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

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*University of North Dakota*

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

by

Lynsey 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

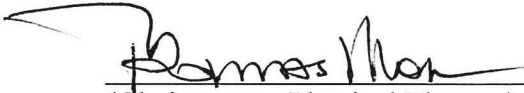
May  
2001



This Independent Study, submitted by Lynsey N. 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)

  
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(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

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## TABLE OF CONTENTS

Acknowledgements.....	v
Abstract.....	vi
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 Requirements 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 .....	48
References .....	50

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## 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 from the 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."<sup>1</sup> 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

Many states experience changes due to the continual community and family growth, change, or revision. North Dakota is no exception to the rule.<sup>2</sup> This chapter is focused on the changing of various demographic components of North Dakota including the population in the surrounding area, family composition, economic status, children's health status, education, child safety and overall attitudes held by the individual family members. Some of these factors may have consequences seen mostly in children. The ways in which these factors affect the delivery and utilization of services and care for children is discussed.

#### **Population**

North Dakota's population is among the smallest in the United States, ranking 47th nationally.<sup>2</sup> Total population in this state is 640,883 with 49,421 of this total comprised of children ages 0 to 5 years of age. Over the past few years, total population has been declining due in part to decreases in agriculture and record flooding throughout the state. Among the states 53 counties, 27 of these have decreases in the number of residents, to below 5,000, with the majority of the population in North Dakota residing in rural areas. It is difficult for families living in rural areas to travel the necessary distance to receive adequate health care services. As a result, those residing in small communities may be drastically affected by shortages in needed resources, including health care workers and services, to support healthy growth.

Population is also affected by the infant mortality rate. The leading cause of infant mortality for the past 20 years in the United States has been birth defects, which have accounted for more than 1 in 5 infant deaths.<sup>3</sup> North Dakota alone has approximately 334 babies born with a birth defect annually, compared to the national estimate of 150,000 babies born with birth defects per year.

### **Family Composition**

The changing composition of families in North Dakota has been affecting children for many years.<sup>2</sup> The percentage of single parent families increased from 13% to 18 % between 1985 and 1995. This fact has left many families struggling to meet the needs of their children. One reason for this struggle is due to the high percentage of these families that are headed by single teen parents, many of which may not be receiving child support payments making it more difficult to provide for their children. In 1995, it was found that 83% of North Dakota's preschoolers had working parents, while the national average of preschoolers with working parents is 20 percentage points lower at 63 percent. It was also found that in 1995, more than 1 in 4 children under the age of 12, in North Dakota, lived in families that were likely to require financial assistance to secure the necessary childcare in order to continue working. These statistics emphasize the hardships and challenges many North Dakota families must face within the childcare system and concerning family issues. It is also estimated that 7% of North Dakota children have more than 4 characteristics that place them in the high-risk category for serious challenges to their well-being. These characteristics include: single parenthood, lack of parental education, below poverty income, lack of secure employment, welfare dependency, and lack of health insurance.

## **Economic Condition**

There has been a slight improvement in the economy in North Dakota over the past decade along with a decline in the number of impoverished children.<sup>2</sup> Conversely, 29 counties and 6 regions in North Dakota continue to have child poverty rates well above the state average. Though declines have occurred, other problems continue to exist which have drastically affected many families. Fewer families continue to be eligible for economic assistance programs due to the numerous changes in eligibility requirements and regulations since 1997. It has been calculated that, in North Dakota, 1 in 6 children live below the poverty line. In 16 of the state's counties the child poverty rate is above 20 % and 13% of children live in "near-poor" families. The effects of changes in policies and programs may also eventually lead to more children entering care out of their homes, and "preliminary findings across the state indicate that reductions in welfare, food stamps and disability benefits are diminishing the ability of some families to meet their children's most basic needs."<sup>2</sup> The accumulation of these factors combined, according to *North Dakota KIDS COUNT!*,<sup>2</sup> may lead to additional risks for the future of children in North Dakota.

## **Child Health**

Overall, the health status of children in North Dakota is favorable regarding national ranking on the number of low birth weight babies, weighing less than 5.5 pounds. However, there has been an increase in low birth weight babies by 15% between 1995 and 1997 which includes 6% of the babies born in North Dakota.<sup>2,3</sup> Research from the *March of Dimes Birth Defects Foundation*<sup>3</sup> concluded that in 1996, nine out of 161

babies born in North Dakota each week were born with low birth weights, accounting for 5.7% of births.

