for women enrolled in the OPOP program.
- **Coordinated Early Childhood Comprehensive Systems (ECCS) Program** supports collaboration and partnerships that support families and communities in their development of children who are healthy and ready to learn at school entry.
- **Donated Dental Services** provides grant oversight to services that provide essential dental care for disabled, elderly and medically compromised individuals who cannot afford dental care.
- **Family Planning Program** provides reproductive health care services to in need and low income men and women.
- **Fetal Alcohol Syndrome Program** provides grant oversight to UND’s Fetal Alcohol Syndrome Center for program activities.
- **Newborn Screening Program** identifies infants at risk and in need of more definitive testing to diagnose and treat affected newborns.

**ND Department of Human Services
Mission Statement:**

The mission statement is “to provide quality, efficient, and effective human services which improves the lives of people” (www.nd.gov/dhs). The services are provided as close to home as possible and is geared to enhance the quality of life which may be threatened by the lack of financial resources, emotional crises, disabling conditions, or an inability to protect themselves.

- **Optimal Pregnancy Outcome Program (OPOP)** provides nursing, social and nutritional services to pregnant women.
- **Oral Health Program** provides prevention education, screening and consultation and administers school fluoride programs.
- **Ronald McDonald Care Mobile** provides grant oversight to plan a mobile dental care services to provide dental treatment, prevention and education services to low income and underserved children in the state with limited or unavailable dental services.
- **Sudden Infant Death Syndrome Program (SIDS)** provides support, education and follow up to those affected by a sudden infant death.
- **Title V Maternal and Child Health** provides consultation, technical assistance and comprehensive services to improve the health, safety and well-being of mothers and children.
- **Women's Health Services** collaborates with programs, both public and private that advocate for women's health.
- **Injury Prevention and Control** is dedicated to reducing the frequency and severity of intentional and unintentional injuries to North Dakota preventing injuries to our state.

Programs within the division include:

- **Child Passenger Safety Program** promotes child passenger safety activities through educational campaigns, car seat distribution programs, car safety seat checkups.
- **Injury/Violence Prevention Programs** promotes the reduction of intentional and unintentional injuries.
- **Domestic Violence/Rape Crisis and Suicide Prevention** supports programs to develop effective law enforcement and prosecution strategies to combat domestic violence, sexual assault, dating violence and stalking crimes.
- **Suicide Prevention** is an early intervention program that works collaboratively with the North Dakota Suicides Prevention Coalition to reduce the number of attempted and completed suicides.
- **Nutrition and Physical Activity** promotes healthy eating and physical activity in order to prevent chronic disease. Programs within the division include:
 - **Maternal and Child Health Nutrition** provides consultation and technical assistance; monitors nutrition data; plans and evaluates nutrition programs; coordinates nutrition-related activities; and acts as a clearinghouse for nutrition information and training.
 - **Special Supplemental Nutrition Program for Women, Infants and Children (WIC)** provides healthy food for proper growth and development, education about choosing healthier ways of eating and referrals to other needed services. WIC serves eligible pregnant, breastfeeding and postpartum women; infants; and children younger than 5 and is available in all counties in North Dakota.
 - **Healthy Weight/Healthy Communities** assists partners in schools, worksites and other community settings build and support environments everything in the sentence before

here is not reading right for me. It could just be me. That makes it easier for North Dakota residents to choose healthy foods and be physically active. The coordinator acts as a resource for many Department of Health programs and provides training, technical assistance and funding with the goal of achieving healthier communities.

- **Diabetes Prevention and Control** supports diabetes prevention, early diagnosis and disease management by working with communities, health professionals and health systems in the areas of policy, disease management, quality improvement and education. Collaborates with other disease programs and statewide partners to develop and coordinate joint efforts.
- **Emergency Medical Services and Trauma** is the lead agency for North Dakota's Emergency Medical Services (EMS) system. The EMS system consists of ambulance services that provide medical care and transportation, quick response units that provide treatment to patients until ambulances arrive, rescue services that extricate people who are entrapped, and hospitals that provide emergency and trauma services.

COUNTY SOCIAL SERVICES OFFICES

These offices are the first point of contact for families who need economic assistance, child welfare services, supportive services for elderly and disabled individuals, children's special health services, or help locating other local resources and programs. County Social Service Offices provide: Food Stamps, Temporary Assistance for Needy Families (TANF), heating assistance, Medicaid, children's health services, basic care assistance, child care assistance, home and community-based services and supports for elderly and disabled individuals, personal care assistance, child welfare (foster care, child protection services, child care licensing, and related services), and referrals to other local resources and programs.

