

# Self-Directing Supports

*A guide for families seeking choice and control*



# Self-Directing Supports in North Dakota

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A University Center for Excellence in Developmental Disabilities

Minot State University

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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.

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.

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

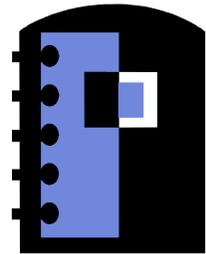
Medicaid is no longer just a program for families who have limited income. Today, Medicaid:

- 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.

# Decision-Making



## *Decision-Making*

**You will make important decisions about self-directing supports. You decide:**

- What outcomes and priorities your family has (example: staying together)
- What supports can help you meet your child's disability-related needs
- Which support option may be the best match for your family
- How much assistance you need to help you plan and manage supports
- How to give your child a greater role in directing supports as he/she ages.

**Resources that might help:**

### **Handouts:**

Learn what the term self-directing supports means. These two handouts give you general information about self-directing supports. Use these to become familiar with this new service.

### **Support Options:**

Learn about three support options available in North Dakota. They include family subsidy, family support and self-directed support. The information is written in everyday terms. The legal source for each definition is included.

### **Evaluation Chart:**

Compare all the different support options. The chart helps you think about services, costs, rules, responsibilities, benefits, and disadvantages. Decide which option is best for you.

### **A Guide to Decision-Making:**

Use this guide to think about self-directing supports. The questions will help you prioritize what is important to your family and decide if you should self-direct supports.

### **Involving Youth in Decision-Making:**

This guide describes why it is important to involve teens with disabilities in selecting and managing resources. Resources and web site links are listed so you can learn more about this process as your child grows.

# ***Self-Directing Supports***

## Handout 1

### **What if you could design a simple plan that would . . . ?**

- Help you raise a child with special needs
- Allow your family to stay together and avoid unwanted out of home placement
- Help meet your child's basic health and safety needs

### **What if you had the information and funds to . . . ?**

- Find the supports you needed to carry out the plan
- Change it as you went along without a lot of red tape

### **What if someone was available to . . . ?**

- Show you how to set up that kind of plan
- Help you set up and manage the budget
- Help with organization and record keeping
- Take care of bills
- Give you ideas about how to get things done

### **What if YOU had the Choice and Control and YOU had the resources and opportunity to make the plan work?**

### **This option is available to families through Self-Directed Supports. Are you . . . ?**

- Living in a rural community without support providers
- Used to running a small business or coordinating activities
- Someone who enjoys making decisions and directing services
- Interested in recruiting and hiring your own care providers
- Someone with the time to take on a new role as long as support is available
- Looking for more choice or control in the services your family receives

If you answered yes to two or more of these five questions then self-directed supports may be right for your child/family.

Self-directed supports are one of 4 support options available to ND families who are raising children with special needs. The following handout compares each program and gives information about the definition, purpose, eligibility, responsibilities, costs and benefits of each program. Why not read more about each one and decide for yourself if self-directed supports are right for you.

# ***Self-Directed Supports***

## Handout 2

Self-directing supports begins when a family develops a **person-centered plan**. The plan is based your child's strengths, dreams, and wishes. The plan supports your family in raising a child with special needs and helps keep your family together. The plan will include:

**Circle of Support:** People, who know, care about and support your child and family.

**Outcomes:** Words that explain what you want the plan to achieve. The results!

**Support:** Steps or actions you and others will take to achieve your goals and make wishes and dreams come true. Steps or actions build support that may be:

**Formal** (Example – a service or support authorized and paid for by state or Federal funds. This can include assistance for a caregiver, therapy, paying for excess child care, help to find or pay for equipment).

**Informal** (Example – a support available to most people that is provided by friends, family, neighbors, or volunteers. This can include a ride to church, a weekly phone call to a teen, a toy for a toddler, getting together with other parents).

**Person-centered:** A plan that meets your child's unique needs. Plans that:

- Build on your child's strengths
- Describe his/her dreams and wishes
- Clearly describe his/her needs
- List outcomes or results to achieve
- Address health and safety needs
- Have back-up strategies

**Choice and control:** Self-directed supports have important differences from other programs.

- **You** choose who is on your team
- **You** decide when, where and how often to meet
- **You** write the plan. **You** decide what it will say
- **You** can get help to make a plan and write it down
- **You** direct the supports that your child receives. **You** can change the plan
- **You** have a budget to help pay for the formal supports in the plan
- **You** have a fiscal agent to help you manage the budget (fiscal agent)
- **You have help** to carry out the plan
- **Your child** can learn to create and direct the plan

**A family support plan helps your child/family get the support they need to:**

- Meet health and safety needs
- Stay together
- Live at home or in your home community if you want to do so

## *Support Options*

### **Family Subsidy**

The family subsidy program helps you meet the excess costs of raising a child with a disability. This program is flexible. You may hire a caregiver directly or use a provider from a licensed agency. Funds may be used to help you . . .

- Meet your child's disability-related needs
- ***Stay together and avoid out of home placement***

Remember: You must pay the excess costs first. Submit proof that the costs have been charged to you and are allowed under program rules. The funds available for Family Subsidy dollars are based on the Department's budget and can vary from year to year.

### **Family Support**

Your case manager can authorize a special caregiver to provide 'in-home support' for your child. The special caregiver *must be hired from a licensed agency and meet special training requirements*. You may choose two kinds of support.

- Someone to stay with your child so you or your spouse can leave and have a break.
- Someone to stay with your child while you are home so you can attend to other children or duties, or get a rest.

You *may* also qualify for the family-care option. Your child can stay in a licensed foster home on a full or part-time basis. For example: If you could not keep your child at home for seven full days, but could manage three or four, then the family-care option might work for you. Again, a licensed provider must supervise the foster home that provides support.

### **Self-Directed Supports**

Create and carry out an individual care plan for your child. Review your child's current hopes, dreams, and needs and identify goals to achieve a meaningful life. List informal and formal supports that you think will help you meet those goals. Your child's case manager will develop a **budget** to fund the formal supports in your plan. Formal supports are not funded if an informal or natural support will work. The program pays for health care, in-home support, materials and supplies or transportation. You direct the budget and carry out the plan.

### **Personal Care Option**

This program can give a payment through the county for families whose children have a disability but do not meet the requirements for Developmental Disabilities (e.g. some children with spina bifida or cerebral palsy) and whose families cannot meet personal care needs (e.g. a parent with cancer or who is elderly). Children must be unable to perform activities of daily living. See your case manager for details about this program.

## Compare Self-Directed Supports with Other Support Options

Questions	Family Subsidy	Family Support Services	Self-Directed Supports
<b>What is this support option?</b>	The <b>Family Subsidy</b> program <b>reimburses families</b> of children with DD <b>for allowable excess costs</b> (e.g. child care, therapy, and equipment) <b>related to a child's disability</b> .	<b>Family Support Services</b> provides families of children having DD with <b>in-home and/or community-based support</b> to assist the family in meeting the needs of a child and prevent unwanted out-of-home placement.	<b>Self-Directed Supports</b> helps families <b>self-direct services</b> needed to carry out a family support plan. Supports include: <b>self-directed in-home supports or disability related supports</b> (skilled supports, materials and supplies, transportation) <b>or employment supports</b> .
<b>What is this program designed to do?</b>	<ul style="list-style-type: none"> <li>• Keep families together</li> <li>• Prevent unwanted institutionalization</li> </ul>	<ul style="list-style-type: none"> <li>• Keep families together</li> <li>• Prevent unwanted institutionalization</li> </ul>	<ul style="list-style-type: none"> <li>• Keep families together</li> <li>• Prevent unwanted institutionalization</li> <li>• Increase family choice and control</li> </ul>
<b>Who is eligible?</b>	Families of children with DD who: <ul style="list-style-type: none"> <li>• are ages 0 to 22 and</li> <li>• receive case management services</li> <li>• may need a specially trained care-giver for excess child care</li> </ul>	Families of children with DD who: <ul style="list-style-type: none"> <li>• are any age (birth –adulthood)</li> <li>• are ages 0-21 for the family-care option</li> <li>• receive case management services</li> <li>• need a specially trained care-giver</li> <li>• would be eligible for services in a special group home (ICF/MR) if a family could no long provide them</li> </ul>	Families of children with DD who: <ul style="list-style-type: none"> <li>• are ages 3 through adulthood for SDS</li> <li>• are ages 3 to 21 for disability related supports</li> <li>• are ages 21 and older for employment supports</li> <li>• receive case management services</li> <li>• need a specially trained care-giver</li> <li>• would be eligible for services in a special group home (ICF/MR) if a family could no long provide them</li> </ul>
<b>How is need determined?</b>	The DD case manager discusses needs with the family and develops a contract based on the minimum amount of support required for the child not to be placed outside of the family. Supports and services must be needed but not available through informal or generic community supports.	The DD case manager discusses needs with the family and authorizes support hours based on the minimum amount of support required for the child not to be placed outside of the family. In-home care from a trained caregiver must be needed but not available through informal or generic community supports.	The family develops a <b>person-centered care plan</b> for the individual with a disability. The team reviews his/her current hopes, dreams, and needs and identifies goals to achieve the lifestyle described in the plan. The plan lists informal and formal supports needed to meet goals. The DD case manager develops a <b>budget</b> to fund the minimum amount of services needed to maintain the child in the family. The budget supports only those <b>formal supports that are needed</b> but not available through informal or generic community supports.