There was a 15% increase in the number of mothers receiving inadequate prenatal care between 1996 and 1997 in North Dakota.<sup>2</sup> On the contrary, studies conducted by the *March of Dimes Birth Defects Foundation* reported that in 1996, 84.7% of mothers in North Dakota began early prenatal care and that between 1991 and 1996, this percentage had risen more than 2 percent.

Children in North Dakota have also been influenced by living without health insurance, as 10% of the children under age 18 do not have a health insurance plan.<sup>2</sup> An estimated 11.2% of children and 13.9% of women also did not have health insurance between 1995 and 1997.<sup>3</sup> This greatly effects the children, because many children who lack health insurance are less likely to have a usual source of health care, be immunized, or have well-baby screenings. These children are more likely to be hospitalized for conditions that otherwise may have been avoided.<sup>2</sup> The percentage of children without health insurance has been shown to increase as their family income descends toward the poverty threshold. A fairly new health insurance program, for those without coverage, called the *Children's Health Insurance Program* (CHIPS) was adopted by the North Dakota Legislature in 1999. CHIPS covers those at 140% of the federal poverty line.<sup>2</sup> This level of coverage still leaves many children uninsured and \$6.7 million in available federal funds unused.

## **Education**

According to the *North Dakota KIDS COUNT!*,<sup>2</sup> early exposure to differing social, economic, scientific, technological and political realities of society is required in

order for students in North Dakota to contribute, compete and flourish in the future. Also, encouraging parents to seek early assistance for their children with disabilities will help the children receive the special services they are entitled which assists in preparing them for school and their future in society. Low per pupil spending is evident in North Dakota at 18% below the national average. Since there has been an increase in the number of children in North Dakota preschools with disabilities of 17% from 1991 to 1997, children with disabilities in preschool are at risk because of the lack of necessary resources and equipment available to them. Children in North Dakota are also at a disadvantage, at times, due to the high number of children living in rural areas. These families may not have access to after school programs or activities, which may make these types of programs unavailable to them.

### **Child Safety**

Rural communities throughout North Dakota have become victims of stress due to the agricultural difficulties, flooding and other weather related difficulties in recent years.<sup>2</sup> This becomes apparent when examining the increase in a number of child safety indicators. Child abuse and neglect has risen by 4 percent from 1996 to 1997 and instances where abuse required services rose 14.5% in this same time period. *Healthy Families* was recently established in Region IV of North Dakota to help alleviate some of the stress related problems families are facing.<sup>2</sup> Through the provision of education and support services to parents at the time of their baby's birth and in the months to years following, this program is designed to increase the use of healthy child-rearing practices and reduce the prevalence of child abuse and neglect.

According to *North Dakota KIDS COUNT!*,<sup>2</sup> there are many possible goals to set in place to ensure the children's achievement of their highest potential. Some of these goals, as stated in *North Dakota KIDS COUNT!*,<sup>2</sup> may include making the well-being of the children the highest priority in all communities; protecting the areas greatest resource, the children, by providing opportunities for future economic growth; creating jobs with benefits to help families support their children; providing good quality and accessible child care for low-income families; ensuring that low-income families are accessing the appropriate resources available; assisting pregnant women in receiving care to support a health baby; providing health insurance to all children; ensuring that schools are equipped to handle every child; creating opportunities for every child to participate in extracurricular activities; and focusing on sharing any individual concerns for children with others in the community to ensure adequate care for the children.



## CHAPTER 3

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

Many recent studies<sup>4-12</sup> have pointed out an increased under-utilization of services by families of children with special health care needs. Reasons for this trend may include family characteristics such as attitudes and beliefs, income level, demographic location and educational employment of the parents, service provider/parental relationship status, parental agreement with recommendations and any dissatisfaction parents have with providers and professionals.<sup>4-6</sup> The variety of determining factors<sup>4-12</sup> in service utilization has enhanced the need for further study about compliance factors within the health care system.

