



2001

A Review of the Process of Accessing Services for Children with Special Health Care Needs in North Dakota

Jana Schmidt
University of North Dakota

Follow this and additional works at: <https://commons.und.edu/pt-grad>

 Part of the [Physical Therapy Commons](#)

Recommended Citation

Schmidt, Jana, "A Review of the Process of Accessing Services for Children with Special Health Care Needs in North Dakota" (2001). *Physical Therapy Scholarly Projects*. 398.
<https://commons.und.edu/pt-grad/398>

This Scholarly Project is brought to you for free and open access by the Department of Physical Therapy at UND Scholarly Commons. It has been accepted for inclusion in Physical Therapy Scholarly Projects by an authorized administrator of UND Scholarly Commons. For more information, please contact zeinebyousif@library.und.edu.

A REVIEW OF THE PROCESS OF ACCESSING SERVICES FOR CHILDREN WITH
SPECIAL HEALTH CARE NEEDS IN NORTH DAKOTA

by

Jana Schmidt
Bachelor of Science in Physical Therapy
University of North Dakota, 2000

An Independent Study

Submitted to the Graduate Faculty of the

Department of Physical Therapy

School of Medicine

University of North Dakota

in partial fulfillment of the requirements

for the degree of

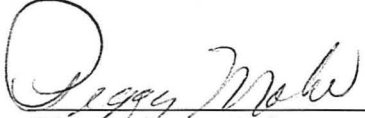
Master of Physical Therapy

Grand Forks, North Dakota


May
2001



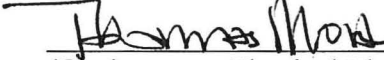
This Independent Study, submitted by Jana L. Schmidt in partial fulfillment of the requirements for the Degree of Master of Physical Therapy from the University of North Dakota, has been read by the Faculty Preceptor, Advisor, and Chairperson of Physical Therapy under whom the work has been done and is hereby approved.



(Faculty Preceptor)



(Graduate School Advisor)



(Chairperson, Physical Therapy)

PERMISSION

Title A Review of the Process of Accessing Services for Children with
Special Health Care Needs in North Dakota

Department Physical Therapy

Degree Master of Physical Therapy

In presenting this Independent Study Report in partial fulfillment of the requirements for a graduate degree from the University of North Dakota, I agree that the Department of Physical Therapy shall make it freely available for inspection. I further agree that permission for extensive copying for scholarly purposes may be granted by the professor who supervised my work or, in his/her absence, by the Chairperson of the department. It is understood that any copying or publication or other use of this independent study or part thereof for financial gain shall not be allowed without my written permission. It is also understood that due recognition shall be given to me and the University of North Dakota in any scholarly use which may be made of any material in my Independent Study Report.

Signature Jan L. Schmidt

Date 11-1-00

TABLE OF CONTENTS

Acknowledgements.....	v
Abstract.....	vii
Chapter 1. Introduction	1
Chapter 2. North Dakota Family Demographics	3
Chapter 3. Factors Influencing the Utilization of Services for Children with Special Health Care Needs	9
Chapter 4. Roles of Health Care Professionals	13
Chapter 5. Methods	19
Chapter 6. Services and Eligibility Requirement in North Dakota	22
Chapter 7. Accessing Services for a Child with a Special Health Care Need in North Dakota	35
Chapter 8. Results	42
Chapter 9. Discussion	44
Appendix A	47
References	49

ACKNOWLEDGEMENTS

I would like to take the time to thank everyone who helped me survive this independent study. I received a generous amount of support and motivation from my friends and family. My parents have always been proud of my accomplishments throughout my schooling, and they encouraged me to continue working hard on this independent study. Thanks Mom and Dad.

I would like to thank my preceptor, Peg Mohr, for taking the time to help out with this independent study. She always kept me on schedule and showed appreciation for my hard work over the summer months. Peg was also good at keeping me calm and seeing that this project wasn't as bad as I expected.

I couldn't ask for a better partner for this project, Lynsey Schmidt. She was great about keeping this project fun and motivating. We were a great team. She has always been a special friend and a great peer in our physical therapy class.

This independent study wouldn't have been made possible without the help of professionals and families working with children with special health care needs. Terry Bohn and the Family Advisory Council in Bismarck, North Dakota gave us the idea for this project and worked with us throughout the summer to meet our goals. Everybody was very willing to help us out and take the time to think of positive new ideas or suggestions. Also, professionals including Donene Feist, Marilyn Arneson, Lillian Thompson, and Joyce Belbus took the time to inform us about their personal experience in obtaining services in North Dakota. I would like to thank Carissa Green from the

Family to Family Network for helping us with questions and computer advice.

Everybody's help and encouragement was greatly appreciated. Thanks!

ABSTRACT

It has been a concern of the Family Advisory Council of Children's Special Health Services, Bismarck, North Dakota, that many families experienced difficulties when trying to access information for medical, financial, educational, and family services for their children with special health care needs. The family members on this advisory board found the process of accessing services confusing and time consuming, and indicated that families were also unclear as to where to begin the process. An abundance of information provided at the time of their child's diagnosis made it difficult for families to make informed decisions about the most important and appropriate services for their family. The problems these families encountered led to the development of this independent study and resulting publication.

The purpose of this study was to outline and describe the services available in North Dakota, the eligibility requirements involved, and how contacts with these services could be initiated. To accomplish this, a literature review was conducted concerning family demographics in North Dakota, utilization of services, and roles of professionals involved in these services. In addition, a review of materials provided by agencies that distribute information to families of children with disabilities and a flow chart and resource guide were completed. This document, available at Children's Special Health Services, North Dakota Department of Human Services, and the Department of Physical Therapy, University of North Dakota, was designed to assist families and professionals in accessing services by outlining entry points along the service continuum, listing types of

assistance available, and providing contact information for agencies/professionals who provide these services.

CHAPTER 1

INTRODUCTION

Introduction

"There are no 'easy to assemble' instructions written clearly enough for the unexperienced to access care in the system."¹ Families may often feel panicked, lost, and confused about where to start getting help for their child with a special health care need. These families not only have to deal with the stress of the new changes in their lives due to the special needs of their child, but they also have to begin the process of being an advocate for their child to ensure the highest quality of care. This is a large burden for many families to take on, but if they are given the appropriate resources and contact personnel, answers to their questions could more easily be obtained. Still the question remains, where should they start in the process of getting appropriate care?

Problem Statement

There is little information available, for parents of children with special health care needs, specifically about services available for their children and families and the process by which they can access these services in North Dakota.

Purpose of the Study

The purpose of this study is 1) to determine the types of services available to children 0-5 years of age with special health care needs and their families in North Dakota, 2) to discuss the eligibility requirements of these services, 3) to explore the means by which parents/caregivers gain access to these services, and 4) to design a

document to aid parents/caregivers of children with special health care needs and professionals in the process of accessing services in North Dakota.

Significance of Study

The data collected from this study will provide helpful information concerning access to services for children with special health care needs in North Dakota. The results obtained from this study will be a reference for families who have children with special health care needs and persons working with families of children with special health care needs including physicians/pediatricians, social workers, physical therapists, occupational therapists, speech/language pathologists, audiologists, care coordinators, case managers, nurses, and any other professionals working with these individuals.

Research Questions

1. What are the types of services available in North Dakota for families of children with special health care needs ages 0 to 5 years?
2. What are the eligibility requirements involved for these services?
3. How can parents/caregivers access these services?

CHAPTER 2

NORTH DAKOTA FAMILY DEMOGRAPHICS

As families and communities change and continue to expand or move on, the states that they reside in also changes in many ways.^{2,3} This chapter is focused on the changing population, family composition, economic condition, child health, education, and child safety issues of North Dakota. Unfortunately, some of these factors may influence the innocent bystanders, our children, the most. These factors are discussed pertaining to how they can affect the delivery of quality services and care to our children in need.