Questions	Family Subsidy	Family Support Services	Self-Directed Supports
<p><b>How does the program work?</b></p>	<p>The DD case manager discusses excess costs with the family and advises them as to which needs might be met through the program. The DD case manager develops a contract for the family.</p> <p>The family pays for services and submits a reimbursement form (usually monthly) with a receipt for an allowable expense. If approved, the family receives payment in about two weeks. Contracts are typically written for six months.</p>	<p>If not already covered, the family applies for Medicaid for the child either directly at the county social service office or from home with help from the DD case manager. A short easy to complete application is used. Families must reapply for Medicaid annually.</p> <p><b>Family assets and income are disregarded ONLY</b> when applying for benefits for the child with a disability. Once found eligible, the case manager authorizes the provider to deliver services for a specific number of hours. That authorization is renewed quarterly.</p> <p>The provider contacts the family to discuss needs and develop a support plan. The provider links the family with caregivers and the family provides the support workers with an orientation to their child/home.</p> <p>Services may be provided in the family home, in the caregiver’s home or in the community.</p>	<p>If not already covered, the family applies for Medicaid for the child either directly at the county social service office or from home with help from the DD case manager. A short easy to complete application is used. Families must reapply for Medicaid annually.</p> <p><b>Family assets and income are disregarded ONLY</b> when applying for benefits for the child with a disability.</p> <p>A budget is developed for the family by the DD case manager based on the person-centered plan. The budget provides for the minimal number of formal services (i.e. disability related services, personal care assistance) needed to maintain the child in the home. The budget covers only those needs that cannot be met by informal family support or community services. The budget must be authorized by the state before the family can access the support dollars. The budget is renewed quarterly.</p> <p>The plan must specify training qualifications for support workers. The plan must also include emergency back-up systems that describe what would happen if a support worker or family were not available.</p> <p>The family hires and trains its own in-home support workers. A fiscal agent is assigned to the family to provide support in accessing the budget. The family draws on the budget as needed and the fiscal agent bills vendors for allowable expenses, writes payroll checks and keeps related financial records. The family has the flexibility to change the plan or use funds differently as a child’s needs change without getting advance approval from the DHS.</p>

Questions	Family Subsidy	Family Support Services	Self-Directed Supports
<p><b>What services are included?</b></p>	<p><b>Case management services</b> (see roles &amp; responsibilities)</p> <p><b>Excess costs</b> related to a disability may be covered. Examples include and are not limited to:</p> <ul style="list-style-type: none"> <li>• In-home care providers</li> <li>• Excess child care</li> <li>• Recreational activities</li> <li>• Special equipment</li> <li>• Speech, OT or PT</li> <li>• Medical or dental care not covered under insurance or federal programs</li> <li>• Home health care</li> <li>• Counseling/behavior intervention</li> <li>• Briefs or special clothing</li> <li>• Housing modifications</li> <li>• Excess cost of health insurance</li> <li>• Excess cost for dietary needs</li> </ul>	<p><b>Case management services</b> (see roles &amp; responsibilities)</p> <p><b>Health care services</b> (e.g. medical, dental, medication, ) covered under ND's state Medicaid plan</p> <p><b>In-home support</b> (in-home and/or community based support). Examples:</p> <ul style="list-style-type: none"> <li>• A direct support worker comes into the home to care for a child with a disability while the family takes a break or attends to other minor children.</li> <li>• A direct support worker cares for the child in their home while the family gets a break.</li> <li>• A direct support worker takes a child into the community to experience recreational activities with same-aged peers and provides support</li> </ul>	<p><b>Case management services</b> (see roles &amp; responsibilities)</p> <p><b>Health care services</b> (e.g. medical, dental, medication, ) covered under ND's state Medicaid plan</p> <p><b>Support brokerage</b> – assistance from a case manager to self-direct services (all families)</p> <p><b>Self-Directed In Home Supports</b> Care given while family is away or present. (if a trained caregiver is needed)</p> <p><b>Disability Related Supports</b> – payment for equipment, therapy, and other excess costs related to a child's disability not covered under the Medicaid State Plan. (if needed &amp; eligible by age)</p> <ul style="list-style-type: none"> <li>• Skill support - a professional is needed to deliver the services</li> <li>• Transportation – mileage, lodging, per diem to access skill supports</li> <li>• Materials and supplies, dietary, housing modifications, special clothing, etc.</li> </ul> <p><b>Fiscal agent</b> – Someone to pay bills, cut paychecks, assist with record keeping, taxes, obtain a background check of support workers (all families)</p> <p><b>Employment supports</b> – on the job training for individuals with DD who need long-term support to maintain a job placement (if needed &amp; eligible by age)</p>

Questions	Family Subsidy	Family Support Services	Self-Directed Supports
<p><b>How is this option different than the other services?</b></p>	<p>Families pay costs up-front and are reimbursed after the fact. This can create a cash-flow problem for families</p> <p>This program does not cover direct health care services. Families do not need to be eligible for Medicaid or meet the level of care criterion.</p> <p>Families can hire their own direct support workers but must pay for taxes and insurance if the number of hours is above \$1300 in a calendar year.</p> <p>Families can also hire direct support workers from a provider but lose some choice and control. A provider may not be available in some rural areas.</p>	<p>Families do not pay costs up front.</p> <p>Health care providers bill Medicaid directly.</p> <p>In-home support workers may be hired only through a licensed provider who bills the DHS directly.</p> <p>The provider helps coordinate services, hires and trains staff, and handles all financial requirements related to being the employer. The support worker works for the agency and not the family.</p> <p>Families may choose to receive <b>both Family Subsidies</b> to pay for excess costs related to therapy or equipment (but not excess child care) and <b>Family Support Services</b>.</p>	<p>Families do not pay for costs up front. Families draw on a budget and so have fewer out of pocket costs. The fiscal agent assists families with financial responsibilities by issuing checks, paying employer taxes and insurance and keeping financial records. The fiscal agent also arranges for employee background checks at no cost to the family.</p> <p>The family recruits and hires support workers.</p> <p>Families have more responsibility and more risk in assuring that their child's health and safety needs are met.</p> <p>Families can ask for assistance in learning to self-direct services. Families receive both in-home support AND help with excess costs.</p> <p>Families may hire relatives, friends, and neighbors. The support worker, works for the family and not a provider.</p>
<p><b>What are the potential benefits of this option?</b></p>	<ul style="list-style-type: none"> <li>• Families get help with excess costs related to their child's disability</li> <li>• Paperwork is minimal when the number of hours is small.</li> </ul>	<ul style="list-style-type: none"> <li>• Families get relief from stress</li> <li>• Families have new ways to involve their children in the community</li> <li>• Families have more time to spend with other children</li> <li>• The work of directing services is turned over to a trained provider</li> <li>• Families have the benefit of health care and services available through Medicaid</li> </ul>	<ul style="list-style-type: none"> <li>• Families choose their own direct support workers.</li> <li>• Families do the work of self-directing services</li> <li>• Families get support to plan and set up supports</li> <li>• Families have choice and control in self-directing services instead of relying on someone else</li> <li>• Support is available in remote rural communities</li> <li>• Families have the benefit of health care and services available through Medicaid</li> </ul>
<p><b>What costs do we have?</b></p>	<p>Families have direct costs until reimbursed.</p>	<p>Families have no direct costs.</p>	<p>Families have no direct costs.</p>

Questions	Family Subsidy	Family Support Services	Self-Directed Supports
<b>What roles and responsibilities do we have?</b>	<ul style="list-style-type: none"> <li>• Think about family needs</li> <li>• Sign contract</li> <li>• Keep track of an submit receipts</li> <li>• Complete paperwork on time</li> <li>• Review needs quarterly</li> <li>• Complete annual satisfaction survey annually</li> </ul>	<ul style="list-style-type: none"> <li>• Apply for Medicaid</li> <li>• Schedule support within the hour limits set by the DHS</li> <li>• Orient new providers to child/home</li> <li>• Complete satisfaction survey annually</li> </ul>	<ul style="list-style-type: none"> <li>• Apply for Medicaid</li> <li>• Develop a person-centered plan</li> <li>• Develop an emergency back-up system</li> <li>• Hire support workers if needed</li> <li>• Train support workers</li> <li>• Direct the fiscal agent to pay bills or write checks</li> <li>• Evaluate worker performance</li> <li>• Complete satisfaction survey annually</li> </ul>
<b>What roles and responsibilities does the case manager have?</b>	The case manager helps families assess needs, connect with informal and formal supports, explore options, weigh decisions, help with referrals access, funding, assure satisfaction with services and resolve new issues.	The case manager helps families assess needs, connect with informal and formal supports, explore options, weigh decisions, help with referrals, access funding, assure satisfaction with services and resolve new issues.	<p>The case manager helps families assess needs, connect with informal and formal supports, explore options, weigh decisions, help with referrals access funding, assure satisfaction with services and resolve new issues. In addition, he or she will</p> <ul style="list-style-type: none"> <li>• Provide families with training to self-direct services</li> <li>• Provide families with training to understand the person centered planning process.</li> </ul>
<b>What support is available to help us use this option?</b>	A detailed manual describing how to hire and direct support workers and manage employer responsibilities under this plan is available from your case manager.	Licensed providers help families assess needs, recruit and hire support workers, conduct employee evaluations and manage payroll responsibilities.	<p>The DD case manager provides families with training materials on how to recruit and hire caseworkers, develop a person-centered plan and develop safety/emergency back-up plans.</p> <p>The Fiscal Agent assists a family to manage and coordinate financial requirements.</p>
<b>What is the application process?</b>	Ask for an application from your DD case manager. Complete all forms & estimate yearly expenses. The Regional DD Program Administrator reviews all applications and prioritizes how regional funds are spent.	Let the DD case manager know that you are interested in the program. If not already covered, they will let you know how to apply for Medicaid or assist you with the application process.	Let the DD case manager know that you are interested in the program. If not already covered, they will let you know how to apply for Medicaid or assist you with the application process.