According to Cadman, Shurvell, Davies and Bradford<sup>4</sup> the need for research into the extent of noncompliance and underutilization of services by parents of children with special health care needs is abundant. Cadman et al<sup>4</sup> reported a 73.2% rate of compliance with recommendations for therapeutic prescriptions, indicating there is a need to address the problem of non-compliance within the health care system. In order to find the root of the problem, Cadman et al<sup>4</sup> researched the major factors influencing parents to utilize services. Parental attitudes and beliefs, clarity of others roles in implementation, overall agreement with the recommendations, client's perception of own qualifications to fulfill recommendations, completeness of explanation of rationale for therapy by the provider, adequacy of time for discussion with professionals, how well parent's and professional's

opinion were considered in assessment, and the belief in efficacy of the recommendations were the major categories that were evaluated. Findings from this study showed that beliefs and attitudes about the recommendations were the most useful factor, over any other measurable attributes, of the child or parents willingness to comply. The most significant attitude factor was the consultant/client relationship and agreement about the specific recommendations. The researchers felt this may prove to be a positive finding because this area is easy to change and alter, therefore, the best care will be given when both parties are willing to communicate openly. While the study indicated professional/client relations to be a major contributor to determining compliance, parent and child characteristics or type of recommendation variables were not significantly related to the rate of compliance.

Kochanek and Buka<sup>5</sup> performed research about the utilization of early intervention services. Through their research, Kochanek and Buka<sup>5</sup> found several other studies<sup>7-12</sup> that reported a significant underutilization of services for children in early intervention programs, especially in entitlement programs such as Women, Infants, and Children, Early Periodic Screening Diagnosis and Treatment, and childhood immunization programs. These studies<sup>7-12</sup> examined factors influencing utilization including: demographic characteristics, economic status, values and attitudes of consumers, and consumers influence on service utilization patterns. Overall, it was concluded that the strongest determinants of underutilization of services were low income, time constraints, and minority group membership. Kochanek and Buka,<sup>5</sup> on the other hand, stated that provider characteristics and the nature of the relationship between consumers and professionals were influential in the utilization of services. The authors

indicated an overall mean utilization percentage of 79.1% for scheduled early intervention appointments by the 146 infants and toddlers involved in their study. No child or maternal characteristics were related to early intervention service utilization while age, educational level, professional discipline and presence of children at home were found to be statistically significant. These findings indicated that younger providers who did not have children but had graduate degrees, were more likely to be working with families who used significantly more services overall. Another major finding was that mothers who believed professional providers should make decisions about services demonstrated a higher utilization rate. Consequently, data pointed out that the assignment of a primary service provider is crucial in the early intervention program use.

According to McKay and Hensey,<sup>6</sup> who interviewed parents of 84 children with cerebral palsy, families voiced frustration about interacting with health professionals when they brought their children to appointments with these professionals. They found that 70% of the families had some type of dissatisfaction with their health care professionals. Complaints included: lack of explanation about the child's condition or about the need for follow-up visits (58%), dismissal of their worries as not important (51%), a need to make repeated visits to the professional before their child's problems were identified (51%), and lack of empathy from professionals when being told of their child's diagnosis (20%). The researchers stated that these results indicate a need for quality improvements to be made within the delivery of services continuum.

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 for Altru Hospital, on March 29, 2000, both of Grand Forks,

North Dakota, it was acknowledged that there is a struggle with underutilization of services within North Dakota. The two professionals stated that many people living in North Dakota value independence, which often leads to the attitude that they can handle any problems on their own. They remarked that a desire for privacy and independence has also led many families to underutilize services that may be of benefit to their children with special health care needs. Both of these professionals have witnessed underutilization of services for children with special health care needs in North Dakota, due in part to these two characteristics of parents, and expressed an ongoing need for understanding and open communication with the parents while continuing efforts to meet the needs of their children.

## CHAPTER 4

### ROLES OF HEALTH CARE PROFESSIONALS

As parents or families of children with special health care needs begin accessing services for their child, they will meet a variety of health care professionals.<sup>16</sup> In most instances, these professionals are part of an interdisciplinary team developed specifically for the needs of the individual child. Interdisciplinary teams work closely with these families, helping to ensure the highest quality of care for the child, and assist families of children with special health care needs as they make life-altering decisions for their child. The team may also help the family make decisions about the current care plan, give referrals for other types of care and assist in accessing financial, medical and emotional support necessary for the family. The interdisciplinary team may consist of: the child, family and family support persons, a pediatrician, nurse, social worker, case manager, physical therapist, occupational therapist, speech and language pathologist, and other pediatric sub specialists. Families may come into contact with some or all of the listed health care workers, therefore an introduction to the interdisciplinary team will be given.