Do you know a child or teen without health coverage?

ND has 3 low-cost and free health coverage programs:

- Medicaid
- Healthy Steps
- Care for Children

Call Toll Free:

1-877-KIDS NOW or
1-877-543-7669

DEVELOPMENTAL CENTER (NDDC)

The Developmental Center is a state-operated, comprehensive support agency for people with mental retardation/developmental disabilities. Located in Grafton, N.D., the center currently serves about 150 people providing specialized services and acting as a safety net for people whose needs exceed community resources.

REGIONAL CHILD SUPPORT ENFORCEMENT UNITS

The Regional Child Support Enforcement Units provide services if they receive a referral from public assistance programs (TANF, etc.) or if custodial or non-custodial parents request services. Services may include: paternity establishment, establishment and enforcement of child support and medical support orders, review and adjustment of court orders, locating a parent, and customer service.

REGIONAL HUMAN SERVICE CENTERS

The Regional Human Service Centers provide help to individuals and families with concerns including family and relationship issues, mental illness, addiction, disabilities, and other needs. Centers are located in Bismarck, Devils Lake, Dickinson, Fargo, Grand Forks, Jamestown, Minot, and Williston.

STATE HOSPITAL

The ND State Hospital is located in Jamestown and provides specialized psychiatric and substance abuse services for individuals whose needs exceed the resources and capacity of other community services.

DEPARTMENT OF PUBLIC INSTRUCTION

The Department of Public Instruction is the state body that supervises the services that support unique educational needs. Educational services within the state of North Dakota are: North Dakota Department of Public Instruction-ND DPI is responsible for administration of the USDA Child Nutrition and Food Distribution program, nutrition education and training programs, as well as commodity assistance for schools, institutions and low-income individuals:

- **Title 1** provides extra help and instruction to students who need it most. These children are identified as at risk of meeting the state's performance standards. Title 1

Having a learning problem doesn't by itself qualify a student for special education services. It's the gap between the student's current school performance and the student's academic potential and intellectual potential. If a significant discrepancy is noted between the two areas, which services would be needed? The purpose of the **No Child Left Behind Act** is "to ensure that all children have a fair, equal, and significant opportunity to obtain a high quality education and reach, at a minimum, proficiency on challenging state academic achievement standards and state academic assessments" (www.wrightslaw.org).

HIPPA: Health Insurance Portability and Accountability Act.
FERPA: Family Educational Rights and Privacy Act.

resources are directed to schools with high poverty levels;

- **Even Start Family Literacy Program** provides learning opportunities to families by integrating four components; 1) early childhood education, 2) adult literacy, 3) parenting education and 4) PACT time-parent and child together.
- **Homeless Children and Youth** ensures that all homeless children and youth have equal access to the same free public education provided to other children.
- **School Health Programs** are responsible for the Safe and Drug Free Program and coordination of health education, including AIDS prevention (<http://www.dpi.state.nd.us>).

DIVISION OF INDEPENDENT STUDY

The Division of Independent Study offers required and elective courses to supplement the curriculum for grades 5 through 12 and to provide an alternate method of earning an alternate method of earning a high school diploma (<http://www.dpi.state.nd.us>).

NORTH DAKOTA SCHOOL FOR THE BLIND

This agency serves as a state resource center that works with agencies to provide a full range of services to individuals who are blind or visually impaired. Services for school age students include evaluation, consultation and instruction in the local education agency in the specific vision related areas such as orientation and mobility, Braille, Braille music, daily living skills, technology, vocational, recreation/leisure and functional vision (<http://www.dpi.state.nd.us>).

NORTH DAKOTA SCHOOL FOR THE DEAF

This agency serves the educational needs of hearing impaired students ages 0-21. Children that are birth to 3 years of age are part of the Parent/Infant program. The children that are ages 3-21 years of age are served through the school program (<http://www.dpi.state.nd.us>).

NORTH DAKOTA STATE LIBRARY

The ND State Library coordinates library services for individuals with needs such as blindness or physical disability that may need technical assistance or do not have access to a local library (<http://www.dpi.state.nd.us>).



NORTH DAKOTA SPECIAL EDUCATION ADMINISTRATIVE UNITS

The ND Special Education Administrative Units are the office of Special Education. The office of Special Education prescribes the rules and regulations for special education; assists school districts in the development and administration of special education programs, and establishes the standards and provides for the approval and certification of schools and facilities. All of which is required by state and federal statutes (<http://www.dpi.state.nd.us>).