Questions	Family Subsidy	Family Support Services	Self-Directed Supports
<p><b>What else should I know about this option?</b></p>	<p>This service is funded only with state dollars.</p> <p>Funding is limited to amount appropriate by the legislature.</p> <p>Direct deposit is available to families.</p> <p>Receipts or bills and credit card records submitted in a timely manner can reduce cash flow problems.</p> <p>Reimbursements are reported to the IRS by the state. The funds are not taxable but must be reported.</p>	<p>This service is funded with state and Federal dollars allowing ND to serve more families</p> <p>Some providers just give the family a list of people to call and families actually do most of the work. Other providers really carry the weight of coordinating services.</p> <p>Families must inform Medicaid about private insurance. Medicaid is the payer of last resort for medical services NOT Family Support services.</p> <p>Requests for unnecessary financial information should be discussed with DD case management.</p>	<p>This service is funded with state and Federal dollars allowing ND to serve more families.</p> <p>Self-directed supports is also the payer of last resort.</p> <p>This is a relatively new service option. You are being a pioneer.</p>

## *A Guide to Decision-Making*

What are your priorities when it comes to support?

<b>Important Needs</b>	<b>Family Subsidy</b>	<b>Family Support</b>	<b>Self-Directed Support</b>
Meet health care costs		√	√
Have in-home support		√	√
Get skilled care or therapy	√		√
Have materials and supplies	√		√
Cover excess childcare costs	√		√
Pay for transportation	√		√

### **Remember:**

- You can get family support *and* family subsidy (but not in-home support and excess child care)
- Self-directed supports are not available for children under age 3
- You must apply for Medicaid to get family support or self-directed supports
- You cannot apply for a support program only to cover health care costs

**What are your priorities when it comes to roles and responsibilities?**

### **You might prefer to work with an agency provider if . . .**

- You live near an agency who is willing to support your child and . . .
- You don't want the responsibility of finding/hiring a caregiver yourself
- You would rather not coordinate or direct the plan yourself even with support
- You want the security of having a caregiver who is certified
- You are willing to accept some turnover in caregivers
- You want a relationship with a skilled service coordinator
- You hope to access other services from the same agency

### **You might prefer to work with an independent provider if . . .**

- You don't live near an agency who is willing to support your child and/or . . .
- You prefer the control that comes with finding/hiring a caregiver yourself
- You would rather direct the plan and support services yourself
- You believe you can avoid turnover and give your child continuity
- You are willing to take on the extra work with support from a case manager
- You have support from family, friends or your community
- You prefer services that are natural and inclusive

Family Subsidy			
This rule is . . . .	No Problem	A Concern	Won't work
I must pay any costs up front and will be reimbursed later			
I must choose between getting funds for excess child care costs or getting funds for in-home support			
I must pay my child's health care costs			

Family Support			
This rule is . . . .	No Problem	A Concern	Won't work
I must use an agency provider			
I must choose between getting funds for excess child care costs or getting funds for in-home support			
I must apply for Medicaid			

Self-Directed Supports			
This rule is . . . .	No Problem	A Concern	Won't work
I am responsible to direct the services (with support)			
I must create or find supports in my community			
I must apply for Medicaid			

**What are your values when it comes to spending public resources?**

My values	Are a match for . . .
Rely <b>only</b> on family and community supports	None of these programs, they all use some form of public dollars
Serve only a few families with state dollars	Family subsidy
Serve more families by using state dollars to capture federal dollars	Family support or self-directed supports

## ***Typical Concerns and Food for Thought***

### **I don't have enough in-home support now. Which program would offer more?**

Concerns about support hours should not be used to make a decision about which support program would work best for you. Whenever you believe that more hours are needed, you are encouraged to approach your case manager and describe your need, regardless of the program you select.

### **I am concerned about turnover? Which options will give my child continuity?**

There is often a 50-70% turnover rate among direct support workers. Some agencies have a higher rate and some have a lower rate. Turnover is affected by the training and pay that the agency offers their employee as well as the skills and patience required to support your child and serve your family. The same is true for you if you decide to self-direct supports. You will balance how much you pay a caregiver with what you believe is legal/fair and what your budget will support. Relationships are as important as money in keeping good help. Both family support and self-directed supports have advantages and risks. Ask yourself:

- Will meeting several different people challenge or overwhelm my child?
- Are area providers available?
- What is the agencies' turnover rate for the family support program?
- How helpful are agency personnel when it comes to assisting us to get what we need?
- Can I pay a caregiver more than a typical agency by using self-directed supports?
- Will a higher wage make a difference in keeping an independent provider?
- If so, is that worth the extra time I will spend planning and finding services?

### **I am concerned about applying for Medicaid. Isn't that a welfare program?**

Medicaid is a public resource that can be used to support families in need. Financial need is only one reason for using Medicaid. Medicaid is a safety net for children and families. You face extra costs and stress in living with a disability. Self-directed supports are a wise use of public funds. The whole community benefits when we invest public dollars in your child and family. This is true even if your child will need lifelong support. Medicaid dollars will be used to support *agencies* unless you are willing to use them to meet *your child's* disability related needs.

## *Involving Youth in Decision-Making*

### **Why it is important to involve teens with disabilities in selecting and managing resources?**

**We learn by doing.** Your teenager may learn something by watching **you** make all the decisions about supports. But what they learn by watching may not be what you intend. It is all too easy for young people to **learn helplessness**. Your teen will learn more by making choices themselves. Giving your teenager an opportunity to make choices and solve problems now can help to prepare them to handle more difficult challenges in the future.

**Our relationships change.** As your teen grows older telling him or her what to do may no longer work. Insisting or demanding or scolding may not work either. Guiding your child in decision-making helps both you and your son or daughter move into a more adult relationship.

**Teens are at risk.** We know that many teenagers are at risk for depression and suicide. This is true for teens with disabilities as well. Giving your son or daughter a chance to make important decisions (with your help) about the people who work with them and the activities they participate in can give them a sense of choice and control that will help with emotional balance when difficulties arise.

**Signals are not given.** Most young people signal that it is time for them to spread their wings when they are ready for change. Children with disabilities may not send us signals in the same way that typical young people do. We create the opportunity for teens to exercise their right to grow up. The pace may be slower. It is up to us to move forward with the last job of parenting and help young people discover themselves, create their own lives and learn to get the support they need.

**Expectations are low.** We often under-estimate what young people with disabilities can understand or accomplish. In our natural desire to protect or control events ourselves we must remember to explore or create ways for young people to manage risk through problem solving experiences.

**Abuse rates are high.** Some young people with disabilities need significant and life-long support. Research shows that learning to make even the simplest choices (Example: Pointing to or looking at one of two outfits to wear) can help individuals communicate with caregivers and reduce the risks that their preferences will be ignored in the future.

**We are not forever.** Some day our children must learn to do without us. Even when a sibling plans to open their home to a brother or sister later in adult life, the transition is eased when the person with a disability makes choices and has some say or control over daily routines and care.

## **What can I do to prepare my son or daughter plan and direct supports?**

Create opportunities for your son or daughter to:

### **Get to know other people**

- Make introductions
- Participate in ice-breakers at school
- Interview a classmate or community helper to learn more about them
- Listen to stories about people they know

### **Exercise choice and control**

- Make a job description for a potential caregiver
- Make a list of concerns to share with a doctor or dentist
- Choose what is for supper one night a week
- Pick out clothes for school and church
- Decide what activity to do when a caregiver comes over to help
- Make a list (with your help) of what they like/don't like when care is given
- Learn to signal that they are ready before being lifted or repositioned

### **Plan for the future**

- Bring a list of questions to a parent-teacher conference or IEP meeting
- Set a goal. Write it down (with help to write/use pictures). Check off steps to meet it.
- Make a scrapbook of dreams that show jobs, preferences, houses or lifestyles

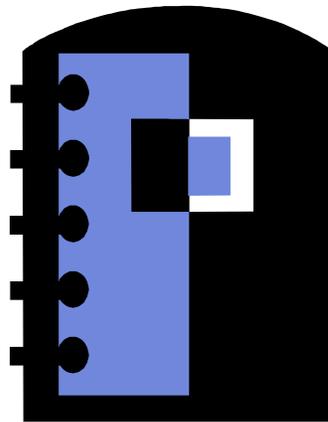
### **Solve problems**

- Figure out the best way to do a job. Which one of 3 cleaning solution works best?
- Get change decide how much to put in three categories: fun, savings, and gifts
- Look at a video together. Stop the action and try to guess what will happen next
- Decide what classes to take at school

### **Reduce risks**

- Learn to clearly say no, get away and tell a person you trust, what happened
- Share important life events in a meaningful way. Tell stories. Keep a scrapbook, or journal
- View a safety film together that shows young people in typical social situations. Decide what behaviors are safe and which ones are not
- Discuss what feelings and body parts are private

# Person Centered Planning



## ***Person Centered Planning (PCP) – The Process***

### **Learn the Process**

Person-centered planning involves several important steps. The first and most important step is to think about your child's special needs. You will use that information to create a plan that will help your son or daughter to achieve a meaningful life. As your child grows he or she will assume a more active role in decision-making.

### **Part One: Planning a meaningful life**

- Bring together people who know your child/family to form a circle of support
- Identify any strengths and special abilities for your child
- Discover his or her interests, wishes, and dreams
- Consider any important health and safety needs
- Decide which outcomes will help your child achieve a meaningful life
- Decide on rules (criteria) to help you decide when each outcome is met

This part of the manual provides information to help you learn the person-centered planning process. Anyone can use these tools. Person-centered planning is easier than other methods used by schools or some adult providers.

### **Resources that may help:**

#### **PCP Worksheets**

Use these worksheets to help you create a person-centered plan for your child working step-by-step. Notice the many examples for very young children, school-age children, teens and young adults. This information is designed to get you to think creatively. You are free to modify change the worksheets as you go. Use only those steps that work best for you.