#### **Pediatrician**

The primary role of the pediatrician is to care for children from birth to adolescence.<sup>14</sup> Duties include: performing child health evaluations, giving, and prescribing medicine and vaccinations, and providing resources for parents about any concerns or questions they have about their child. The pediatrician also assumes role of a gatekeeper, overseeing and coordinating all aspects of medical care for the child.<sup>15</sup> The

gatekeeper/pediatrician is in charge of pre-authorizing and referring for other specialized care.

### **Nurse**

Registered nurses (R.N.s) work in many facilities including hospitals, medical centers, schools, physicians' offices, and community health facilities.<sup>16</sup> They perform such duties as caring for injured or sick individuals and educating these individuals and families about staying well.<sup>8</sup> Nurses are also expected to observe and assess children and record information about any reactions, symptoms or progress the patient may be demonstrating. Nurses may instruct parents and family members how to correctly care for children with special health care needs and how to improve or maintain the child's current health status.

### **Social Worker**

Since basic needs of an individual are intensified by illness or disability, social workers assist the patient and family in dealing with any personal problems resulting from long or severe disabilities.<sup>14,16</sup> These professionals also help the child and family with problems related to social, emotional or financial difficulties including money, housing, adaptive equipment, employment, recovery and rehabilitation. Social workers are concerned about immediate needs, long term planning for children whose condition may be permanent, and they may serve as a link from the hospital to returning to life at home following a hospital stay.

### **Case Manager**

Case management, as defined by *Core Curriculum for the Nursing Care of Children and Their Families*, "is 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."<sup>13</sup> This definition may sound similar to an interdisciplinary team, and in essence, it is. A case manager usually heads the case management or interdisciplinary team. The role of case manager is assumed by the individual health care professional on the team who will have the most input into the child's care. Therefore, the case manager may be a physician, nurse, social worker, physical therapist, occupational therapist, speech pathologist, educational specialist and in some cases, a parent or family member.

Responsibilities of the case manager may include: providing leadership and consultation to the team by planning goals/outcomes and interventions and providing background information about the child that is crucial for the team to know about the diagnosis.<sup>13</sup> The case manager completes documentation on the process of the team, evaluation of the effectiveness of care given by the team, evaluation of the current plan and proposes any possible changes or new interventions to assure the highest quality of care for the patient. Case managers may assist families of children with special health care needs in accessing early intervention programs in the state and in locating other services including recreation, childcare, or family support groups.<sup>17</sup>

### **Physical Therapist**

The physical therapy profession is primarily involved with the promotion of optimal health and function.<sup>16</sup> The role of a physical therapist includes: evaluation of the individual's history, functional status, strengths and weaknesses, organization of a plan of rehabilitation and implementation of this treatment plan. The plan of treatment is based on information gathered through the evaluation of the musculoskeletal, neurological,

pulmonary and cardiovascular systems, and the individual's functional abilities. The main objectives of physical therapy are to help individuals achieve the highest amount of functional independence, muscle strength, and physical skills, while helping them adjust to any changes in their physical abilities or lifestyles. Treatments may include: exercises for strength, coordination, endurance, and range of motion, and the use of heat, cold, or electrical stimulation to assist with pain or swelling relief or in stimulating motor activity. Physical therapists may also provide instructions for the individual or family in daily activities and home exercise programs.

### **Occupational Therapy**

Occupational therapists are also involved with promoting health and function.<sup>16</sup> The therapists utilize a variety of techniques to assist individuals in developing or maintaining skills of daily living, and help children and families learn to cope with the emotional and physical implications of an illness or disability. Through the various interventions, an occupational therapist's main goal is to help children establish an independent, productive and satisfying lifestyle. Occupational therapists, like physical therapists, perform an evaluation and plan and implement a treatment plan based on findings in the evaluation. Interventions may include strengthening, practicing cognition and perceptual skills including memory, sequencing, and coordination skills, and following safety precautions. Occupational therapists also help children to master the skills of daily living, by helping individuals cope with their current status. Many occupational therapists also help individuals adjust to the changing experiences by providing instruction in use of adaptive equipment and designing specialized equipment needed to provide more independence to the child in everyday life.