Population

Between 1996 and 1997, North Dakota's population declined slightly from 643,539 to 640,883.² Much of this decline is believed to be due to a downturn in agriculture and flooding throughout the state. Between 1990 and 1997, the number of children under the age of five declined in all but two of the state's 53 counties. A loss of 8,733 preschoolers and a loss of 1,629 school-age children occurred between 1990 and 1997. This decline in preschoolers and school-age children influences the successful economic growth and development of our country with less adult leaders for the future.² Success will be dependent on contributions from every child.

In the United States, birth defects have been the major cause of the declining population in infants, as they account for more than 1 in 5 infant deaths.³ In North

Dakota alone, approximately 334 babies are born with a birth defect each year. This data is compared to national estimates of 150,000 babies born with birth defects each year.

Family Composition

Between 1985 and 1995, the percentage of children headed by a single parent increased from 13% to 18 percent.² This may seem like a huge increase, but North Dakota still ranks second lowest in the nation for the proportion of single parent families. A concern may arise when these single parents are teenagers and can't afford appropriate care for their child.

Another concern is parents who are struggling to meet their basic needs.² In North Dakota in 1995, 83% of parents with preschoolers were working due to rising economic pressures. The national average of preschoolers with working parents is only 63 percent. Likewise, in North Dakota 62% of parents with elementary children in 1995 were working to provide for their families. The national average of elementary children with working parents is only 51 percent. These percentages reflect the challenges and struggles of North Dakota's child care system. In 1995, more than 1 in 4 children under the age of 12 were living in families with working parents, but were still ranked as low-income families. This fact illustrates the need for affordable childcare in the state.

It is estimated that 7% of children in North Dakota are categorized as having 4 or more characteristics that put them at risk for serious challenges to their well-being.² These risks may include chronic family conditions, including single parenthood, lack of parental education, below poverty income status, lack of secure parental employment, welfare dependence, and lack of health insurance.

Economic Condition

Between 1990 and 1995, a decline from 17.1% to 15.9% was noted in the proportion of impoverished children in North Dakota under the age of 18 years.² This indicates that economic conditions for North Dakota children have improved slightly. Even though these numbers look hopeful, caution should be utilized when reviewing the interpretation of these declines.² Since 1997, drastic changes in eligibility requirements and regulations for virtually all economic assistance programs has resulted in fewer eligible families for assistance and decreased participation numbers. This has been reflected in key economic condition indicators. With fewer children eligible for these services, the results of economic hardships may be more influential for these affected children.

Although it may seem like economic conditions for children are improving, 1 in 6 children in North Dakota still live below the poverty level.² In addition, 13% of children live in “near-poor” families. Findings² across the United States indicate that reductions in welfare, disability benefits, and food stamps are limiting the ability of some families to meet their children's most basic needs.

Child Health

In North Dakota the relative status of children's health is varied.² A low birth weight baby is described as less than 2500 grams or 5.5 pounds.³ North Dakota ranked the lowest in the country in the number of low birth weight babies in 1995, but unfortunately this number has increased by 15% from 1995 to 1997.² Approximately 516 babies in 1997, about 6% of the total number of babies born that year, were of low birth weight in North Dakota. Similar studies³ by the *March of Dimes Birth Defects*

Foundation in 1996 found 9 out of 161 babies born each week in North Dakota are born with low birth weights, resulting in 5.7% of the total birth rate being low birth weight babies on the average each year. Similarly, between 1996 and 1997, there was a 15% increase in the number of mothers receiving inadequate prenatal care in North Dakota.² On a good note, in 1996 84.7% of pregnant women began prenatal care in their first trimester.³

An estimated 10% of children in North Dakota under the age of 18 were not covered by a health insurance plan in 1998.² It is estimated that between 1995 to 1997 this proportion of children was at 11.2 percent.³ Children lacking health insurance coverage are less likely to be provided with a usual source of health care, are less likely to be immunized and receive well-baby or well-child checkups, and are more likely to be hospitalized for conditions that possibly could have been avoided.² In 1996, 17% of North Dakota's two year olds were not immunized for protection against infectious diseases.² Some of this could be avoided with proper health insurance coverage, so parents could get the care and nutrition they need for their children. The 1999 North Dakota Legislature adopted a program for uninsured children known as the *Children's Health Insurance Program* (CHIPS).² This policy provides health insurance for children living in families with incomes up to 140% of the poverty level.

Education

Reports² show a 17% increase in the number of North Dakota children with disabilities in preschool between 1991 and 1997. Parents should be encouraged to get early assistance and the specialty services that they are entitled to for their children with developmental disabilities.² This will help prepare their children for kindergarten.

Child Safety

A 4% increase in the number of children in North Dakota abused and neglected was seen between 1996 and 1997, totaling nearly 7,000 children.² These numbers generally increase during times of intensified stress in families such as flooding or a depressed agricultural economy in rural areas. *Healthy Families* was recently implemented in Region IV of North Dakota to provide education and support services to parents around the time of the baby's birth.² Programs like this are important to reduce the risk of child abuse and promote healthy child-rearing practices.

Another important factor in child safety is the quality of child care. In 1998, a 43.8% decrease was found in the number of licensed child care providers and a 22% decrease in the capacity of children they could hold.² These numbers again lead to a decline in the quality of care available to children, leading to more parents staying home to care for their children or sending them to unlicensed providers.

Child safety issues may be as simple as encouraging children to wear bicycle helmets to reduce the risk of a head injury.² A recent survey reported that 57% of children seldom or never wear a bicycle helmet.

*North Dakota KIDS COUNT!*² has provided examples of many goals that can be set pertaining to the categories listed above to ensure the safety and the quality of care given to children as they grow. These goals may include making the well-being of children the highest priority in every community, ensuring that poor and low-income families with children are utilizing all resources available to them, providing health insurance and immunizations to every child, ensuring that schools are equipped and dedicated to helping every child succeed, and providing home visits to new families to

support the development of positive parenting skills and decrease the likelihood of child abuse.

CHAPTER 3

FACTORS INFLUENCING THE UTILIZATION OF SERVICES FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS

National studies⁴⁻¹² generally have shown an underutilization of services for children with special health care needs. Compliance rates with consultants' recommendations are also lower than expected. Several studies⁴⁻⁶ researched factors such as the child and family characteristics, provider characteristics, early contacts with health professionals, reasons for dissatisfactions with health professionals, and values and beliefs about the recommendation to determine the effect on utilization and compliance rates.

Kochanek and Buka⁵ researched the utilization rates of scheduled early intervention services. They found that several studies⁷⁻¹² in the past have reported significant underutilization of entitlement programs such as Women, Infants, and Children (WIC), Department of Health and Human Services, and Early Periodic Screening Diagnosis and Treatment. Overall, authors concluded that the strongest determinants of underutilization of services were low income, time constraints, and minority group membership. Kochanek and Buka⁵ studied 146 infants and toddlers for whom services were scheduled, totaling 1861 services or events recorded. The overall mean percent of service utilization was 79.1% for the scheduled events. This percentage was notably high demonstrating that providers positively engaged families with early intervention services.

Further research by Kochanek and Buka⁵ investigated child, maternal, and provider sociodemographic variables and their influence on service utilization rates. Studying the child's age, need complexity, or length of program involvement, and the mother's education, employment status, income, insurance status, race, or single vs. dual parent style found no statistically significant data relating these to early intervention service utilization. Provider characteristics including age, education level, professional discipline, and presence of children at home did reveal a statistically significant relationship to service utilization. Providers who were younger and close in age to mothers evidenced significantly higher utilization rates. Also, providers who did not have their own children at home, who had graduate degrees, and who were educators revealed a higher utilization percentage of scheduled services by families. An interesting finding by Kochanek and Buka⁵ revealed that mothers who believed service decisions should be made by professionals evidenced higher utilization rates. Kochanek and Buka also found that families in which therapists served as the primary service provider had the lowest utilization rates. Overall, the data suggests that the placement of a primary service provider with a family is a critical event in the early intervention experience.