#### **Outcome Examples**

Use these examples to help design clear outcome statements for your plan. You may wonder what a good outcome might look like. Statements should tell what results you want and why. Outcomes must also state when and how the outcome will be considered met.

#### **Training Options**

Look at these books, videos and materials to find out more about person centered planning.

## Person Centered Planning Worksheets

### Build a circle of support

#### Think about *who* you are supporting . . .

- A very young child who depends on you to make decisions
- An older child who wants more choice and control in your family life
- A young adult who will graduate and begin adult life in a few short years



**Think about the support** your child will need to grow, do well and meet his or her goals. Who could help your child participate as fully as possible in family and community life?

Everyone needs support. A supporter knows and spends time with you, is willing to help you grow or get ahead in life and stays involved over time. A friend! We all depend on one another for support. The people who support your child and family are your circle of support.

#### Decide if your child/family . . .

- Has a new or very small support circle that needs to grow
- Has many supporters who needs to organize or come together
- Has a well established circle of support that works well together

#### People in your child's circle of support may be:

- |  |   |
|--|---|
| <input type="checkbox"/> Parents/guardians                           | <input type="checkbox"/> Therapists                   |
| <input type="checkbox"/> Grandparents                                | <input type="checkbox"/> Child care providers         |
| <input type="checkbox"/> Foster parents                              | <input type="checkbox"/> Teachers                     |
| <input type="checkbox"/> Brothers/sisters                            | <input type="checkbox"/> Employers                    |
| <input type="checkbox"/> Relatives ( <i>aunts, uncles, cousins</i> ) | <input type="checkbox"/> Pastors or ministers         |
| <input type="checkbox"/> Neighbors                                   | <input type="checkbox"/> Social workers/case managers |
| <input type="checkbox"/> Friends of the family                       | <input type="checkbox"/> Community leaders            |
| <input type="checkbox"/> Friends from school                         | <input type="checkbox"/> Co-workers                   |

#### You decide who will be in your child's circle of support

##### Supporters may be someone who . . .

- |  |  |
|--|--|
| <input type="checkbox"/> Give TLC (tender loving care)                   | <input type="checkbox"/> Your child relies on when the going gets tough    |
| <input type="checkbox"/> Your child might like to imitate                | <input type="checkbox"/> Knows how to get services or to get things done   |
| <input type="checkbox"/> Has faced similar challenges                    | <input type="checkbox"/> Knows your child's history & life story           |
| <input type="checkbox"/> Makes your child laugh                          | <input type="checkbox"/> Helps your child grow and be all that they can be |
| <input type="checkbox"/> Helps them feel important                       |  |
| <input type="checkbox"/> Your child calls friend                         |  |
| <input type="checkbox"/> Keeps a watchful eye on your child now and then |  |
| <input type="checkbox"/> Needs your child in some way                    |  |
| <input type="checkbox"/> Knows about child development                   |  |
| <input type="checkbox"/> Coaches or mentors your child from time to time |  |



Remember, your child can be involved in choosing a circle of support in several ways:

- Small children will *show* you who is important to them by how they respond to the people they meet.
- Young children and teens will also *show and* may be able to *tell* you who they want in their circle of support. Show pictures of possible supporters. Ask them!

<i>Picture of Your Child</i>	<b>Questions to Ask:</b>
	<ul style="list-style-type: none"> <li>• Who would you like in your circle?</li> <li>• Who is important to my child?</li> <li>• Is this person involved with my child/family now?</li> <li>• Is this someone who we need to get involved with our child/family?</li> <li>• Is this person a good fit for our child and our family?</li> <li>• Is this person able to spend time and plan with our family?</li> <li>• Is this person willing/likely to stay involved?</li> <li>• Would this person be helpful?</li> <li>• Do I know how to contact this person?</li> <li>• What is the best way to invite them to plan with our family?</li> </ul>

## ***Choose a Circle of Support***

Write down the names of people you want to have in your child's support circle. Expect the circle to grow or change over time.

\_\_\_\_\_ 's circle of supporters are:  
Child's Name

**Name**

**Contact Information**

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## ***Bring the Team or Circle of Support Together***

**Invite people in the support circle (even family members) to an informal meeting.**

**Decide if the team needs to:**

- Create a picture of your child's strengths, dreams, needs and use that information to make a new plan
- Review a plan you have already made and talk about progress, roadblocks and solutions
- **Explain the purpose of the meeting.** Let them know what the meeting is about

*We are meeting to develop some plans with/for \_\_\_\_\_.* We wonder if you could meet with us to help plan. You are important <sup>child's name</sup> to our child and we would like you to be part of his/her circle of support.

**Tell them when and where the meeting will take place.** Ask for their suggestions. Think about meeting at:

- Your house
- The school
- An office
- A coffee shop
- A community meeting room
- A church
- A relative's house

**Give them important information about the meeting.** Ask for their suggestions.

- Let them know the meeting will be short (1 hour)
- Let them know how they can help at the meeting (*Tell us your hopes, wishes & ideas*)
- Ask them if they are willing to come
- Ask them the best time to hold the meeting
- Send a written note to help everyone remember to come
- Tape large pieces of paper on the wall. Write down decisions made by the team so that everyone can see
- Decide who will be a recorder for the team and take notes
- Decide if you want to have food and drinks at the meeting

**Decide if your child . . .**

- Is too small to be at a meeting. You can have his/her picture there to give the team focus. Or your child may play nearby if that is not too distracting.
- Can make a brief appearance and tell about his dreams or goals. Maybe your child could sit near-by with a book or toy and chime in from time to time. He or she may want to come and go freely and may need attention.
- Can ask questions or make suggestions if he or she is given the support to know when to speak and what to talk about
- Might be ready to learn how to direct the meeting by asking each person to share their ideas and have someone record the plan for the team.

**Create a picture of your child's strengths, dreams, needs:**

Get a poster or tack paper on the wall. Draw a symbol or picture to represent strengths. See the examples below. Can you draw symbols like these on your paper?

**Strengths: Strengths could be . . .**

Things your child is good at doing. Skills he or she may have. A list of what is special or wonderful about your child. Talents!	Milestones your child has met. Complements he or she receives. Prizes he or she has won. Things he or she did you never expected.
Special relationships or resources from family or friends	Adventures or special experiences your child enjoys or that tell the world who he/she is

**Here are some examples of strengths that were created by other families. . .**

<b>Ella at 3 months. She has Down syndrome.</b>	<ul style="list-style-type: none"><li>• A beautiful smile</li><li>• Two wonderful parents</li><li>• A happy home</li><li>• A grandma who loves her</li><li>• Makes eye contact</li></ul>
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<b>Ron is 6 years old and deaf.</b>	<ul style="list-style-type: none"><li>• Signs fluently</li><li>• Reads lips</li><li>• A happy home</li><li>• Loves to ride his bike</li><li>• Good at math</li><li>• Goes camping with Dad</li></ul>
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<b>Mary is 17 years old. She is blind.</b>	<ul style="list-style-type: none"><li>• Has a new guide dog</li><li>• Has a part time job with a florist</li><li>• Is learning to ride the bus</li><li>• Loves to cook</li><li>• Good at knitting</li></ul>
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**Record dreams & wishes:** Use these questions to help you make a list of the dreams, wishes and interests for . . .

**Your infant or toddler who is still small and depends on you to choose**

- If only he or she could . . .
- If only we had a way to . . .
- Wouldn't it be great if . . .
- Things would be much better if . . .
- To start things out it would be nice if . . .

**Your young child who depends on you to listen to his interests, choices and play**

- He or she really likes to . . .
- It would help him so much if we had . . .
- We could support him or her better if we had . . .
- He or she really wants to . . .
- We could enjoy experiences that other children or families have if we . . .
- We could stay together if . . .

**Your older child who depends on you to develop an identity and self-confidence**

- He or she would really like to try . . .
- He or she could get out more if . . .
- He or she will make friends if . . .
- Our family could support him or her best if we had . . .
- He or she would benefit from . . .
- He or she is growing up and needs an opportunity to . . .
- He or she has always wanted to . . .

**Your teenager who depends on you to learn to meet responsibilities, enjoy a safe and healthy lifestyle, manage friendships and grow up**

- He or she would really like to try . . .
- He or she could get out more if . . .
- He or she wants friends who . . .
- Our family could support him if we had . . .
- He or she needs an opportunity to . . .
- He or she might enjoy work like . . .
- We could become less involved if we . . .
- Someday he or she would like to . . .
- We could help him or her transition after graduation if . . .

**Look at these examples of interests, dreams that were written by other parents.**

**Tabitha – Age 6 months – cerebral palsy**

- If only she could roll over by herself and reach for a toy instead of crying
- If only we could support her in sitting up without always holding her
- Wouldn't it be great if we could get out without her once a week
- Things would be much better if we knew what she could see and hear
- It would be nice if she had more musical toys. She really likes her radio

**Frank – age 4 – blind**

- He really likes to rock, pet our cat mittens, watch TV, turn up the sound.
- It would help him so much if we had time to work with him
- We could support him or her better if we knew what to do to help him learn.
- He or she really wants to run outside in the back yard.
- We could enjoy experiences that other children or families have if we could meet other families who have a child who is blind
- Our family will stay together if we get a break once in a while

**Samantha – age 11 – intellectual disability**

- She would really like to try riding horses
- She could get out more if friends invited her out on weekends
- She will make friends if she could join other kids after school
- We need childcare after school. Then we could keep working.
- She would benefit from a chance to use a computer at home
- She is growing up and needs an opportunity to learn the facts of life
- Things would seem less difficult if she did not get so frustrated with communication

**Jack – age 17 – Cornelia D' Lange Syndrome**

- He would really like to try playing video games with a friend
- He would like to get together with kids from his class
- He wants friends who are like him, not way ahead of him in school.
- Our family could support him best if we had child care for teens in the summer
- He would benefit from a chance to learn computer skills
- He is growing up and needs an opportunity to sleep away from home
- He might enjoy carrying stuff and building things on a job
- We could become less involved if we knew he was safe and supported
- We could help him transition if he could sleep through the night without us.
- Someday he would like to ride on an airplane

**Record the interests, wishes and dreams for YOUR child and family.** Now that you have looked at some examples why not make a list of the interests, wishes and dreams you have for your child and family.