## **Speech/Language Pathologist and Audiologist**

Speech and language pathologists assess and treat individuals who have speech or language problems resulting from any condition and may also help these individuals and family members cope with the stresses of the misunderstanding that often accompanies communication difficulties.<sup>16</sup> Speech/language pathologists often select and teach alternative ways of communication for those individuals with little or no speech. Some alternatives may include automated devices or sign language. These professionals use a variety of tools including computers, tape recorders, audiovisual equipment, and mirrors to help teach individuals how to make sounds, improve their voices, or increase their language skills. Speech/language pathologists also work, in the same manner, to prevent future communication disorders from developing.

Audiologists are concerned with the identification, assessment, treatment, and prevention of hearing problems.<sup>18</sup> Tools used by audiologists include audiometers to measure how well an individual hears and distinguishes sounds and to test the extent of hearing loss. Through this testing, results are compared to medical, educational, and psychological information to make a diagnosis and determine a plan of treatment.

## **Parents and Family Members**

Parents and family members play a crucial role in the interdisciplinary team.<sup>13</sup> Contact with the child with a special health care need is made by parents and family members on an ongoing, daily basis and through this contact, information can be provided the other members of the team that is critical to the child's needs. Family support members including extended family, friends, professional friends, and clergy also assist the team by providing their thoughts and ideas about the needs of the child to the

team. The collaboration of ideas from all team members allows for a better understanding of the child's abilities, goals, and needs and leads to better overall care.

## 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.<sup>18,19</sup> 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.<sup>20</sup>

Need rather than financial status is the basis for eligibility.<sup>21</sup> 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.<sup>18,21</sup> 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.<sup>20</sup> 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.<sup>20</sup> 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.<sup>20</sup> 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.<sup>20</sup>

### **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.<sup>22</sup> 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.<sup>23</sup> 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.<sup>18</sup>

### *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.<sup>18</sup> 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.<sup>24</sup> 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.<sup>18</sup>

### *Medical Assistance/Medicaid*

This program is designed to assist people who cannot afford health care services.<sup>25</sup> 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.<sup>22,26</sup>

### *ND Health Tracks, EPSDT*

This preventative health program for children birth to 21, uses Health Tracks Providers appointed by the County Social Service office.<sup>27</sup> 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.<sup>28</sup>

#### *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.<sup>28</sup> 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.<sup>29</sup> 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.<sup>30</sup> 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.<sup>31</sup> 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.<sup>32</sup> 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.<sup>33</sup> 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.<sup>34</sup> 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.<sup>35</sup>

### National Organizations

There are many organizations dedicated to specific conditions or disabilities such as the American Diabetes Association.<sup>18</sup> 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.<sup>36</sup> 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.<sup>37</sup>

### North Dakota Center for Persons with Disabilities

This center was designed to promote independence, productivity, integration, and inclusion of people who have disabilities.<sup>28,38</sup> 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.<sup>39</sup>

#### Gillette Children's Specialty Healthcare

This facility, located in St. Paul, Minnesota, is devoted to research, education and treatment for children with disabilities.<sup>40</sup> 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.<sup>41,42</sup> 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.<sup>41</sup>

### 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.<sup>28</sup>

### 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.<sup>28</sup>

### 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.<sup>43</sup> 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.<sup>44</sup> 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.<sup>45</sup> 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.<sup>46</sup> 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.<sup>47</sup> 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.<sup>48</sup> 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.<sup>18</sup> 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.<sup>17</sup> This department is in charge of eight regional Human Service Centers located in Bismarck, Devils Lake, Dickinson, Fargo, Grand Forks, Jamestown, Minot, and Williston.<sup>49</sup> 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.<sup>17</sup> 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.<sup>17</sup> 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.<sup>21</sup> 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).<sup>17</sup> 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,<sup>50</sup> 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 105-17<sup>51</sup> 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.”<sup>52</sup> 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.<sup>17</sup> These groups are important for families to share information, emotional and practical support, and common concerns with other families like themselves.<sup>52</sup> 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.<sup>17</sup>