If a learning problem is suspected, ask your child's school staff about the free, special educational services. Sometimes teachers or principals are reluctant to request a consultation or make a referral. Instead of the preceding sentence, I would say "Teachers and principals are not the only ones that are able to initiate..." Public school systems must make special services available under the Individuals with Disabilities Education In order to receive federal funds, every state and school district must have a procedure for identifying, assessing, and planning an educational program for these children from age three to twenty-two. This law covers not only children with learning disabilities, but also those with perceptual problems such as hearing or visual impairments, cerebral palsy, other brain injuries, mental retardation, orthopedic problems affecting mobility, and serious behavioral and emotional difficulties that can interfere with the process of education. This law provides five basic rights including the right to:

1. a free, appropriate public education;
2. an individual educational plan (IEP) based on a complete developmental assessment and approved by parents;
3. access to records or the right of parents to review the child's educational records;
4. due process, or giving parents the right to participate in the evaluation and decision-making process; and
5. the least restrictive educational environment (www.wrightslaw.com).

One of the cornerstones of the Individuals with Disabilities Act is that students with disabilities be educated alongside their nondisabled peers when possible (www.healthychildren.org). An ideal situation for CYSHCN/DD is to be included in the regular classroom in the regular school building but with added services. For example, the schedule should include flexibility to cover the differing needs such as speech therapy, OT or going to the resource room. Often times, the accommodations can be handled when the student is in the elementary grades.

Fewer options exist in junior high and high school than at the elementary-school level, where special education often takes place in separate, self-contained classrooms. As early as kindergarten, a student may spend one or two periods in a



regular classroom, with an eye toward full mainstreaming before going on to middle school. In U.S. public schools, four in five youngsters with learning disabilities and nearly two in five boys and girls who are mentally retarded are taught in regular classes.

Students with mild or moderate disabilities are almost always mainstreamed. However, they may receive special accommodations in classroom environment or instruction to help them learn, depending on their needs. Below are some examples of special measures that might be implemented in a regular classroom:

- Having the student sit front center, near the teacher's desk and away from windows, doors, air conditioners, radiators and other potential distractions.
- Simplifying instructions and avoiding multiple commands.
- Allowing the student to take exams in a small, quiet room.
- Allowing the student extra time to finish tests and other classroom assignments.
- Reviewing test instructions or homework assignments on the blackboard.
- Allowing a student with an auditory-processing problem to wear earplugs, to block out extraneous noise. Or alternately, having her wear a wireless device that transmits the teacher's voice directly to an earpiece while blocking out ambient noise.
- Ordering a second set of books to keep at home, in the event that a student leaves his books in his locker—a not-uncommon occurrence.
- For dyslexic students who have difficulty spelling and poor penmanship, grading papers primarily on content rather than on spelling and neatness.
- Allowing students with learning disabilities to use word processors, calculators, audio books, tape recorders, spellers and other assistive technology



Keep in mind that schools can be particularly challenging for children with attention-deficit/hyperactivity disorder (ADHD), who often experience poor academic performance, behavior problems, and difficulties with social interaction. Coexisting conditions such as a learning disability, an anxiety disorder, or disruptive behavior problems can make it even more difficult for a child to succeed. The situation can be further complicated by the fact that there is no typical, predictable classroom style common to all children with ADHD—some parents of children with ADHD may receive reports that their child is “not trying hard enough” academically, while others may be told that their child turns in acceptable work but frequently violates classroom rules. It can be hard for a parent to tell how much of any problem identified by a teacher falls into the normal range of child development, how much is due to ADHD, and how much is due to a coexisting problem. Add to this the fact that the focus of your child's problems may change from year to year—from largely behavioral to academic from academic to social, and so on.

ADVOCACY AND FAMILY SUPPORT GROUPS

FAMILY VOICES OF NORTH DAKOTA

This agency is a grassroots network of families and friends speaking on behalf of children with special health care needs and disabilities. Family Voices of North Dakota has a resource for children with Special Health Care Needs called New Beginnings. The guide is available at www.fvnd.org.

PARENT TO PARENT PROGRAM

This agency is a support network based on the philosophy that parents who have successfully adapted to their children's disabilities or special health care needs, are the best support for other parents of children with special needs. The Family to Family match provides emotional support and understanding, shared experiences, and support in accessing resources. It is designed to be broad based, to serve children with all types of disabilities and special health care needs and their families, and accommodate the needs of families in rural environments.