A study performed by Cadman, Shurvell, Davies, and Badfield⁴ researched the causes and potential cures of non-compliance among clients of community consultation services for children with developmental handicaps. A sample of 30 children with developmental handicaps related to 77 family members was used. They reviewed 143 therapeutic recommendations including medical, developmental programming, behavioral/psychosocial, education placement, and others. Overall, clients complied with 73.2% of the recommendations. Family members said they were unaware of 6.5% of the

recommendations made. The results of this study indicated more than 25% of consultants' recommendations for children with developmental handicaps were not fulfilled, which Cadman et al⁴ believe is a problem worthy of attention. Explanations for non-compliance focused on the attitudes and beliefs about the recommendation, rather than the attributes of the child, the family, or the type of recommendation. Cadman et al found the most significant attitude factor to be the quality of the family-consultant interaction and agreement about specific recommendations was very important.

McKay and Hensey⁶ interviewed parents of 84 school-age children with cerebral palsy about their early relationships with health care professionals. Seventy percent of parents expressed some form of dissatisfaction with their early contacts with health services regarding initial diagnosis and referral. Fifty eight percent of the parents complained about the lack of explanation about their child's diagnosis and reasons for continuing follow-up services. Fifty one percent complained about having their worries dismissed by the doctors and the need for continuous repeated visits before a problem was recognized. Twenty nine percent of parents complained about the way in which their child's disability was explained to them. These results indicate a need for continuing improvement in the quality and delivery of services.

In a conversation with Marilyn Arneson, a Developmental Disabilities Case Manager at the Northeast Human Service Center, on March 7, 2000 and Joyce Belbus, a Licensed Social Worker at Altru Health Systems of Grand Forks, North Dakota, on March 29, 2000 it was noted that in North Dakota some families believe in wanting to do it all. These families have grown up cherishing the value of independence and the importance of being self-sufficient in everyday duties and activities. These professionals

believe this may lead to underutilization of services. Marilyn Arneson indicated that families in North Dakota may need to be encouraged to ask for help, so that they realize asking for support is a strength not a weakness.

CHAPTER 4

ROLES OF HEALTH CARE PROFESSIONALS

As parents/caregivers or families begin accessing services for their children, many new and different health care professionals may begin to be involved in their daily lives.¹³ In this chapter, the roles of the main health care professionals involved in an interdisciplinary team for children with special health care needs are introduced. An interdisciplinary team develops a collaborative plan of care for the child by using a variety of disciplines, including the family, and often identifying a case manager.¹³ The composition of an interdisciplinary team may include the child and family members, family support members, pediatrician, nurse, social worker, physical therapist, occupational therapist, speech-language pathologist and audiologist, case manager, and other subspecialties. Many children will work with more than just these professionals listed, depending on their disability and specialty needs. An introduction to the interdisciplinary team members is given below.

Pediatrician

A pediatrician is a physician who specializes in care for children from birth to adolescence.¹⁶ Duties of a pediatrician may include checking the health of a child, prescribing and giving medication, and vaccinating children against disease. Pediatricians are also important as a reference for parents/caregivers on medical questions about their children. Generally, a pediatrician is the child's gatekeeper for

medical needs. A gatekeeper may be defined as a primary care physician who is responsible for coordinating and overseeing all aspects of medical care and pre-authorizing specialty care, so the child gets the appropriate care for their diagnosis.¹⁵

Nurse

Registered nurses may be found working in the local hospital, medical center, school, physician's office, or community health facility.¹⁶ Registered nurses are responsible for caring for the sick and injured and helping people stay healthy.¹⁴ Their duties may include observing, assessing, and recording symptoms, reactions, and progress, administering medications, and assisting in rehabilitation. The nursing staff can help teach an individual and their families proper care techniques to continue at home for improving or maintaining their health. Registered nurses not only provide physical care, but also mental and emotional care. Nurses may specialize in caring for children with special health care needs.

Social Worker

When a child is diagnosed with a severe or long-term disability, the child and the family both may develop personal problems that are difficult to deal with alone.¹⁴ This is where the role of the health care social worker begins. They help children and their families deal with social, emotional, and financial problems. Social workers can assist families, whose child has been diagnosed with an ongoing chronic health condition, learn how to manage the condition within their family activities. In the acute care hospital, social workers are generally involved with discharge planning.¹⁶ They will arrange for financial assistance or home health services, so the individual may return to the

community with as few problems as possible. The social worker also plays an important role in informing families about community resources available to them.¹⁴

Physical Therapist

The main role of a physical therapist includes restoring functional mobility, relieving pain, and preventing or limiting permanent disability after a serious illness or injury.^{14,16} Physical therapists evaluate and treat a variety of individuals with diagnoses that may include stroke, sports injuries, spinal cord and brain injuries, multiple sclerosis, heart disease, motor vehicle accidents, arthritis, and children with disabilities such as cerebral palsy. All ages including infants to the elderly may be treated by a physical therapist. Duties of the physical therapist include evaluating the child, developing an individualized therapeutic program including interventions utilized and goals to achieve, and educating the child and their family about their diagnosis and an exercise program to continue at home. Physical therapists help individuals achieve maximum function, muscle strength, and physical skills through the use of mechanical devices and manual treatments, along with helping them adapt to changes in their lifestyle. Treatment plans may often be decided together with the interdisciplinary team to help the child achieve their highest function and satisfaction. The child and their family along with the physical therapist need to work together to obtain optimum results.

Occupational Therapist

Occupational therapists assist individuals in developing or maintaining daily living skills, and they help individuals cope with their disability and the resulting physical or emotional effects.^{14,16} These individuals are educated on strengthening muscles and improving fine muscle coordination and dexterity, so they can become independent in

activities of daily living at home, work, school, or in the community. Similar to physical therapy, a lot of the same types of children are seen and often occupational and physical therapists work together within the interdisciplinary team to treat the child. Occupational therapists also perform evaluations, plan and implement a therapeutic program and a home program. Therapy includes using arts and crafts, computers, homemaking skills, functional work related activities, muscle strengthening activities, or providing individuals with adaptive equipment such as wheelchairs, splints, and aids for eating and dressing.

Speech-Language Pathologist and Audiologist

A speech-language pathologist assesses persons with speech or language problems and provides interventions to assist individuals to communicate effectively.^{14,16} Types of conditions assessed include children with cleft palate or cerebral palsy, stroke victims, brain injury, total or partial hearing loss, mental retardation, faulty learning, or voice pathology. For children with little or no speech, the use of automated devices or sign language may be taught to the child and their family. Speech-language pathologists teach other children how to make sounds, improve their voices, or increase their language skills through the use of audiovisual equipment, mirrors, tape recorders, or computers.

Audiologists identify, assess, and treat persons with hearing problems or try and prevent hearing problems.^{14,16} Viral infections, genetic disorders, or exposure to loud noise may all result in a hearing disorder. Audiologists may examine and clean the ear canal, fit the child with a hearing aid, use auditory training, or teach the child to read lips to treat the hearing problem. Audiologists may be found working in hospitals, schools, clinics, rehabilitation centers, or in private practice.

Case Manager

A case manager will be assigned to a family and their child with a special health care need once the child is found eligible for services.¹⁷ Case management is defined as “the collaborative provision of coordinated care by professionals from multiple disciplines, in one or more settings, over a stated period of time, to achieve specific outcomes.”¹³ A case manager should have a background in early childhood development and experience working with children with developmental delays.¹⁷ They should also know the policies for early intervention programs and services in the state. The case manager is generally the professional who works with the child and has the most input into their plan of treatment.¹³ They may vary from a physical therapist to a nurse depending on the child’s diagnosis. The case manager has many responsibilities to insure that the child is provided with optimum care. They provide leadership and consultation to the family about goals for the child and expected outcomes, plans for treatment interventions, and resources available in the community to carry out the plan of care. Resources may include recreation, child care, or family support groups.¹⁷ Case managers provide background information on the child and his or her diagnosis to the team to assure the current plan of care is appropriate for the individual and to acknowledge strengths or gaps that may exist in the plan of care.¹³ Case managers document information shared at team meetings such as sources of referral for the child and the family’s financial status, and they document decisions made by the team for the child’s plan of care. The case manager evaluates the present plan of care for quality, access, and cost effectiveness. Finally, the case manager evaluates the present plan for achievement of goals within a given time period. The plan may be readjusted to meet the

goals successfully or new services may be added such as education, therapy, or social supports.

