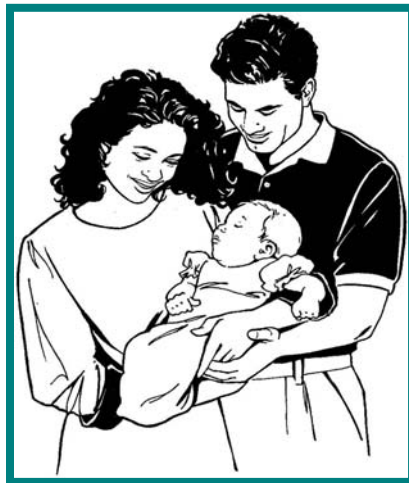


# Self Directing Supports

*A guide for families seeking choice and control*

*Cathy Haarstad, MS  
2005*



# Self Directing Supports in North Dakota

*A guide for families seeking choice and control*

*By Cathy Haarstad, MS*



North Dakota Center for Persons with Disabilities  
A University Center for Excellence in Developmental Disabilities

Minot State University

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This manual uses resources developed by the Center for Self-Determination. The material has been greatly altered and modified to address the needs of families in North Dakota.

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**Review:** Due to the technical nature of the information, this manual has undergone exhaustive review in order to ensure its accuracy. Reviewers include: Ms. Deb Balsdon, and Ms. Vicki Pederson, ND Department of Human Services, Disabilities Services, Regional ND Developmental Disabilities Case Managers

## Regional ND Infant Development Specialists and NDCPD Staff

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## Overview

*We love our children. Our hearts break when we think anything might happen that would put them in harm's way. While disabilities are part of the human condition, raising a child with special needs is not a typical experience. Most families find that they need some extra support to get the job done. Beginning with the downsizing of Grafton and the closing of San Haven during the 80's, the North Dakota Department of Human Services began to help families meet the complex needs of children with developmental disabilities so that those children could live meaningful lives within their own homes and communities. Unfortunately, supports that families needed were not always available. This was especially true in remote rural communities where few provider agencies operated.*

*Over time we have learned that while the needs of families and children for support are endless, resources to meet those needs are not. Current limits imposed by an aging population and shrinking tax base challenge families and human service agencies to do more with less. These circumstances have caused policymakers, advocates, and families to re-examine exactly what our tax dollars are buying. North Dakota resources have largely gone to pay for services that are provided in congregate settings such as group homes and sheltered workshops. Congregate services are expensive and result in large numbers of individuals who remain unemployed or exist on sub-minimum wages. Services are specialized and may keep individuals away from everyday life.*

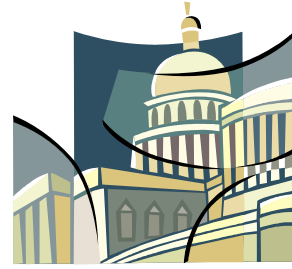
*North Dakota families overwhelmingly prefer supports and services to be available in their home communities and to look and feel like services available to any other North Dakotan. Youth with disabilities and their families are seeking opportunities to achieve personal goals through person-centered planning with the help of a support network from their home community. This vision has given rise to a new and less expensive form of service delivery called self-directed supports.*

*Self-directed supports give people with disabilities and their families the freedom to direct resources to achieve a meaningful life in their community. Self-directed supports use public funding as an investment in the lives of children and families. An investment implies that an outcome is achieved and something is gained in return. Money is not allocated without expectations. Children are assisted to grow up in a family setting. Eventually these children learn to generate income, help to manage a household and give something back to their community. Families receive the support they need to contribute to North Dakota's economic development by working outside the home as desired. This helps families to stay together and prepare young people develop for adult life.*

*Self-directed supports balance the use of public and private dollars and build on contributions from families and communities. Families are challenged to move from relying solely on a program, placement or service to creating new opportunities and resources within their home communities.*

## Background Information

North Dakota uses your tax dollars to provide your family with support. Your government uses federal and state taxes to fund Medicaid. Medicaid started as a program for low-income families. Medicaid:



- Provides excellent health care benefits and supports for children and families.
- Was expected to be temporary for most people.

Then Congress began to look for ways to fund family support programs. Congress found that Medicaid:

- Included many of the supports that families of children with special need require.
- Was less expensive than starting a whole new system for family support.

Congress decided to make it possible for states to tap into Medicaid dollars to fund support programs.



The Centers for Medicare and Medicaid (CMS) administers Medicaid programs at the federal level. Certain income and asset limits must be followed in deciding which families may receive services.

A waiver from CMS allows states to **waive or bend the usual rules** about income to allow certain exceptions. CMS administers several different waiver programs that states use to fund family support. States apply for a waiver and put in matching dollars according to a formula based on each state's population and income.

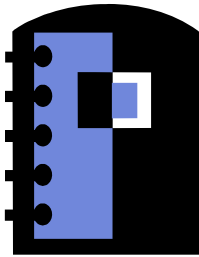
*North Dakota can obtain more services for families by using a limited number of state dollars to access federal dollars.*

Knowing this, the North Dakota State Legislature went one step farther, and passed legislation that disregards the use of assets as well as income. This makes even more ND families eligible for family support and allows the state to serve up to two additional families for every one served before.

Medicaid is no longer just a program for families who have limited income. Today, Medicaid:

- Provides an important safety net for children with disabilities and their families
- Invests in children and families now so that later care and support may cost less
- Makes sense because the cost of raising a child at home is much less than caring for a child in an institution

Investing in families by preventing unwanted institutional placements and assuring that important health and safety needs are met are two bedrock principles that most Americans support.



Self-directed supports are the result of a relatively new waiver option available in North Dakota. This waiver:

- Gives families' greater choice and control in making decisions and obtaining support.
- Allows families the option of directing a fixed amount of public dollars through an individual budget.

Several protections and resources are included in the waiver to help families learn to self-direct supports and take care of some of the more intensive responsibilities related to hiring people and accessing services.

Self-directing supports is **not** for everyone! This manual will help you discover if self-directing supports is right for you and provides resources that you can use to learn how to self-direct supports. We invite you to look through the materials and use what is most helpful for you at this time.