CHILD PLACING AGENCIES

These agencies are a collective group of agencies and organizations that assist with adoption, problem pregnancies, guardianship services, life education, and marriage preparation and education. The agencies that work with the child placing agencies would be Catholic Charities of North Dakota, Christian Family Life Services, LDS Social Services, Lutheran Social Services of North Dakota, New Horizons Adoption Agency, and P.A.T.H.



Prevent Child Abuse ND

This agency provides materials and presentations on topics concerning child abuse prevention, parenting, and community organizing. Most of the material is at no charge and can be accessed at <http://www.pcand@btinet.net>. Prevent Child Abuse ND promotes a child abuse free environment by creating public awareness and education, training and technical assistance, coordination of services, strategic partnerships and advocacy.

Kids Now (Children's Insurance)

Kids Now is a toll free number that has information on health coverage for children which would include medical care, immunization, hospital care, mental health, substance abuse and dental care. Should the toll free number be included?

Federation of Families

Federation of Families is a state and national parent-organization focused on the needs of children and youth with emotional, behavior or mental disorders and their families.

Pathfinder Family Center

Pathfinder is the state's federally funded special and regular education parent training and information resource center. Pathfinder Family Center is centrally located and serves parents and professionals of children birth to 22 years of age.

Protection and Advocacy (P&A) Project

P&A is a state agency whose primary purpose is to advocate and protect the rights of people with disabilities. The services are free to eligible individuals.

North Dakota Disabilities Advocacy Consortium (NDDAC)

The NDDAC Mission advocates for public policy to ensure that people with disabilities have the supports and services they need to be as productive and independent as possible. NDDAC Works to:

- Improve the quality of life through greater independence, empowerment, and self-determination.
- Guarantee the freedom to exercise rights and responsibilities as citizens of North Dakota including the option of receiving services in the least restrictive environment.
- Promote universal accessibility.
- Identify and research public policy issues, provide testimony and policy recommendations, and encourage innovative solutions to public concerns.
- Educate policymakers to assist their efforts to improve public policies for individuals with disabilities.
- Help people with disabilities and their families advocate for themselves.
- Advocate for consumer-friendly services.
- Coordinate grassroots advocacy efforts (retrieved from <http://www.nddac.org>)

Child Care Resource and Referral Network

This agency is available to assist families, child care professionals, and communities address child issues. The resource and referral network explores solutions to make child care affordable and good for children.

Easter Seals Goodwill ND, Inc.

Easter Seals is a statewide organization which offers a wide range of programs and services for individuals with disabilities or special health care needs. Easter Seals is designed to provide relief or respite care to families who may need a break from the daily duties of providing for an individual with a disability or special health care needs. The level of care can be custodial such as personal care type of duties or skilled services that require additional training or the skills of a registered nurse. The DD case manager at one of the eight regional human service center authorize the hours of service for persons with disabilities.

NDSU Extension Service Programs

These service programs offer a wide array of programs such as food and nutrition for children and adults, 4-H, stress and anger management, parent education, financial decision making, and farm programs.

NDSU Extension Service County Offices

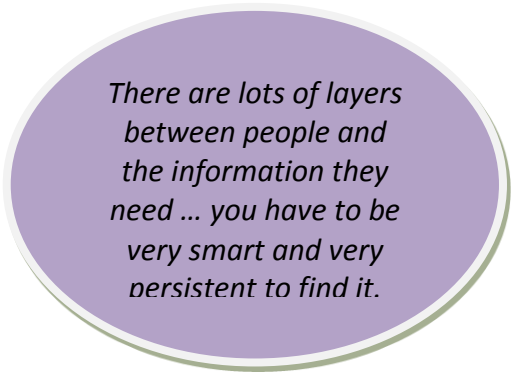
These offices are located across the state with the majority of the extension offices being housed within the county courthouse. Some of the areas of education are geared towards helping recipients on a low income budget the nutritional value of the food choices that are selected. Education programs focus on buying foods, managing resources and learning better food handling practices.

The ARC

The ARC provides help with education and health needs, problem getting services, and help for children with developmental disabilities or special health care needs.

Special Education Units

Special Education Units prescribe the rules and regulations for special education; assist school districts in the development and administration of special education programs and establish the standards and provide for the approval and certification of schools and facilities.



There are lots of layers between people and the information they need ... you have to be very smart and very persistent to find it.