Parents and Family Members

The family of a child with a special health care need are equally important as any other professional on the interdisciplinary team.¹³ The family knows the child best because they are the constant factor in the child's life, and they have the best personal input for the team's individualized plan of care. The parents/caregivers along with extended family, friends, professional friends, and clergy can make up the family's support section of the interdisciplinary team.

CHAPTER 5

METHODS

On February 1, 2000, Terry Bohn of Children's Special Health Services, Department of Human Services of North Dakota contacted the University of North Dakota Physical Therapy Department on behalf of the Family Advisory Council. In his conversation with Peg Mohr, advisor for this project, Terry stated a need for a fact sheet or flow chart to be developed pertaining to how families of children with special health care needs access services in North Dakota. The Family Advisory Council agreed to oversee this project, shaping and focusing the direction, and providing consultation and review.

To begin data collection for this project, it was decided that the researchers should follow the avenues available to families in seeking assistance. Therefore, a variety of professionals were contacted who provided informative handouts and materials. In addition, families with children who have special health care needs also provided information. Meetings were set up to gather information and discuss the process of accessing medical, financial, educational, and family services for children with special health care needs in North Dakota ages 0-5. Major questions raised included 1) What are the major services available in North Dakota, 2) What are the eligibility requirements for these services, and 3) What are the major entry points and contacts in the process of accessing services. As the information provided is for distribution to the general public,

no written consent was requested, but verbal consent was given by each professional for use of any gathered information for this independent study and resulting publications.

The parent director, Donene Feist, for the Family to Family Network and a parent of a child with a disability provided information on February 17, 2000 about services including early childhood tracking, County Social Services, social work, human service center, the Family to Family Network, Supplemental Security Income (SSI), Indian Health Services, Medicaid, case management, preschools and special education, North Dakota Family Voices, medical insurance, Children's Special Health Services, Pathfinder, Infant Development and Development Disability in the Department of Human Services, Respite Care, Easter Seals, primary care physicians and pediatricians, and Childfind.

In a meeting with Marilyn Arneson, a case manager for the Developmental Disabilities Department of the Northeast Human Service Center, on March 7, 2000, information was made available pertaining to Medicaid, Children's Health Insurance Plan, the Public Health Department, Shriners Hospital, the Childcare Assistance Program, SSI, the Arc, the Department of Human Services, case management, family support, the public school system, social workers, County Social Services, and the North Dakota Association for the Disabled (NDAD). Numerous informational pamphlets were supplied by and are available at the regional human service centers, which described many of the services listed above.

Lillian Thompson, a registered nurse at the Public Health Department in Grand Forks, North Dakota, was contacted by phone on February 15, 2000 and later mailed various publications, on March 3, 2000, concerning care coordination through the Public

Health Department, financial services, family support services, information and referral services, organizations, statewide tribal programs, and websites.

Joyce Belbus, a licensed social worker at Altru Hospital in Grand Forks, North Dakota, provided pamphlets on March 29, 2000 with information on County Social Services, Medicaid, North Dakota Early Childhood Tracking, Infant Development, the Child Evaluation and Treatment Program, the Public Health Department, Neonatal Intensive Care Unit Follow-up Clinic, support group listings, case management, SSI, and Head Start.

Through a review of the literature listed above along with library research, a literature review was completed and a flow chart and resource guide outlining the process of accessing services for children with special health care needs in North Dakota developed. The flow chart was reviewed by the Family Advisory Council in Bismarck on May 20, 2000, June 29, 2000, August 19, 2000 and September 14, 2000. Discussions regarding development of the document were completed through conference calls on May 20, 2000 and personal meetings/phone calls on June 28 and 30, 2000. The first draft of a brochure was completed on September 14, 2000 and reviewed by Terry Bohn of CSHS on September 15, 2000. On September 14-15, 2000, the brochure was reviewed by individuals providing services to families of children with special health care needs at the Family Summit Meeting in Bismarck, ND. The final revisions were completed on September 30, 2000. A copy of this brochure is included in Appendix A of this independent study.

CHAPTER 6

SERVICES AND ELIGIBILITY REQUIREMENTS IN NORTH DAKOTA

As a result of this independent study, a brochure was developed which includes a flow chart and resource guide for parents and care givers of children with special health care needs. A copy of this brochure can be found in Appendix A. This chapter will define the services listed on the resource guide that are available to families in North Dakota. The eligibility requirements of each program are also provided.

Information, Referral, and Medical Services

Department of Human Services:

Children's Special Health Services

Eligibility includes families with a child who has or may have a disability or chronic medical condition age 0 to 21.^{18,19} There is no direct cost for services but a cost share for services based on income may be required. Coordinated health care services for children that require more than routine and basic care or who have conditions, which may hinder their growth and development, are provided. Services included are diagnosis and treatment, clinical/specialty services, information and referral, or care coordination services.

Human Service Centers

Developmental Disabilities Services

Eligibility requirements for the following sections are based on criteria established by the North Dakota Department of Human Services for each program.²⁰

Need rather than financial status is the basis for eligibility.²¹ These services are available to people of all ages who meet specific eligibility requirements.

Early Intervention/Infant Development Program

This program provides services to families with children who have developmental delays, or who are at risk for developing delays due to risk factors.^{18,21} Developmental delays can be characterized as an activity such as crawling, that a child is not performing while other children their age are able to accomplish without difficulty. Children zero to three years of age are eligible for this program. Services are individualized and based on the specific family needs including communication, cognition, physical development, adaptive development, and social and emotional development.

The following services are offered through the regional human service centers:

Case Management Services

Case managers help eligible persons including infants, toddlers, school age children and adults with developmental delays access services they may require.²⁰ Individuals are assisted by case managers with the application process for many of the available forms of financial assistance, transition from children's services to school or adult services, and residential living. Case managers also help ensure the quality of services an individual receives and help families by offering a single contact within the interdisciplinary team.

Family Support Services

Services include respite care, supportive home care, and family care option.²⁰ Respite care is provided when the family of an individual with a disability needs relief from the stress of caring for the individual. Supportive home care provides personal

assistance in the family home setting. The family care option provide for part time care outside of the home for children ages 0-21 years when 24 hour in home care is not available.

Family Subsidy

This service provides financial assistance for expenses incurred while the child with a disability is living at home.²⁰ Expenses may include adaptive equipment, counseling, transportation, excess costs, home health, or special diets. Eligibility requirements are based on the severity of the child's disability, the amount of coverage by other sources, the amount of stress on the family, and the availability of services and Family subsidy funds. There are no restrictions based on family income. Children ages 0-22 may be eligible.

Psychological Services

This entity provides services to people of all ages to maintain a positive holistic approach to treating the individual by performing evaluations, behavior development, consultations and social skill development.²⁰

County Social Services

Services offered through County Social Services pertaining to young children with special health care needs include personal attendant care and respite care.²² Personal attendant care assists with health related care, self care, environmental and support safety care and community support care on a 24 hour basis. Respite care includes a care program for eligible individuals to provide relief for the individual's primary care giver for a specified period of time.

Public Health Department

Regardless of ability to pay, all community members are eligible for services from the Public Health Department.²³ Public health provides for care coordination, which includes assisting families find appropriate resources and services for their children, birth to 21 years of age, with chronic illness, disabling conditions, or other special health care needs. Community health care nurses deliver local services including immunization clinics, child health nursing conferences, early and periodic screenings, diagnostic and treatment services, school screenings and services under the Women, Infant and Children (WIC) program.¹⁸

Women, Infants and Children (WIC)

Services under WIC include nutritional counseling, referrals for pregnant, breast feeding, and postpartum women and their children up to 5 years of age.¹⁸ This service is available to those whose gross family income is at or below 185% of poverty. For example, if the poverty level is set at \$10,000, a family who earns \$11,850 per year or less would be eligible to receive this service.