Many families may also find numerous resourceful materials at the local public, college or university library.<sup>52</sup> *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.<sup>53</sup> 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*,<sup>54</sup> 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.<sup>24</sup> 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.<sup>52,54</sup> Medicaid is also a federal program, which may be applied for at any local county social service office.<sup>25</sup>

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.<sup>28</sup> 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.<sup>52</sup> 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.<sup>52</sup> 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.<sup>52,55</sup> 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.<sup>55</sup>

Local colleges and universities also have a variety of useful programs available to the public.<sup>55</sup> 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.<sup>17</sup> 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**

There were limitations that may have affected the results obtained in this study. A major limitation of this study is the fact that the services available in North Dakota and the method of accessing these services are continually changing. These changes may be due in part to the possibility of new services being added to the process, eligibility requirement alterations, and the combination of services to form new agencies or departments. Due to these constant changes in the process of accessing services, the results of this study may be accurate only for the time period in which the research was conducted. However, this study will continue to be useful, in the future, in providing students, professionals, and families with a list of possibilities and starting points in the search for accessing services in North Dakota.

Due to the complexity of the process of accessing services for children with special health care needs in North Dakota and the vast number of agencies, a second limitation of this study is that not all of the available services may have been reported. Also, each department or agency that is involved with health care, financial assistance, family support, or care coordination may have differing suggestions in the process of accessing services. This difference of opinion may become apparent between cities or towns within North Dakota and may vary widely from state to state.

Another limitation of this study involves the generality of the flowchart. The flowchart is based on a 'typical' situation of accessing services for children ages 0 to 5 years of age with special health care needs in North Dakota. All situations are unique to the individual child and each child may not need all the services listed or may require additional services according to their age and type or severity of their health difficulty. The agencies listed in the publication may help assist families find other services not listed, that more specifically address their needs.

### **Recommendations**

It is the researcher's belief that this independent study could be expanded in the future by the development of individual flowcharts that provide information about accessing services based on specific diagnoses. These flowcharts could assist professionals and families address more specifically the individual needs of the child and avoid any difficulties encountered when trying to use the more generalized version that resulted from this independent study. However, if a child has more than one diagnosis, confusion may arise when deciding which path to follow.

It may also be useful to include varying age groups in future studies. This would help to address specific age related difficulties. By dividing the project into different age groups and extending it to 21 years of age, the publication could assist professionals, families and children in planning for various life transitions without being too overwhelming. These changes may include: transitions between schools, transitions to independent living, and employment preparation. Information provided to these individuals would also be helpful in educating and preparing parents and children about what to expect in planning for the future.

## **Conclusions/Clinical Implications**

According to Joanne Folts Mackey, a parent of a child with special health care needs in *A Parent's Perspective*,<sup>1</sup> "Medical/professional schools traditionally offer little training, or place a low priority on the referral of families for resource information, but rarely do they have the tools needed to access accurate information through the scattered available networks...add to this vast array of limitations, the parents' need for immediate, accurate, and comprehensive information." The findings of this independent study can help remedy this problem by assisting students, physicians, nurses, case managers, social workers, physical therapists, occupational therapists, speech and language pathologists and other health professionals, along with parents, in their search for answers concerning how to access care for children with special health care needs. This publication is a useful tool in alerting professionals of many possible avenues of assistance for families. It is imperative these professionals and parents are provided with the most accurate and timely information to help children with special needs receive referrals when necessary for financial, medical, information, and family services available and assist their family in accessing the most appropriate care to help the child obtain their fullest potential.

Clinical implications for physical therapists working with children with special health care needs include a variety of topics. Physical therapists typically see a child 1 to 3 times per week and are involved in the planning and implementation of a care plan for the individual. They work closely with other members of the interdisciplinary team and the child's parents to help provide the best possible care for the child. Working closely with the family also involves providing help in accessing services, providing educational materials to assist the family in caring for the child at home, and offering support to the

child or family. These areas of physical therapy may be just as important to the development of the child as the implementation of exercises or functional activity training which makes the professional of physical therapy all the more important for families and children with special health care needs.

## 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*

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*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.

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