\_\_\_\_\_ 's Wishes, Dreams,  
**Interests**

Record everyone's ideas:

Team member

Thought of this wish, dream, interest!

\_\_\_\_\_

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<p><b>Think about your Family and Child(ren)</b></p>	<p><b>Describe a perfect day in your child's life. Tell what the immediate future might look like.</b></p>
	<p><b>List specific wishes &amp; dreams for your child/family</b></p>
<p><b>Photo of your child or Family</b></p>	<ol style="list-style-type: none"><li>1.</li><li>2.</li><li>3.</li><li>4.</li><li>5.</li></ol>

## *Think about your child's needs*

A life worth living needs balance between

- Security and opportunity
- Routine and adventures
- Independence and support
- Demands and solitude
- Safety and risk

Use the *examples* below to think about your family and child

All children need help to meet . . .	To meet these needs for our child in this community, our family will need to obtain?
<p><b>Basic needs by getting</b></p> <ul style="list-style-type: none"> <li>• Nutritious food</li> <li>• Adequate shelter</li> <li>• Adequate clothing</li> <li>• Good health care</li> </ul> <p><b>Emotional needs by</b></p> <ul style="list-style-type: none"> <li>• Being loved</li> <li>• Be raised in a family home</li> <li>• Be close to others</li> <li>• Make friends</li> <li>• Learning self control</li> <li>• Accept appropriate limits</li> </ul> <p><b>Growth and development needs to</b></p> <ul style="list-style-type: none"> <li>• Move around freely</li> <li>• Play safely</li> <li>• Communicate effectively</li> <li>• Express identity</li> <li>• Take acceptable risks</li> <li>• Gain independence</li> </ul> <p><b>Safety needs by</b></p> <ul style="list-style-type: none"> <li>• Be treated with respect</li> <li>• Being free from harm</li> <li>• Being protected from risk</li> <li>• Being healthy</li> <li>• Being well</li> </ul>	<p><b>Financial Support</b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Income and benefits</li> <li><input type="checkbox"/> Employment services</li> <li><input type="checkbox"/> Health insurance</li> <li><input type="checkbox"/> Legal assistance</li> <li><input type="checkbox"/> Money management</li> <li><input type="checkbox"/> Excess health costs</li> <li><input type="checkbox"/> Equipment/supplies</li> </ul> <p><b>Family Support</b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Respite care</li> <li><input type="checkbox"/> Disability information</li> <li><input type="checkbox"/> Emotional support</li> <li><input type="checkbox"/> Sibling support</li> <li><input type="checkbox"/> Behavior intervention</li> <li><input type="checkbox"/> For next transition</li> <li><input type="checkbox"/> Advocacy</li> <li><input type="checkbox"/> Parenting</li> <li><input type="checkbox"/> Anger management</li> <li><input type="checkbox"/> Counseling</li> </ul> <p><b>Learning Support</b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Early Intervention</li> <li><input type="checkbox"/> Adapted toys</li> <li><input type="checkbox"/> Lessons / tutoring</li> <li><input type="checkbox"/> Vision devices</li> <li><input type="checkbox"/> Hearing devices</li> <li><input type="checkbox"/> Assistive technology</li> <li><input type="checkbox"/> Play group</li> <li><input type="checkbox"/> Role models</li> <li><input type="checkbox"/> Unique learning tools</li> <li><input type="checkbox"/> Play therapy</li> </ul> <p><b>Support for Health and Safety</b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Health care specialists</li> <li><input type="checkbox"/> Treatment / therapy</li> <li><input type="checkbox"/> Special diets</li> <li><input type="checkbox"/> Modify home / car</li> <li><input type="checkbox"/> Trained care provider</li> <li><input type="checkbox"/> Car seat / positioning</li> <li><input type="checkbox"/> Clothing / briefs</li> <li><input type="checkbox"/> Safety plan</li> <li><input type="checkbox"/> Transportation</li> </ul>

As they grow children need to	What would it take to meet these needs for our child? What are his/her needs for support? Think about . . .
<ul style="list-style-type: none"> <li>• Learn self control</li> <li>• Mange moods</li> <li>• Develop an identity</li> <li>• Succeed in school</li> <li>• Gain work experience</li> <li>• Have adventures</li> <li>• Gain confidence</li> <li>• Manage relationships</li> <li>• Meet responsibilities</li> <li>• Get around the community</li> <li>• Give to family and community life</li> <li>• Transition to adult life</li> </ul>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Behavior Intervention</li> <li><input type="checkbox"/> Play experiences</li> <li><input type="checkbox"/> Ways to make friends</li> <li><input type="checkbox"/> Things to do around town</li> <li><input type="checkbox"/> Clubs and groups</li> <li><input type="checkbox"/> Sports for players or spectators</li> <li><input type="checkbox"/> Chores, allowances,</li> <li><input type="checkbox"/> Computer skills</li> <li><input type="checkbox"/> Volunteer activities</li> <li><input type="checkbox"/> Transportation skills</li> <li><input type="checkbox"/> Managing money</li> <li><input type="checkbox"/> Housing options</li> <li><input type="checkbox"/> Work experiences</li> <li><input type="checkbox"/> Financial assistance</li> <li><input type="checkbox"/> Benefits</li> <li><input type="checkbox"/> Supported employment</li> <li><input type="checkbox"/> Sharing a room</li> <li><input type="checkbox"/> Learning to cook</li> <li><input type="checkbox"/> Sleeping alone or through the night</li> </ul>

Avoid listing problems as needs. Think about the message your child sends with his or her behavior. Think about a health concern and list the need. **For example**

Don't list a behavior such as:  
Instead list the need

He cries all the time.  
He needs a way to calm down and relax

Don't list a behavior such as:  
Instead list the need

He is too impulsive and lazy to help at home  
He needs to gain experience in solving problems  
He needs to get started without being told

Don't list a medical problem:  
Instead list the need

His seizures are bad  
He needs medicine to control his seizures

## ***A Guide to Person-Centered Planning***



This guide can help you can create a happy and meaningful life for your child. The first step is to bring together a team of family members, friends, and professionals to help you plan. This team will form a circle of support for your child who an important member of the team. The next step is to spend some time thinking and deciding what your child's dreams and goals may be.

*When your child is very small, **you** will decide what goals and dreams are important to give your child a good life. As your child grows, **he or she** will learn to make choices. Your role will gradually change from directing and guiding to assisting and supporting.*

Once you have chosen some goals, dreams or outcomes, ask the team to help you find out what skills and abilities your child may have. These **strengths** are what will really help your child/teen achieve his/her goals.



Early goals may include playing, moving around easily, enjoying meals or making friends. Later goals may be enjoying sports or fitness activities, reading or sending messages, getting a job, living in an apartment/house, going to college and/or taking part in community life.

Finally, invite the team to help you/your teen decide what kind of assistance and support you need to build on strengths and achieve goals?

This kind of planning is called **person-centered**. Supports and services begin with your child's dreams, goals, strengths and abilities and NOT his or her disabilities. Services provide what your child needs and NOT what a school, agency or program may typically offer.

### **Traditional Planning Methods**

Families, schools and providers sometimes focus too much on the "disabilities" or the deficits of a child or youth with a disability. This viewpoint can lead the team to try to "fix the child" or focus on correcting learning and behavior problems. When this happens people begin to think of the young person with disabilities as "immature," or "disabled." Many people assume that person is not capable of being part of or making a difference in their school or community. Teams start deciding that young people are "not ready" for certain activities or better off "with their own kind" and begin to see individuals as less than whole. This way of thinking has led to isolation, missed opportunities, fear, ridicule and even abuse towards people with disabilities.

Traditional planning methods focus on a child's disability and lack of skills or talents. Goals are set by families, professionals and service providers. While setting goals for very young children is appropriate the families may continue to set goals without teaching children about this important step. And goals may be focused on "fixing" the child "John will articulate sounds clearly," "Mary will use eye contact." If those identified deficits are fixed, the child is re-evaluated and more deficits are found. Over time, because the gap between a child's skills and his or her peers is likely to widen, this approach, makes it unlikely that a person with disabilities will ever "catch up" or be viewed as "ready" for life in the community. This has been the guiding principle that led communities to institutionalize people with disabilities for decades. Although we seldom send children to institutions any more, this negative approach often keeps teams from figuring out how to help people to enjoy a happy and meaningful life.

### **The problem with traditional planning methods**

Traditional planning methods work from the theory that people with disabilities are not qualified to decide for themselves how they want to spend their lives. This notion, if applied to anyone else, would be rejected immediately as contrary to our values of freedom and liberty. And while young children need families to provide guidance and set limits, they also need an opportunity to experience choice and control in growing up and taking part in community life.