Financial Services

Supplemental Security Income (SSI)

Monthly payments are provided through this service for those who are 65 or older, blind, or have a disability.²⁴ Children can receive benefits due to disabilities that affect everyday life or blindness. Eligibility is based on disability and financial requirements determined by the state.

County Social Services

Eligibility is based on guidelines pertaining to age, income, state, reservation, and/or tribal enrollment.¹⁸

Medical Assistance/Medicaid

This program is designed to assist people who cannot afford health care services.²⁵ Individuals and families who meet the following requirements are eligible: recipients of financial assistance and families whose financial assistance terminates. Individuals who are aged, blind, or disabled with enough income to meet basic maintenance needs, as defined by the state, may be partially or fully eligible. Families with sufficient income to meet basic needs, as defined by the state, may be eligible for Medicaid. Elderly persons (over age 65) receiving care from the state hospital and who have low income with assets may qualify for Medicaid. Other individuals who may qualify include persons under age 21 in the state mental institution, individuals under age 21 in foster homes, certain adoptive children (as defined under the state subsidized adoption law), other individuals under age 21 who do not have enough income or assets to meet their medical needs. Pregnant women and infants to the age of six, who meet income standards based on the poverty level, and children age six to nineteen, with income within the poverty level, may qualify for Medicaid. Qualified Medicare beneficiaries, qualified disabled and working individuals whose income falls within specified asset and poverty levels, and special low income Medicare beneficiaries including individuals who are blind, aged or disabled who meet the set poverty and asset level standards also may be eligible.

Child Care Assistance Program

This program provides assistance for childcare costs to low-income families while they are working or pursuing an education.^{22,26}

ND Health Tracks, EPSDT

This preventative health program for children birth to 21, uses Health Tracks Providers appointed by the County Social Service office.²⁷ It can pay for many services including counseling, hearing and vision care, developmental test, shots, lab tests, medicines, dental care, and specialists.

Blue Cross Blue Shield (BCBS)

Caring Program for Children

This program provides free primary and preventative health and dental insurance for children up to age 19 whose parents cannot afford health insurance, are underemployed or marginally employed, and not eligible for Medicaid.²⁸

Comprehensive Health Association of North Dakota (CHAND)

Individuals with health conditions that limit their access to standard health insurance are provided assistance through this division of BCBS.²⁸ In order to be eligible, an individual must have written evidence of rejection by an insurance carrier and a sixth month waiting period for pre-existing conditions is required.

Healthy Steps/Children's Health Insurance Plan (CHIPS)

This is the newest insurance plan to provide health insurance to working families with uninsured children.²⁹ A child may be eligible if they are less than 18 years of age, do not have health insurance, do not qualify for the North Dakota Medicaid program, and

who live in families with qualifying incomes. Families may qualify with net incomes at 140% of the federal poverty level.

Children's Special Health Services (CSHS)

Medical assistance for diagnostic clinic and contracted services is provided for medically eligible children under the age of 21, regardless of their income.³⁰ Financial assistance is available to those who fall within 150% of the poverty level for specialty treatment services.

North Dakota Association for the Disabled, Inc. (NDAD)

This is a nonprofit, charitable organization to assist citizens of North Dakota with mental and physical disabilities.³¹ NDAD raises funds through community projects to generate funds to help relieve financial stress. Funds may be used towards disability related equipment and supplies, travel expenses to distant medical facilities, attendant care, hospital, clinic, and doctor bills, or other disability related costs.

Family Services

North Dakota Family Voices

Family Voices is a network of families, caregivers, professionals, and friends throughout the United States touched by children with special health care needs who provide information to families, policy makers, researchers, the media, and the general public.³² Projects implemented by this group help to improve well being and health of the children with special needs and their families. North Dakota has a statewide Family Voices organization that provides a local resource and newsletter.

Family to Family Network

This network matches families of children with special health needs, who were able to adapt successfully to these needs, with families in a similar situation who may be just learning about their child's diagnosis.³³ It is a volunteer support network designed to provide emotional support and understanding, shared experiences, and guidance in accessing resources.

Easter Seals/Goodwill

Services provided by Easter Seals/Goodwill include respite care, supportive home care, family care option, warm water therapy pool, equipment loan, children's camp, information and referral, and advocacy for individuals with disabilities.³⁴ Respite care includes care for an individual with special health care needs to enable their family or primary caregiver to have relief of this position. Supportive home care offers assistance to the primary caregiver and together, they meet the needs of the person with the disability. Family care option allows a person with a disability under age 21 to be placed in a home outside their family. Easter Seals assists in coordinating and monitoring the placement into a home. Children's Summer Day Camp program and camping session at a North Dakota lake are fun, free activities for children with special health care needs. Direct service staff is available to any children who need it to assist with daily cares and other activities. Easter Seals charges a small monthly fee, for equipment maintenance, for use of equipment such as wheelchairs, walkers and other assistive equipment an individual with a disability may need to borrow.

Respite Care

This topic was previously explained and may be provided by Easter Seals Society, licensed and registered day care providers, private providers, persons who are specially trained, center-based child care providers, friends and family members, and college students.³⁵

National Organizations

There are many organizations dedicated to specific conditions or disabilities such as the American Diabetes Association.¹⁸ Most of these organizations are easily accessible through the yellow pages, Internet websites, or local newspapers.

March of Dimes Birth Defects Foundation

This foundation is designed to provide support for the prevention of birth defects and infant mortality to make access to health care, research, prevention programs, and support for not-for-profit programs readily available.³⁶ Funds are raised through "WalkAmerica", a national fundraising walk in over 1,400 communities, to fight to save babies from birth defects, low birth weight, and infant death.³⁷

North Dakota Center for Persons with Disabilities

This center was designed to promote independence, productivity, integration, and inclusion of people who have disabilities.^{28,38} These goals are met through submitting proposals to the government to change legislation, allowing equal rights to individuals with disabilities. NDCPD also submits proposals for funding for training programs, to create the Institute for Rural Human Services designed to support human services needs in rural North Dakota, to allow for inclusive education for high schools students who are

deaf and/or Native American, and to enhance the training and services for those with disabilities in rural areas.

Shriners Hospital

This is a network of pediatric specialty hospitals for orthopedic, burn, or spinal injury patients. All services are provided free of charge to patients under the age of 18 whose condition has a reasonable possibility to be helped.³⁹

Gillette Children's Specialty Healthcare

This facility, located in St. Paul, Minnesota, is devoted to research, education and treatment for children with disabilities.⁴⁰ Gillette Children's Specialty Healthcare is also known for using the latest forms of treatment and technology, leading the forefront for medical services provided to their patients. Parents and families from North Dakota are able to seek care from this facility if they desire.

Pathfinder Family Center

This center was developed to provide parent training to parents of children with special needs. Parent training is intended to help parents better understand the needs of their child with a disability, participate in the decision making process, interact with professionals, obtain resource information and available support.^{41,42} Most of the resources provided by Pathfinders Family Center is free of charge with a yearly \$25 Family/Individual Membership fee. This organization also organizes Families Helping Families, which links families of children with disabilities who have similar concerns and a need for support from someone who understands their situation.⁴¹

Interagency Project for Assistive Technology (IPAT)

This program assists in providing assessment of need for assistive technology, organizes equipment loans, advocates for those with needs for technology, and provides free technical assistance to individuals with disabilities through the NDAT info-line.²⁸

National Information Center for Children and Youth with Disabilities (NICHCY)

NICHCY is an information clearinghouse that provides individuals with information about disabilities and disability related issues.²⁸

The ARC of North Dakota

The ARC provides services including individual advocacy, education/training, information/referral, systems advocacy, volunteer opportunities, sibling support, public policy development, membership, self-advocacy, and family support.⁴³ Services provided by the ARC are funded by membership dues and donations.

Mothers United for Moral Support, Inc. (MUMS)

This organization is the National Parent-to-Parent Network for parents or care providers of a child with any disability, condition, or disorder.⁴⁴ It provides support to parents through a networking system matching them to parents of children with similar conditions. Families in North Dakota may access these services through the Pathfinder Family Center, the Federation of families for Children's Mental Health, or the Family to Family Network.