Child Development/Early Intervention

This is programming which is part of the Department of Human Services.

Advocacy and Legal Services

Advocacy and Legal Services provide advice and enforcement of custody battles, divorces for victims of domestic violence, custody of Indian Child Welfare Act.

Children's Defense Fund (CDF)

CDF is a non-profit child advocacy organization that champions policies and programs that lift children out of poverty; protects them from abuse and neglect; and ensures their access to health care, quality education and a moral and spiritual foundation. A screening tool has been developed for nine different public assistance programs operating in North Dakota. For more information: <http://nd.bridgetobenefits.org/>

CONCLUSION

Having a child with special health care needs or developmental disabilities can be a very taxing experience for any family. In addition to all of the day to day activities that go on, tending a sick child's complexity of the health care needs can be overwhelming. The key thing to keep in mind is that "you are not alone." Many organizations and agencies have the ability to help. Don't be afraid to ask or keep trying to find a solution that works for the child and family. Establish a system for organizing important information and share it with the family. Encourage families to do the same.

GLOSSARY

- **Activities of Daily Living (ADLs)** include bathing, dressing, eating, mobility, transferring, toileting and grooming. The need for assistance with ADLs is often part of the criteria to qualify medically for institutional or community-based long term care services.
- **Centers for Medicare & Medicaid Services (CMS)** is the federal agency that administers Medicare and oversees the states' are we referring to one state or more than one state? If more than one, leave as is, if just one, move apostrophe to before the last "s" administration of Medicaid.
- **Durable Medical Equipment (DME)** is health-related equipment that is not disposable, such as wheelchairs, walkers, or oxygen concentrators.
- **Early Intervention (EI)** is developmental services provided to children between birth and age 3 who have, or in states with broad eligibility are at risk of, developmental delay. State Early Intervention programs can receive federal education funds to subsidize these services.
- **Early Periodic Screening, Diagnosis, and Treatment (EPSDT)** is Medicaid benefits and services for children and youth under 21; designed to assure preventive treatment and to promote early diagnosis and treatment of identified health needs. Under EPSDT, Medicaid programs must pay for medically necessary services such as dental care, eyeglasses, hearing aids, special therapy, etc., without cost-sharing, even if they are not ordinarily covered by the Medicaid program.
- **Instrumental Activities of Daily Living (IADLs)** include meal preparation, medication management and administration, money management, communication (such as use of the telephone), transportation, employment and sometimes, laundry and other household chores. The ability to perform IADLs is often used as part of the criteria to qualify for [long-term care](#) and support services.
- **State Children's Health Insurance Program (SCHIP)** is a program established in 1997 to provide health assistance to uninsured, low-income children either through expanded eligibility for state Medicaid programs or through separate state programs. In most states, SCHIP programs expand health care coverage to children in families with incomes up to 200% of the FPL Federal Poverty

Level, would spell out first time around but in some states it is as high as 350% of the FPL; in others it is lower than 200%. SCHIP programs may charge nominal premiums, and some programs also cover the uninsured parents of uninsured children.

- **OPOP** is the Optimal Pregnancy Outcome Program that is located on a local level and the county social services office.
- **ECCS** is the coordinated Early Childhood Comprehensive Systems Program supports collaboration and partnerships that support families and communities in their development of children who are healthy and ready to learn.
- **Supplemental Security Income (SSI)** is a federal program for low income individuals with disabilities or over the age of 64 that pays cash benefits of up to \$603/month (2006). SSI disability status also confers Medicaid eligibility in all but 11 states. See 209(b) States just take out this last line or is more coming?
- **Response to Intervention (RTI)** is both an early intervention strategy within the general education and one part in the process by which students may be identified to receive special education and related services within all public schools in the United States. This NICHCY (spell out) National Information Center for Children and Youth with Disabilities Connections piece synthesizes what we know about RTI, provides access to RTI related information, and discusses RTI from the perspective of people directly involved in the RTI process.
- **Temporary Assistance to Needy Families (TANF)** is a federal block grant program designed to help welfare recipients find work, TANF replaced Aid to Families with Dependent Children in 1996. Most people who receive TANF benefits also receive Medicaid benefits. The ND Health Department is divided into seven sections that have divisions or subsections within each division. The divisions or subsections within the North Dakota State Health Department that would be a valuable resource for CYSHCN/DD, their parents, educators and care coordinators are:
 - **Public Information** supports the department's communication of public health information, policies and resources to the citizens of North Dakota.
 - **Vital Records** documents all vital events in the state, including births, deaths, fetal deaths, marriages and divorces.
 - **Local Public Health Units** are located across the state to assist with public health issues, wellness checks and immunization clinics.
 - **Field Medical Officers** provides medical consultation to programs throughout North Dakota with emphasis on the health implication of environmental pollution, newborn metabolic screening, communicable disease control, immunizations, infant mortality, adolescent suicide, cancer cluster investigation and the Children's Health Insurance Program.
 - **Disease Control** identifies and analyzes disease trends and implements appropriate intervention activities to reduce morbidity and mortality. The federally funded program within the division is immunization, sexually transmitted disease, HIV/AIDS and Tuberculosis.