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***Just because someone calls it a "Person-Centered Plan" doesn't mean that it really is***

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**How can you tell the difference between a real plan and a paper plan?**

#### **A Real Plan**

- Your teen eventually sets the agenda. Your child's agenda is respected and valued
- Your teen chooses people for the team who are important to him/her
- The team works on your child's agenda
- There are measurable outcomes
- The team celebrates those outcomes
- The plan is about your child's *life*

#### **A Paper Plan**

- Team meets only once a year
- Planners are mainly professionals
- Programs drive the plan
- Nothing seems to change
- Meetings are a drudge
- The plan is about a document

## What are the qualities of good planning?

A good plan matches the dreams, goals, and needs of your child. It results in real actions and outcomes for your son or daughter. A good Person-Centered Planning team builds and sustains relationships. The people on the team work together to solve problems and help your child build a more desirable future.

## Individualizing the Plan

A plan is individualized if the planners focus on the individual's interests, gifts, and talents. Team members should know the individual or wish to know the person so the team can gain a shared appreciation of the individual over time. A real PCP team will work to discover the individual's agenda and design a process that works for the individual.



## Questions to ask about the planning process

- Are we talking about what's "*wrong*" with my child or how to support my child?
- Are we sitting at a table or spending time together?
- Are we gathering and discussing progress in a way that works for my child?
- Are we working on the changes that I want?

## Building the team

Invite the "right people" to plan. Look at family members and friends, but also people that have contacts in the community that can help the individual reach their goals. Look for naturally occurring relationships and resources.

## Questions to ask about team members

Are all the planners committed to making the changes *I want to* happen?

Are we adding people who can help with changes?

Are we looking at a broad range of community resources?

Are we using our own connections?

Are people doing what they say they will?

## Planning a more desirable future

As the team begins to mesh, they should spend time with your child to discover what is behind their hopes and dreams and then develop a vision that is grounded in those preferences. The team should seek to make the ideal a reality, and not settle for a compromise because it is easier or quicker to accomplish.

## Questions to ask about future planning

Do the dreams and goals we are working toward come from things about my child and not just services that are available?

Are my supporters helping me understand our options?

Are my supporters taking time to explore a life that makes sense for my child?

How can I express my vision for the future?

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*A vision of the future is personal and not a one-size-fits-all plan. It is the heart of the plan and can be expressed in many forms, through words, art, music, or pictures.*

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### **Getting action and reaching goals**

Above all, the team must be doers, not just talkers! They should develop concrete goals and action steps to achieve those goals. The team should be developing the ability within the community to support the individual and promote changes within organizations to provide the supports needed. Finally, the team should celebrate their accomplishments together.

### **Questions to ask about actions and goals**

Are my supporters doing their work?

Are they assisting me in doing my work?

Do we have an action plan that is moving toward a future that makes sense?

Are things getting done?

Are these the things I wanted to happen?

### **Solving problems**

Team members should explore every option for available resources, supports, and assistance the individual will need that makes sense to them. Every team member should also commit to an ongoing process of listening, learning, reflecting, and taking action.

### **Questions to ask about problem solving**

Do we face up to challenges or put off the difficult questions?

Are we putting together the supports and services that will make my life go better?

Do we look beyond what we know?

## ***Person Centered Planning - Plan***

Once you have figured out what a meaningful life will look like (for now anyway) use that information to create a support plan (or case plan) to help your child achieve the outcomes. As your child grows he or she will assume a more active role in building the plan. Now that you have a vision for the future you can build a plan to bring it to life.

### **Part Two: Building a support plan**

- List activities that must happen to achieve each outcome
- Indicate who will be responsible for carrying out each activity and by what date
- Include formal and/or informal supports needed to achieve outcomes
- Identify criterion that caregivers must meet to support your child
- Identify training that caregivers must have to support your child
- Develop an emergency back-up plan for your child/family
- Meet to discuss how the plan is going and make revisions as needed

This section provides information to help you build/modify the support plan. You can build the plan yourself or ask your case manager for help. Remember, you do not have to think of criteria or action steps on your own. You have the support of family, friends, neighbors, relatives and professionals to help you create a meaningful life for your child.

#### **Self-Directed Supports Forms**

Record your child's plan and budget on these forms. You may fill out these forms on your own, or ask a case manager for assistance. Examples of the required forms are included.

#### **State Medicaid Plan Services**

Use this form to find out what services are available to you already in our state Medicaid plan. You may include these supports in your child's plan. Self-directed support dollars can be budgeted for additional supports needed. Services must be necessary, cost effective, and reviewed by state administrators before dollars will be allocated for their payment. This information can change so ask your case manager for an update each year.

#### **Evaluation Guidelines**

These worksheets can help you discover if everyone is satisfied with the plan. Children and friends quickly learn to tell us what they know we want to hear. It is important to find ways to discover the truth. Evaluation is an on-going process. The case manager will ask you about your satisfaction with services on a quarterly basis.

## ***Self-Directed Supports Forms***

***Outcomes, Criteria and Activities:*** Use this form to record the I goals or outcomes in your plan. You must describe how you will know if the outcome is met and what will happen to achieve the outcome. Look at the example to see what a plan might look like for a small child. The plan includes both formal and informal supports.

### **Outcomes, Criteria and Activities**

**Meeting Date:**

**Review Date:**

**Status:**

**Outcome Categories:** Cognitive (problem solving) Development, Communication Development, Social/Emotional Development, Family Support

*We want \_\_\_\_\_ to be able to communicate better with us so he is not frustrated.*

**Outcome 1:** \_\_\_\_\_ *will imitate sounds (pa-ba-da-ga, etc.) in play*

**Activities:** *The case manager will assure that \_\_\_\_\_ gets regular home visits from staff in the infant development program. \_\_\_\_\_ will also get a hearing evaluation and be referred for direct speech therapy. Periodic checks for fluid in*

*\_\_\_\_\_’s ears will also be scheduled with the hearing specialist.*

*\_\_\_\_\_’s family and home visitors will encourage him to imitate sounds such as vowels (ah, a, ee, o, oo) and vowel-consonants (pa, ma, ba ba, dee, moo etc) during play and care routines so that he learns that making these sounds is fun and meaningful.*

*\_\_\_\_\_’s family will use 3 signs (more, eat, drink) in daily activities and encourage \_\_\_\_\_ to imitate the signs. Family members and home visitors will pair the signs with words so that \_\_\_\_\_ learns that using the signs can help him to ask for toys or food that he likes and reduce frustration.*

**Measurement Criteria (how we know the outcome is met):** \_\_\_\_\_ *will be observed using at least 3 signs or words to request what he wants.*

**Case Planning Service List:** List the formal services that will be included in your budget on this form. Your child's case manager will help you record this information.

## Case Planning

*Name*

*Address/Phone*

### Outcomes:

1. *We want help planning for medical follow-up so we understand what options we have*
2. *We want financial support and help with time together so there is less stress*

**Outcome Categories:** Cognitive (problem solving) Development, Communication Development, Social/Emotional Development,

3. \_\_\_\_\_ *will use more words so he can express what he wants without frustration*

**Outcome Categories:** Family Support

4. *We will be happy with our jobs so we can see each other more and be tired less*

**Outcome Categories:** Cognitive Development, Physical Development Communication Development, Social/Emotional Development, Adaptive Behavior, Family Support and Transition

5. \_\_\_\_\_ *will be around other kids every week so he can watch and imitate other kids*

**Service:** AUDIOLOGY

**Disp:** AUTHORIZED

**Provider:** FIRE AUDIOLOGY

**Start:** 07/01/04    **End:** 06/30/05

**Funding Source:** TTLXIX-HCBS-DDD

**Service Amount:** 1 Hours per Quarter

**Associated with Outcome:** 01

**Service:** DD CASEMANAGEMENT

**Disp:** AUTHORIZED

**Provider:** NEHSC-GRAND FORKS

**Start:** 07/01/04    **End:** 06/30/05

**Funding Source:** TTLXIX-HCBS-DDD

**Service Amount:** 4 Hours per Quarter

**Associated with Outcome:** 01, 02

**Service:** DIET SUPERVISION SUPPORT

**Disp:** N-DD Lic Service RC

**Provider:** WIC-GRAND FORKS

**Start:** 07/01/04    **End:** 06/30/05

**Funding Source:** OTHER SERVICE AGENCY

**Service Amount:** 1 Hour per Every Other Week Term

**Associated with Outcome:** 01, 02

**Self-Directed Supports Authorization:** Use this form to record the budget for your plan. The blank copy of this form shows how a budget will appear. Ask your case manager to help you fill the budget out on the computer. As you fill in the age of your child, some items that appear on the blank form may disappear. For example, although Employment Supports are shown on the blank form in your manual, they will not appear on YOUR budget if your child is under the age of 21.

## ***Services Covered by North Dakota Medicaid***

This information was taken from the Department of Human Service website. Information may change or be updated. To get current information go to this address:

<http://www.state.nd.us/humanservices/services/medicalserv/medicaid/covered.html>

Medicaid pays for many different medical services. Sometimes there are limitations on what Medicaid will cover. It is your job to ask a health care provider if a service that you need is covered by Medicaid. Do not assume that all of the medical services you receive are covered. Non-covered medical services may be covered under your self-directed support budget if:

- They are necessary to achieve goals in your child's plan and
- They have been authorized at the state office level

The services listed below are a general list. Some services have limits or restrictions.

### **Hospital**

- **Inpatient:** Covers room and board, regular nursing services, supplies and equipment, operating and delivery room, X-rays, lab and therapy.
- **Outpatient:** Covers emergency room services and supplies, lab, X-ray, therapies, drugs, biologicals, and outpatient surgery

### **Nursing Facility**

- Covers room and board, nursing care, therapies, general medical supplies, wheelchairs, and durable medical equipment

### **Clinics, Rural Health Clinics**

- Covers outpatient medical services and supplies furnished under the direction of a doctor

### **Hospice**

- Provides health care and support services to terminally ill individuals and their families

### **Physicians**

- Covers medical and surgical services performed by a doctor; supplies and drugs given at the doctor's office; and X-rays and lab tests for diagnosis and treatment

### **Prescription Drugs**

- Covers many but not all, prescription drugs, insulin, family planning prescriptions, supplies, and devices. Your pharmacist can tell you if a drug is covered by Medicaid

## **Chiropractor**

- Covers X-rays and manual manipulation of the spine for certain diagnosis

## **Health Tracks (EPDST)**

- Covers screening and diagnostic services of physical and mental status, and treatment to correct/eliminate defects or chronic conditions and prevent health problems from occurring for children under 21. Covers orthodontia and vaccinations.