Options Resource Center for Independent Living(MN)

Options Resource Center is a not-for-profit organization formed to promote independence for individuals with disabilities.⁴⁵ It provides information and referral, assists individuals in identifying available services, teaches individuals about their rights,

advocacy, independent living skills, peer counseling, and community education and outreach.

The Federation of Families for Children’s Mental Health

This state and national parent-run not-for-profit organization provides services for children and their families with emotional, behavioral, or mental disorders.⁴⁶ Support to families includes: advocacy education to parents, organization of support groups and help for existing support group growth, provision of information to families about needed resources, and services and activities to enhance family support. The Federation also has relationships with many professionals and organizations involved in the care of children with special health care needs in order to access their expertise to help families. The Federation's primary focus is on family support and their Families Helping Families network links families to others with similar circumstances.

Tracking and Screening Services

North Dakota Early Childhood Tracking System

This free multi-agency service monitors children’s growth and development, identifies developmental concerns, and helps families by providing a single point of referral.⁴⁷ Teams consist of doctors and nurses from various hospitals and clinics, community health programs, infant development programs, WIC, Head Start, Public Schools, County Social Services, North Dakota Health Tracks, County Extension Services, Regional Human Service Centers, and others serving young children and their families.

Follow-Up and Referral Multidisciplinary Clinics

A service provided for children born at less than 35 weeks gestational age, weighing less than 4.4 lbs, and children with previously identified neurodevelopmental risk factors.⁴⁸ Services include neurodevelopmental assessment, assisting in infant care and feeding questions, assessment of early signs and symptoms of developmental delay, as well as referrals as needed. These services are currently only provided in Bismarck, Fargo, and Grand Forks, North Dakota.

Educational Services

Early Head Start/Head Start

Early Head Start is available in various counties for children ages 0 to three, from families with low income, while Head Start includes children three and four years of age, from families with low income. These children are provided with early intervention programs to enhance development and decreased problems.¹⁸ Each year a poverty line is established by Congress which serves as eligibility criteria for participation in Head Start, each state is allowed to serve 10% enrollment over their set income level. Ten percent of the children in Head Start must have a disability and may or may not fall within the income eligibility criteria. Head Start fosters family and community involvement through its services of transportation, meals, parent training, social services, educational services, and health, mental health, and nutrition. Early Head Start is offered by some towns to assist expectant parents/caregivers how to provide for the healthy growth of their children.

CHAPTER 7

ACCESSING SERVICES FOR A CHILD WITH A SPECIAL HEALTH CARE NEED IN NORTH DAKOTA

This chapter outlines and describes the many avenues of services available for children with special health care needs, including early intervention and developmental disability services, education, support groups, and financial assistance.

Information, Referral, and Medical Services

Early intervention services, developmental disability services, and the public health department are all important to families when starting to find resources for their child with a special health care need. One of the most important first contacts for a child 0-3 years of age should be with the lead early intervention agency in the state, which in North Dakota is the Department of Human Services.¹⁷ This department is in charge of eight regional Human Service Centers located in Bismarck, Devils Lake, Dickinson, Fargo, Grand Forks, Jamestown, Minot, and Williston.⁴⁹ Parents/caregivers may contact the Department of Human Services or the Human Service Center in their region to arrange for an evaluation and assessment, which will determine if their child is eligible for early intervention services.¹⁷ Early intervention services may assist in identifying and treating problems or delays, enhancing communication and cognition, and physical, adaptive, social, and emotional development. In a conversation with Marilyn Arneson, Developmental Disabilities case manager at North Dakota Northeast Human Service Center, on March 7, 2000, it was stated that a child may be eligible if they have a high

risk diagnosis or are assessed with a 25% delay in two areas or a 50% delay in one area. The various areas a child may have a delay in include: physical, cognitive, communication, social or emotional, and/or adaptive development.¹⁷ Once a child is found eligible for services, the family will be assigned a case manager who may assist in locating other services in the area. The case manager will work with the family while the child is receiving early intervention services and help transition the child and family to programs for children ages 3 and older when necessary.

Arneson also stated, on March 7, 2000, that developmental disability services are provided for children with developmental disabilities after the age of three. A developmental disability may be defined as an individual's inability to perform an activity or skill that other children his/her age are able to do.²¹ Developmental Disability Services can be accessed through the Department of Human Services or the regional Human Service Center. These children will also be assigned a case manager who performs similar duties as the early intervention case manager. In the Public Health system, care coordinators can be assigned to families and their children to aid in accessing needed information and medical services. The Department of Public Health can be contacted through the local Public Health Department.

Along with medical personnel, therapists, child development specialists, social workers, and others, the case manager/care coordinator working together with the family can help develop an Individualized Family Service Plan (IFSP).¹⁷ The IFSP recognizes the family as the child's greatest resource and builds on the strengths the family demonstrates. An IFSP must describe the child's developmental level, list family information and make-up, list the major goals and outcomes expected to be achieved by

the child and the family, state the services the child will be receiving, identify the location these services will be administered, list a time frame the services are given in, list the steps that are taken to support a child's transition to another service or program and state the name of the service coordinator for the child and family. Through the gathered information, the IFSP helps to identify areas of needed services including financial information and what steps the family must take to ensure their child will reach their highest potential.

Education

In a conversation with Donene Feist, Parent Director of the North Dakota Family to Family Network, on February 17, 2000, it was recommended that the local public elementary school be contacted at least 6 months before the child turns 3 years old. Feist stated that a parent may contact the school's principal and be referred to the special education unit, or they may contact the special education director at the school. Public law 94-142,⁵⁰ which was known as The Education for All Handicapped Children's Act (1975), stated that all schools must provide special education services to eligible children ages 3 to 5 years who have disabilities. In 1997, the Public Law 105-17⁵¹ amendment changed the Education for All Handicapped Children's Act to the Individual's with Disabilities Act (IDEA). The basic premise of IDEA includes the right to free appropriate public education; the right to an educational placement based on assessment and evaluation of the child's specific needs; the right of the child with special needs to receive instruction that is designed to meet their needs as stated in an Individualized Educational Program (IEP); the right to full range of educational services that may include counseling, transportation, speech/ language pathology, occupational or physical

therapy; the right of parents being included in their child's educational plan; and the right to appeal any decisions they deem necessary.

Support Groups

“I belonged to a group of moms and from them came the reassurance that I was going to be okay...Here I could let it all hang out. We talked about resentment at mismanaged pregnancies and birthings; frustrations with case managers that didn't manage, doctors who didn't listen, and spouses who didn't help. This was a safe place to express my feelings where the listener would really understand and wouldn't think I was “falling apart” or “still grieving” or “not handling it too well.” We laughed together. We cried together. Even though our children had different disabilities, we were alike: Alike in our anger, alike in our fear, alike in our hope.”⁵² This quote is an example how support groups may influence individuals through open communication and understanding. Family support groups come in all types including support groups for families of children with disabilities, training and information programs, and groups for children with specific disabilities.¹⁷ These groups are important for families to share information, emotional and practical support, and common concerns with other families like themselves.⁵² Support groups may be accessed by contacting the local, state, or national representative for the group. The group representative may be contacted by asking a case manager at the local Human Service Center or the Department of Public Health, local schools special education employees, medical professionals including physicians, nurses and social workers, newspaper notices, church bulletins, telephone directories, through world wide web searches, and posted notices or advertisements throughout the community.¹⁷

Many families may also find numerous resourceful materials at the local public, college or university library.⁵² *The Special Needs Reading List: An Annotated Guide to the Best Publications for Parents and Professionals* is a starting point for researching various books on disability issues. The Prevention Resource Library located in Bismarck, North Dakota has an extensive collection of books and other resources about Early Intervention.⁵³ The Harley E. French Medical Library, University of North Dakota, also has an Early Intervention resource collection.

