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
2005

Funded by the U.S. Department of Health and Human Services,
Administration on Developmental Disabilities,
Administration for Children and Families,
North Dakota Family Support Project. Grant #90DF0049-01
North Dakota Center for Persons with Disabilities  
A University Center for Excellence for Persons with Developmental Disabilities  
Minot State University  
500 University Avenue West  
Minot, ND 58707

Copyright 2004. We encourage families and people with disabilities to copy and use the forms and tools in this manual to assist them in self directing supports. We give permission for non-profit organizations to publish all or part of these materials for educational and research purposes. We request that appropriate acknowledgement be given. The consent does not extend to other kinds of copying, such as copying for general distribution, for advertising or promotional purposes, for creating new collective works, or for resale. Requests for use of this publication for any other purpose should be submitted to: Self-Directing Supports in ND Project Director, Minot State University, North Dakota Center for Persons with Disabilities, 500 University Ave. W., Minot, ND 58707.

Suggested citation:


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.

DISCLAIMER: This manual was published using funds awarded to Minot State University by the Administration on Developmental Disabilities. The contents reflect the expressed opinion of its’ authors and are not necessarily the opinion of the Administration on Developmental Disabilities or the Federal Government or the North Dakota Department of Human Services or Minot State University. The authors are not attorneys and this manual is not intended to provide legal or tax advice; rather, it is intended as an information resource.

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
Table of Contents

Introduction
Overview
Background Information

Make Decisions
Resources
Handouts
Support options
Compare services chart
A guide to decision making
Involving youth in decision making

Make a Person Centered Plan (PCP)
Learn the Process
Resources
PCP worksheets
Outcome examples
Training options

Build a Plan
Resources
PCP forms
State Medicaid Plan Supports
Evaluation guidelines

Make Emergency Back-Up Plans
Resources
Planning checklist
Emergency forms
Emergency information

Build an Individual Budget
Resources
Support definitions
Budget forms
Budget guidelines
Self-Direct Supports

Get Started
Resources
Planning worksheets
Evaluation guides
Youth involvement checklists

Use Community Services
Resources
Using the web to find out what’s available
A list of community service providers
A guide for building generic services

Hire and Manage Support Staff
Resources
Fiscal agent responsibilities
Family and caregiver roles and responsibilities
Finding a caregiver
Using an employment agency
Interview guide
Evaluating employee performance
Preventing abuse and neglect

Train Family and Friends
Resources
Planning checklist
Training guidelines
Training resources

This material was developed by the ND Center for Persons with Disabilities at Minot State University and may be reproduced only with permission.
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.

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.