## **Home Health**

- Covers nursing care, therapy and medical supplies when provided in a recipient's home. Care must be ordered by a physician and provided by a home health agency.

## **Durable Medical Equipment and Supplies**

- Covers medical supplies such as oxygen and catheters and reusable equipment that is primarily medical in nature. Items must be medically necessary and do not include exercise equipment, personal comfort or environmental control equipment.

## **Dental**

- Covers exams, X-rays, cleaning, fillings, surgery, extractions, crowns, root canals, dentures (partial and full) and anesthesia

## **Family Planning**

- Covers diagnosis and treatment, drugs, supplies, devices, procedures and counseling for persons of child bearing age

## **Sterilization**

- Covers sterilization procedures if: (1) The recipient is at least 21 years old; (2) The recipient is legally competent; (3) The recipient signs an informed consent form; and (4) At least 30 days but not more than 180 days have passed between the signing of the consent form and the sterilization.

## **Podiatry**

- Covers office visits, supplies, X-rays, glucose & culture checks, and surgery.

## **Mental Health**

- Covers psychiatric and psychological evaluations, inpatient services in a psychiatric unit of a hospital, individual-group-family psychotherapy, partial hospitalization services, and inpatient psychiatric and residential treatment centers services for individuals under 21 for the care and treatment of mental illness or disorders.

## **Ambulance**

- Covers ground and air ambulance trips, attendant, oxygen, and mileage when medically necessary to transport a recipient to the closest health care facility meeting his needs. House Bill 1282 permits ambulance personnel to refuse transport to an individual where medical necessity cannot be demonstrated

and recommend an alternative course of action for the individual. If the ambulance was not medically necessary, Medicaid will not pay for the service.

### **Transportation**

- Covers non-emergency transportation services to and from the recipient's home to the closest medical provider capable of providing a medically necessary examination or treatment

### **Vision**

- Covers exam, glasses, frames and some hard contact lenses for the correction of certain conditions. Replacement eyeglasses are provided after a minimum of 12 months for children under 21 or 24 months for adults if a lens change is medically necessary. An exception to the replacement limitation may be made if new eyeglasses are required for a significant change in correction and the eyeglasses are prior approved. Lost or broken glasses for individuals over 21 will not be replaced within the first two years.

### **Therapies**

- Covers physical and occupational therapy and speech and language pathology

### **Home and Community Based Services, Traumatic Brain Injury**

- Provides personal care and services not otherwise covered under the Medicaid program to individuals who are at risk of institutionalization in a nursing facility

### **Out-of-State Services**

- Medically necessary covered services may be provided outside of North Dakota if the services are not available within North Dakota and have been prior approved by the department or if the services are provided in an emergency situation.

## ***Non-Covered Services***

The items or services listed below are generally not covered by the Medicaid program. Sometimes an exception will be made. To be included, item or service must be:

- medically necessary
- ordered by a physician

Remember that even if a service is NOT covered by Medicaid it can be included in your individual budget and be authorized under the Self-Directed Supports Waiver. Services that are generally NOT covered include:

- Items or services which have been determined by the DHS Medical, Optometric or Dental consultant or the peer review organization to not be medically necessary
- Items or services provided by immediate relatives/members of the recipient's home
- Over-the-counter drugs, home remedies, food supplements, nutritional items, vitamins, or alcoholic beverages except for when prescribed by a doctor
- Broken or missed appointments
- Medical equipment/supplies for a person in a nursing facility, swing bed or ICF/MR
- Custodial care
- Services for individuals over 21 and under 65 in the state hospital, a public institution or an institution for mental disease
- Health services which are not documented in the recipient's medical record
- Services, procedures, or drugs which are considered experimental by the US Department of Health and Human Services or another federal agency
- Drugs and which the federal government has determined to be less than effective
- Cosmetic surgery to improve the appearance of an individual when not incidental to repairs following an accidental injury or any cosmetic surgery which goes beyond what is necessary for the improvement of functioning of malformed body members
- Acupuncture
- Organ transplants which are not prior approved
- Procedures for implanting an embryo
- Procedures and services to reverse sterilization
- Autopsies
- Reports required solely for insurance or legal purposes
- Record keeping, charting or documentation related to providing a covered service
- Vocational training, educations activities, teaching, or counseling
- Self-help devices, exercise equipment, protective outerwear, personal comfort items or services, and environmental control equipment
- Computers, computer hookups, or printers except for assistive communication devices
- Payment to hold a bed in a nursing facility, swing bed or ICF/MR unless specifically provided for by the department
- Payment for a private room in a nursing facility or basic care facility

## ***Evaluation Guides***

These worksheets will help you discover if everyone is satisfied with the plan. Since children and friends quickly learn to tell us what they know we want to hear, it is important to find ways to discover the truth. No formal evaluation process is required but teams will want to stop and evaluate how the plan is going.

Name: \_\_\_\_\_ Date: \_\_\_\_\_

Let's look at \_\_\_\_\_ goals.  
(Child's Name)

**Were any of these goals met? Please list the goal below:**

- 1.
- 2.
- 3.

**Important questions:**

- What really worked for (child's name)?
- What did we do to overcome problems?
- How do we know this goal was really met?
- What does (child's name) tell us about this goal?
- What should we work on next?

**Were any of these goals NOT met? Please list the goals below:**

- 1.
- 2.
- 3.

**Important questions:**

- Do these goals still work for (name)?
- What can we do to overcome problems?
- How do we know this goal was not met?
- What does (child's name) tell us about this goal with words or behavior?
- What should we do now?
- Who can help us with this problem?
- What goals should we work on next?

**Team members who participated:**

**Names**

**Attendance (F2F or Phone)**

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**Guidelines**

<b>Outcomes</b>	<b>Met</b>	<b>Not Met</b>	<b>Comments / Report</b>

**How are we doing?**

<b>Big Priorities</b>	<b>Yes</b>	<b>No</b>	<b>Comments / Report / Concerns</b>
_____ is treated with respect			
_____ is happy with his life			
_____ has adventures			
_____ is close to family			
_____ has friends			
_____ is safe and well			

## ***Questions to Guide Evaluation***

1. What has \_\_\_\_\_ been telling others about the supports in his/her plan?
2. Have any big changes happened in his/her life in the last few months?
3. How do we know that \_\_\_\_\_ is happy with his/her life?
4. What steps are helping \_\_\_\_\_ achieve his/her outcomes?
5. When does \_\_\_\_\_ say NO to his/her daily routine?
6. What could we change to make it easier for \_\_\_\_\_ to meet goals?
7. What would a perfect day in \_\_\_\_\_'s life look like to him/her?
8. What opportunities does \_\_\_\_\_ need to grow and prosper?
9. How can we support \_\_\_\_\_ to make friends?
10. Is \_\_\_\_\_ able to get where he needs to go?
11. What new skills would help \_\_\_\_\_ achieve educational goals?
12. Who would \_\_\_\_\_ like to be present in her life more often?
13. What support does \_\_\_\_\_ need to stay safe?
14. What support does \_\_\_\_\_ need to be well and happy?
15. Do we need someone else on the team to help us tackle problems?
16. Who needs to follow through to help this plan work?
17. What would \_\_\_\_\_ change in his/her life if he/she could?
18. What is coming up in the near future that could be a problem?
19. What training do caregivers need to support \_\_\_\_\_?
20. Is this plan working the way we want it to? What haven't we thought of?

# Family Support Evaluation

## Stress Level

Low/OK  High/Too Much

Plan to support	
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## Community Support

Yes/For Now  No/Not Really

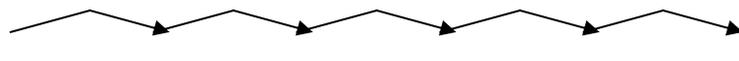
Plan to support	
-----------------	--

## Sibling Support

Good/OK  Unmet needs

Plan to support	
-----------------	--

## Family Support

Good/OK  Unmet needs

Plan to support	
-----------------	--

## ***Developing Emergency Back-Up Plans***

Make an emergency back-up plan for your child and family. This plan will help other people care for your child. The plan should include contact information and instructions for caregiver's in case of emergencies. Your child's disability and health and safety needs will help you decide what information to include. Think about:

1. Important information about services when you cannot be reached
2. Names of responsible caregivers who can care for your child in an emergency
3. Information about where to locate you in an emergency
4. Evacuation and care procedures to follow in an emergency
5. Important medical information that a health care professional should know
6. Helpful information is your return is unexpectedly delayed for a long period of time

Putting together this information will help you in many ways. Your plan can be useful when you need to fill out forms for your child's school or childcare setting. Your spouse or partner may find the information helpful and gain confidence in caring for your child with a disability. Keep this information near the phone. Advise caregivers to take it with them in case of an emergency.

## ***Resources in this Section***

### **Planning Checklist**

This checklist can be used as a quick guide for planning.

### **Emergency Forms**

You may use these forms or you can design your own materials to share this information. The forms can be filled out and updated by your to help care-givers have important information in an emergency.

### **Emergency Guidelines**

This information will help you plan for the worst. Of course we hope that nothing will happen but in case it does, you want to be prepared. These guidelines help you think through possible emergencies and decide what would be best for your child.