Financial Assistance

When beginning the search for financial assistance, Irving Dickman and Dr. Sol Gordon, authors of *One Miracle at a Time*,⁵⁴ recommended the first resource to contact unquestionably is Supplemental Security Income (SSI). This is a federal program, which can be applied for at any local Social Security Administration office.²⁴ Once an individual is accepted for SSI, he/she is automatically qualified for Medicaid and other local and federal entitlement programs, which may assist in paying for various services.^{52,54} Medicaid is also a federal program, which may be applied for at any local county social service office.²⁵

Statewide programs that may provide additional assistance include: ND Health Tracks, WIC, CHIPS, Caring Program for Children, CHAND, CSHS, NDAD, and the Childcare Assistance Program.²⁸ Information and applications for the Caring Program for Children, CHIPS, and CHAND may be obtained through Blue Cross/ Blue Shield of North Dakota. Financial assistance through CSHS can be applied for with any local county CSHS worker. NDAD has offices located in Grand Forks, Minot, and Williston, which can provide information about financial services available. ND Health Tracks and

the Childcare Assistance Program may be applied for at the local county social service office.

According to the National Information Center for Children and Youth with Disabilities (NICHCY), a family's private health insurance plan should not be forgotten when searching for financial assistance.⁵² Reimbursement through a private health insurance plan may include: nursing, psychological services, nutrition services, and physical, occupational, and speech therapies. Arneson indicated, on March 7, 2000, that it is important for families to be familiar with their individual plan and all it entails.

Additional resources which may be beneficial to contact for financial assistance and information include hospital social workers, public health departments, public health nurses, volunteer agencies, disability organizations, and state government agencies.⁵² It is also important for families to keep accurate records of their medical, dependent care, and educational expenses because these may be deducted on the Federal income tax return.^{52,55} Examples may include devices to aid citizens with a handicap, such as braces, eyeglasses, and wheelchairs, transportation expenses including ambulance fees or general everyday travel, and medical expenses from special diets to hospital fees.⁵⁵

Local colleges and universities also have a variety of useful programs available to the public.⁵⁵ These institutions offer a variety of services at little to no cost to the consumer. Services are provided by students in numerous fields of study including education, psychological, and medical services. The college students are overseen by their supervising faculty and are allowed to provide the needed services while furthering their education.

Specialty Services

Services for families in the rural area, Native American communities, or involved in the military have additional contacts and assistance programs.¹⁷ For families in rural areas there are two national groups that may be of assistance, the American Council on Rural Special Education and the Rural Institute on Disabilities. In addition to contacting the services listed in this chapter, Native American families living on reservations can contact the office of the tribal leader, the tribal education committee, local schools, or Indian Health Services (IHS). Military families with children with special needs may find additional information through the national Specialized Training of Military Parents (STOMP) or by contacting the local Community Service Center.

CHAPTER 8

RESULTS

The resultant product of this independent study is a brochure including a flowchart and resource guide designed to assist professionals and families in North Dakota access services for children ages 0-5 with special needs. The flowchart outlines the pathways that may be used, from the time of the child's diagnosis until age 5, to access available services including hospitals, information, referral, and medical services, financial assistance, family services, and education. The flowchart provides entry points and directional assistance through the steps involved in accessing each service. This document also illustrates many possible avenues for accessing care, as each child is different and so is their process of finding the appropriate services for their care. Therefore, parents/caregivers and professionals may find certain pathways on the flowchart more helpful than others, based on the child's individual needs.

A supplemental resource guide is provided to assist in contacting the many services available in North Dakota. Phone numbers and web sites are listed to assist parents/caregivers and professionals in finding more information about these services including eligibility requirements, how to apply for the service, and what benefits the child will receive from the service. The resource guide is categorized according to the type of services providing including hospitals, information, referral, and medical services, financial assistance, family services, tracking and screening services, education, rural services, Native American services, and military services.

The flowchart and resource guide were compiled to form a brochure containing all the information from both sources. It is anticipated that this brochure will be made available to families, caregivers, professionals, and students at hospitals, clinics, and in other areas where services for children with special health care needs are administered. The brochure will also be available by contacting Children's Special Health Services of North Dakota in Bismarck, North Dakota.

CHAPTER 9

DISCUSSION

Limitations of Study

The major limitation of this study is the continuous change of the services available in North Dakota and changes in the process of accessing these services. New services may be developed in the area of financial services, medical services, or family support to supply a certain group of individuals in North Dakota. Existing services may vary their eligibility requirements or converge with other services. The fact that this information is always changing makes this independent study accurate only for the year it was developed. However, this study is still useful for the future, if certain information is updated. Families, students, and professionals can still use this information to identify primary entry points to access services.

The process of accessing services and the variety of services available in North Dakota is very complex. Therefore, a second limitation of this study is that some of the specialty services available in North Dakota may have been left out from this project. Also, various agencies in different counties and cities may have different ways of accessing services within their department, making this information inappropriate for their agency.

A third limitation of this study is the broadness of the flowchart design. This flowchart was designed to provide informative pathways for accessing services for a typical family with a child with special health care needs. Certain steps in the process of

accessing services may be slightly different depending on the type of diagnosis of the child and the services rendered. Families may use different pathways depending on their child's needs.

Recommendations

Recommendations for further study could be expanding the outline of this flowchart to design a specialty flowchart for each major childhood disability. This may be more individualized for families and easier to follow. At the same time, it may be more confusing if their child has multiple diagnoses, and they don't know which pathway to follow.

A second recommendation may be expanding this project to include children up to the age of 21. This may include additional services such as independent living and career planning. The project could be divided into age groups, so it is not too overwhelming for families to understand. This may be useful for families and professionals to be more educated and prepared as the child transitions through different stages of their life.

Conclusion/Clinical Implications

This independent study and the supplement flowchart and resource guide were primarily developed for families of children with special health care needs. The supplemental documents were developed to educate these families on the process of accessing services for their children. The information should be useful for a variety of families throughout North Dakota with children who are between 0-5 years of age.

This independent study is also beneficial for students and professionals involved in health careers to learn about the process families of children with special health care

needs must go through to access services. According to Joanne Folts Mackey, a parent of a child with special health care needs in *A Parent's Perspective*,¹ “Medical/professional schools traditionally offer little training, or place low priority on the referral of families for resource information.” This independent study can provide students and professionals with ideas for further referral services. These professionals and students may include pediatricians, nurses, physical therapists, occupational therapists, speech-language pathologists, audiologists, social workers, and case managers. In the health care profession, it is important to be a person families can turn to for advice and questions. Without the proper education on resource information, families may lose confidence in professionals abilities to care for their child, if they are not a knowledgeable and resourceful person.

Physical therapists working with children with a special health care need often see these children 1-3 times per week. Frequently, the families come with to therapy sessions for educational benefits and support. It is important to provide the best quality service by not only treating the child, but additionally supplying their families with educational information to continue helping their child at home. Being able to provide these families with resource information and referral services, limits some of the confusion these families are encountering and makes the physical therapy profession even more valuable.

APPENDIX A

A Guide for Parents and Caregivers in North Dakota:

Accessing Services for Children Birth to Age 5 Years with Special Health Care Needs



*Provided by
Children's Special Health Services of North Dakota*

*Developed by Jana Schmidt, Lynsey Schmidt and Peg Mohr
Department of Physical Therapy
University of North Dakota*

in collaboration with the

*Family Advisory Council and Terry Bohn
Children's Special Health Services
North Dakota Department of Human Services*

If the brochure is missing from this page contact Terry Bohn of Children's Special Health Services at 1-800-755-2714 or Peg Mohr at the University of North Dakota Physical Therapy Department at 701-777-2831.