- **Microbiology** provides diagnostic and referral services to physician, veterinarians, clinics, hospitals, local public health units, other state agencies and the public in the areas of bacteriology, mycology, mycobacteriology, parasitology, immunology, virology, and dairy and water bacteriology.
- **State Epidemiologist**-primary responsibilities include coordinating epidemiological studies, investigations, and surveillance activities; conducting data analysis; and providing technical expertise and consultation with public and private health professionals. **Community Health** –supports families and communities working to improve the health and safety of North Dakotans. Many of the services are provided through the public health units.

SOURCES

www.dpi.state.nd.us

www.fvnd.org

www.healthychildren.org

<http://nd.bridgetobenefits.org>

<http://www.nddac.org>

www.nd.gov/dhs

www.nd.healthygov/doh/overview

www.wrightslaw.com

APPENDIX A: Health Related Websites

American Academy of Pediatrics: <http://www.aap.org>

American Lung Association: <http://www.lungusa.org>

American Public Health Association: <http://www.apha.org>

Centers for Disease Control and Prevention (CDC): <http://www.cdc.gov>

Centers for Medicare and Medicaid Services: <http://cms.hhs.gov>

Child Care Resource and Referral Network: <http://www.ndchildcare.org> Child Development/Early Intervention: <http://www.ndearlyintervention.com>

ND DPI Transition website: www.dpi.state.nd.us/transitn/index.shtm

North Dakota Council on Abused Woman's Services: <http://www.ndcaws.org>

ND DPI website: <http://www.dpi.state.nd.us>

Catholic Charities: <http://www.catholiccharitiesnd.org>

Catholic Adoption: <http://www.cflsadoption.org>

APPENDIX B: ADDITIONAL RESOURCES OR WEBSITES

Alliance for Work-Life Progress – a membership organization committed to the development and advancement of the field of work-life effectiveness www.awlp.org

The Arc - a national organization of and for people with mental retardation and related developmental disabilities and their families (301) 565-3842 www.thearc.org

Children's Public Health Insurance - information on children's public health insurance (877) 543-7669 www.insurekidsnow.gov

DisabilityInfo.gov - information on federal government resources relating to disabilities www.disabilityinfo.gov

Employee Benefit Research Institute (EBRI) - nonprofit, nonpartisan organization committed exclusively to data dissemination, policy research, and education on economic security and employee benefits. www.ebri.org

Family Voices - national grassroots organization of families and friends of children with special needs (888) 835-5669 www.familyvoices.org

Federation for Children with Special Needs - provides advocacy and support for families in the areas of health, education, early childhood, and transition for children and young adults with special needs (617) 236-7210 www.fcsn.org

Exceptional Parent - a monthly publication and library for families compiled by the Maternal and Child Health Bureau of the U.S. Department of Health and Human Services www.eparent.com

Maternal and Child Health Bureau (MCHB) of the Department of Health and Human Services – the nation’s oldest federal program serving mothers and children www.mchb.hrsa.gov

National Information Center for Children and Youth with Disabilities (800) 695-0285 www.nichcy.org

P2PUSA-Parent to Parent USA –Provides emotional and informational support for families of children who have special needs.

<http://www.p2pusa.org/p2pusa/sitepages/p2p-home.aspx>

Learning Disabilities Association of America - provides information, resources, and support to families about learning disabilities (412) 341-1515 www.Ldanatl.org

State Title V Programs - list of all state Title V program directors and how to contact them

<http://cshcnleaders.ichp.edu/TitleVDirectory/PDF-Files-2003/CSHCNDIR%2010-1-03.pdf>

Technical Assistance Alliance for Parent Centers - a national network of state parent centers providing information and training for families of children with disabilities (952) 838-9000

www.taalliance.org