REFERENCES

1. Mackey JF. A parent's perspective. In: Kavanagh L, Paul N, eds. *Genetic Services for Underserved Populations*. Volume 26. Washington, D.C.: National Center for Education in Maternal and Child Health; 1990:105-108.
2. 1998 Fact Book North Dakota Kids Count. Grand Forks, ND: North Dakota KIDS COUNT; 1999.
3. March of Dimes Birth Defects Foundation. Perinatal profiles: statistics for monitoring state maternal and infant health. North Dakota 1999 Edition. Available at: <http://www.PerinatalDataCenter@modimes.org>.
4. Cadman D, Shurvell B, Davies P, Bradfield S. Compliance in the community with consultants' recommendations for developmentally handicapped children. *Dev Med Child Neurol*. 1984;26:40-46.
5. Buka SL, Kochanek TT. Influential factors in the utilization of early intervention services. *Journal of Early Intervention*. 1998;21:323-338.
6. McKay M, Hensey O. From the other side: parents' views of their early contacts with health professionals. *Child Care Health Dev*. 1990;16:373-381.
7. Children's defense fund. In: Buka SL, Kochanek TT. Influential factors in the utilization of early intervention services. *Journal of Early Intervention*. 1998;21:323-338.
8. Department of health and human services. In: Buka SL, Kochanek TT. Influential factors in the utilization of early intervention services. *Journal of Early Intervention*. 1998;21:323-338.
9. Institute for medicine. In: Buka SL, Kochanek TT. Influential factors in the utilization of early intervention services. *Journal of Early Intervention*. 1998;21:323-338.
10. Kahler L, O'Shea R, Duffy L, Buck G. Factors associated with rates of participation in WIC by eligible pregnant women. In: Buka SL, Kochanek TT. Influential factors in the utilization of early intervention services. *Journal of Early Intervention*. 1998;21:323-338.
11. Meisels SJ. Prediction, prevention, and developmental screening in the EPSDT program. In: Buka SL, Kochanek TT. Influential factors in the utilization of early intervention services. *Journal of Early Intervention*. 1998;21:323-338.
12. Selby MA, Riportella-Muller R, Sorenson J, Quade D, Sappenfield M, Potter H, Farel A. Public health nursing, interventions to improve the use of a health

- service: using a pilot study to guide research. In: Buka SL, Kochanek TT. Influential factors in the utilization of early intervention services. *Journal of Early Intervention*. 1998;21:323-338.
13. Chronic conditions: the continuum of care. In: Broome ME, Rollins JA, eds. *Core Curriculum for the Nursing Care of Children and Their Families*. 1st ed. Pitman, NJ: Jannetti Publications, Inc.; 1999:333-341.
 14. Stanfield PS, Hui YH. *Introduction to the Health Professionals*. 3rd ed. Sudbury, MA: Jones and Bartlett Publisher; 1998.
 15. Glossary of Health Care Terms. Delaware Healthcare Association glossary of health care terms and acronyms. Available at: <http://www.deha.org/Glossary/GlossaryG.htm>. Accessed July 18, 2000.
 16. Birchenall JM, Streight ME. *Health Occupations Exploration and Career Planning*. St. Louis, MO: The C.V. Mosby Company; 1989.
 17. National Information Center for Children and Youth with Disabilities. A parents guide to accessing programs for infants, toddlers, and preschoolers with disabilities. Available at: <http://www.nichcy.org/pubs/parent/pa2txt.htm>. Accessed April 15, 2000.
 18. North Dakota Services Directory for Persons with Developmental Disabilities. Bismarck, ND: Department of Human Services; 1996. Funded by North Dakota Center for Disabilities and Department of Human Services, Developmental Disabilities Division. Grant provided by US Department of Education. H181A50034.
 19. Children's Special Health Services Division. *Children's Special Health Services*. Bismarck, ND: Dept of Human Services; March 1998. Publication DN 1496.
 20. Northeast Human Service Center. *Developmental Disability Services*. Grand Forks, ND: Northeast Human Service Center.
 21. Northeast Human Service Center. *Infant Development Program*. Grand Forks, ND: Northeast Human Service Center.
 22. Grand Forks County Social Service Center. *Grand Forks Herald*. April 16, 2000; Supplement:5.
 23. Grand Forks Public Health Department. *Care Coordination for Children with Special Health Needs*. Grand Forks, ND: Public Health Dept.
 24. Social Security Administration. *Supplemental Security Income*. ND Northeast Human Service Center; May 1995. SSA Publication 05-11000.

25. North Dakota Department of Human Services Medicaid Division. *Medicaid*. ND Dept of Human Services; December 1998. Publication DN 555.
26. North Dakota Department of Human Services. *Child Care Assistance Program*. ND Dept of Human Services; July 1998. Publication DN 861.
27. *ND Health Tracks, EPSDT: Healthy Children Right from the Start*. ND Northeast Human Service Center.
28. Children's Special Health Services. *Resources for Children with Hearing Loss*. ND Dept of Human Services.
29. Medical Services Division. *Healthy Steps: Children's Health Insurance Plan*. ND Dept of Human Services.
30. Institute for Child Health Policy. Children's Special Health Services: North Dakota. Available at: <http://www.state.nd.us/>.
31. North Dakota Association for the Disabled, Inc. NDAD home page. Available at: <http://www.ndad.org/>. Accessed July 21, 2000.
32. About family voices. *Family Ties*. Spring 2000: vol 1, issue 3;2.
33. Family to Family Network. *Helping Hands*. Grand Forks, ND: Family to Family Network.
34. *Easter Seals Goodwill ND: Serving North Dakota Since 1947*. ND Northeast Human Service Center.
35. Region IV Children's Services Coordinating Committee. *Respite Child Care*. ND Northeast Human Service Center.
36. March of Dimes Birth Defects Foundation. Available at: <http://www.hoovers.com/co/capsule/9/0,2163,46999,00.html>. Accessed May 23, 2000.
37. March of Dimes Birth Defects Foundation. *March of Dimes WalkAmerica*. ND Northeast Human Service Center.
38. North Dakota Center for Persons with Disabilities. About NDCPD. Available at: <http://www.ndcpd.org/ndcpd/about/index.html>. Accessed May 23, 2000.
39. Shriners Hospitals. Shriners hospitals for children. Available at: <http://216.221.177.158/Hospitals/index.htm>. Accessed July 21, 2000.

40. Gillette Children's Specialty Healthcare. About Gillette children's. Available at: <http://www.gillettechildrens.org/aboutgillettecover.html>. Accessed July 21, 2000.
41. North Dakota Pathfinder Family Center. *Public Information Packet #202*. Minot, ND: ND Northeast Human Service Center; April 1997.
42. North Dakota Pathfinder Family Center. *Guide to Family Support Services*. ND Northeast Human Service Center.
43. *The Arc, Upper Valley*. Altru Health Systems, Grand Forks, ND.
44. MUMS National Parent-to-Parent Network Newsletter. *The Matchmaker*. Green Bay, WI: Mothers United for Moral Support, Inc; February - April 1999.
45. *Options Resource Center for Independent Living*. East Grand Forks, MN: Altru Health System, Grand Forks, ND.
46. *North Dakota: The Federation of Families for Children's Mental Health*. Grand Forks Public Health Dept.
47. North Dakota Departments of Health, Human Services, and Public Instruction. *North Dakota Early Childhood Tracking System*. Bismarck, ND: Altru Health System, Grand Forks, ND.
48. Child Evaluation and Treatment Program. *Neonatal Intensive Care Unit (NICU) Follow-Up Clinic*. Grand Forks, ND: Altru Health System.
49. Public Human Services Directory. *North Dakota*. Vol 60. Washington, DC: American Public Human Services Assoc; 1999:340-347.
50. 20 U.S.C. Secs. 1400-1485 (As of Oct. 8, 1986)
51. Part 300.13. Rules and Regulations. Federal Register. Vol.64, No. 48, March 1999.
52. National Information Center for Children and Youth with Disabilities. Parenting a child with special needs: a guide to reading and resources. Available at: <http://www.nichcy.org/pubs/newsdig/nd20txt.htm>. Accessed April 15, 2000.
53. Early Intervention Library Catalog. Bismarck, ND: Department of Human Services; 2000.
54. Dickman I, Gordon S. *One Miracle at a Time*. New York, NY: Simon & Schuster; 1985.

55. Deppe PR, Sherman JL. *The High Risk Child: A Guide for Concerned Parents*. New York, NY: MacMillan Publishing Co, Inc; 1981.