***Emergency Planning Checklist***  
*Emergency Back-Up Plan*

1. **Service information when you cannot be reached.**
  - Health care providers (primary physician and dentist)
  - Hospitals or clinics
  - Specialists who may be treating your child
  - DD case managers and Emergency help from the state after hours
  
2. **Caregiver information if you are temporarily unable to care for your child.**
  - Other legally responsible family members (a spouse or legal guardian)
  - Siblings / Grandparents
  - Other relatives
  - Close friends or neighbors
  - Individuals who are forbidden contact with your child (court order)
  
3. **Personal contact information for you in case of emergency**
  - Location where you will be staying
  - Phone numbers including cell phones
  - Addresses including an email address if helpful
  - Name and phone number of person's able to help contact you
  
4. **Emergency procedures that a caregiver should know and follow.**
  - 911 or other emergency numbers for police, fire, ambulance
  - Fire evacuation route and safe house
  - Location and use of fire extinguishers
  - Instructions for rescue personnel
  - Alternate shelter in case of tornado or loss of power or water
  - Responding to aggression or self-injurious behavior
  - Resuscitation orders
  
5. **Emergency medical information about your child including**
  - List of medications including dose, route, time, type
  - List of pharmacies that routinely fill prescriptions
  - Health history for emergency treatment (allergies, illnesses and surgeries)
  - List of special diet requirements
  
6. **Helpful information in case of your unexpected and lengthy absence**
  - Special equipment your child uses daily. Information for maintenance/repair
  - Schedule for routine health care or therapy appointments
  - List of clothing sizes and resources for any specialized clothing
  - Location of will to clarify your wishes for the well being of your children
  - A list of critical dietary supplements and ordering information
  - Location/status of immunization records

**Personal Information**  
*Emergency Back-Up Plan*

Child's Name: \_\_\_\_\_ Date Completed: \_\_\_\_\_

Date of Birth: \_\_\_\_\_ Address: \_\_\_\_\_

Phone: \_\_\_\_\_ SS# \_\_\_\_\_

Parent/Legal Guardian(s): \_\_\_\_\_

Address: \_\_\_\_\_

Day Phone(s) \_\_\_\_\_ Evening Phone(s) \_\_\_\_\_

Non-custodial parent: \_\_\_\_\_

Address: \_\_\_\_\_

Day Phone(s) \_\_\_\_\_ Evening Phone(s) \_\_\_\_\_

Siblings: \_\_\_\_\_ Phone: \_\_\_\_\_

Address: \_\_\_\_\_

Siblings: \_\_\_\_\_ Phone: \_\_\_\_\_

Address: \_\_\_\_\_

Foster Care Placement (if any): \_\_\_\_\_

Address: \_\_\_\_\_ Phone: \_\_\_\_\_

Religion: \_\_\_\_\_ Phone: \_\_\_\_\_

Pets: \_\_\_\_\_

Veterinarian: \_\_\_\_\_

**Contact Information**  
*Emergency Back-Up Plan*

Name: \_\_\_\_\_ Phone: \_\_\_\_\_

Email: \_\_\_\_\_

Cell Phone: \_\_\_\_\_

Car Make/model: \_\_\_\_\_ License # \_\_\_\_\_

Car Make/model: \_\_\_\_\_ License # \_\_\_\_\_

**While I am gone, you can locate me in case of emergency at:**

Date: \_\_\_\_\_ Location: \_\_\_\_\_ Phone: \_\_\_\_\_

Address: \_\_\_\_\_

Date: \_\_\_\_\_ Location: \_\_\_\_\_ Phone: \_\_\_\_\_

Address: \_\_\_\_\_

Special documents: (example: living will, birth certificate) \_\_\_\_\_

\_\_\_\_\_

**Emergency help from the Department of Human Services:**

Help can be obtained 24/7 at this number in case accident or illness prevents my/our return \_\_\_\_\_

**Service Information**  
*Emergency Back-Up Plan*

Name: \_\_\_\_\_ Date: \_\_\_\_\_

Preferred Hospital: \_\_\_\_\_ Phone: \_\_\_\_\_

Primary Physician: \_\_\_\_\_ Phone: \_\_\_\_\_

Clinic: \_\_\_\_\_

Hospital: \_\_\_\_\_ Phone: \_\_\_\_\_

Specialist/Type: \_\_\_\_\_ Phone: \_\_\_\_\_

Clinic: \_\_\_\_\_

Dentist: \_\_\_\_\_ Phone: \_\_\_\_\_

Clinic: \_\_\_\_\_

DD Case Manager: \_\_\_\_\_ Phone: \_\_\_\_\_

Special Education Teacher: \_\_\_\_\_ Phone: \_\_\_\_\_

School: \_\_\_\_\_ Phone: \_\_\_\_\_

Therapists: \_\_\_\_\_ Phone: \_\_\_\_\_

Therapists: \_\_\_\_\_ Phone: \_\_\_\_\_

Therapists: \_\_\_\_\_ Phone: \_\_\_\_\_

Counselor: \_\_\_\_\_ Phone: \_\_\_\_\_

Childcare Provider: \_\_\_\_\_ Phone: \_\_\_\_\_

**Emergency Plan**  
*Emergency Back-Up Plan*

In case of emergencies dial:  (Keep these numbers by the phone)

Police: \_\_\_\_\_ Fire: \_\_\_\_\_ Ambulance: \_\_\_\_\_

**Prevention Plan:**

Smoke detector:  battery  hard wired  both Inspection date: \_\_\_\_\_

Carbon Monoxide detector:  battery  hard wired  both Inspection date: \_\_\_\_\_

Location/use of fire extinguishers: \_\_\_\_\_

Matches/fire starters secured: \_\_\_\_\_

Comments: \_\_\_\_\_

**Evacuation Plan:**

Plan if exit or stairway is blocked \_\_\_\_\_

Caregiver can give special instructions to emergency dispatch on how to safely lift or move your child in an emergency:  Yes  No  Training needed

Bedroom windows marked: (Get stickers from local safety supply store)

Nearest safe house: \_\_\_\_\_

Alternate shelter in case of tornado: \_\_\_\_\_

Comments: \_\_\_\_\_

**Power Loss Preparations:**

For loss of electricity call \_\_\_\_\_ Phone: \_\_\_\_\_

Breakers are located: \_\_\_\_\_

For loss of water call \_\_\_\_\_ Phone: \_\_\_\_\_

Emergency water supply located \_\_\_\_\_

**Responding to aggression or self-injurious behavior:** In an emergency only, restraint can be used as follows: Describe procedure:

**Resuscitation orders:**

My wishes are on file at local hospital. My living will is located \_\_\_\_\_

A physician order detailing my wishes is available \_\_\_\_\_

<p><b>Caregiver Information</b> <i>Emergency Back-Up Plan</i></p>
---

Please contact these individuals if accident or illness prevents my/our return:

Legally responsible adult \_\_\_\_\_  
 Address \_\_\_\_\_ Phone \_\_\_\_\_  
 Relationship to Child \_\_\_\_\_

Nearest living relative who can help with care \_\_\_\_\_  
 Address \_\_\_\_\_ Phone \_\_\_\_\_  
 Relationship to Child \_\_\_\_\_

Other relatives who can help with care \_\_\_\_\_  
 Address \_\_\_\_\_ Phone \_\_\_\_\_  
 Relationship to Child \_\_\_\_\_

Other relatives who can help with care \_\_\_\_\_  
 Address \_\_\_\_\_ Phone \_\_\_\_\_  
 Relationship to Child \_\_\_\_\_

Friends or neighbors who could help in an emergency \_\_\_\_\_  
 Address \_\_\_\_\_ Phone \_\_\_\_\_

Friends or neighbors who could help in an emergency \_\_\_\_\_  
 Address \_\_\_\_\_ Phone \_\_\_\_\_

Important symptoms or behavior	What this means	How to respond

***Emergency Medical Information***  
*Emergency Back-Up Plan*

Name: \_\_\_\_\_ Date: \_\_\_\_\_

Allergies: \_\_\_\_\_

Medication	Dose	Route	Time	Type
Comment				
Comment				
Comment				
Comment				
Comment				

Pharmacies: \_\_\_\_\_ Phone: \_\_\_\_\_

Pharmacies: \_\_\_\_\_ Phone: \_\_\_\_\_

Health History: \_\_\_\_\_

- Heart/Lungs    Brain/seizures    Vision    Hearing    Mobility    Kidney/bladder
- Stomach/intestines    Cancer    Foot/ankle/knee    Endocrine    Metabolic
- Reproductive/menses    Pneumonia/upper respiratory    Diseases    Speech/language
- Diabetes    Obesity    Tremors/tics    Celiac disease    Multiple Sclerosis    CP

Immunization Records: \_\_\_\_\_

Comments:

Diet: My child has the following restrictions to their diet:    None    Behavioral    Special

Special Food Purchases: \_\_\_\_\_ Phone: \_\_\_\_\_

Preparation: \_\_\_\_\_

***Daily Routines***  
***Emergency Back-Up Plan***

Caregivers will find this information to be helpful in case of my/our unexpected and lengthy absence:

**Weekday schedule**

Wakeup:

Dressing:

Breakfast:

Getting Ready:

School Communication:

After School:

Supper:

After Supper:

Bedtime:

**Weekend schedule**

Wakeup:

Dressing:

Breakfast:

Chores/Worship:

Lunch:

After Lunch:

Supper:

After Supper:

Bedtime:

Special equipment: \_\_\_\_\_

Maintenance/repair: \_\_\_\_\_

<b>Item</b>	<b>Phone</b>	<b>Agency</b>
1.		
2.		
3.		
4.		
5.		

**Schedule for routine health care or therapy appointments**

Physical Exam:

Dental Exam:

Orthodontist:

Hearing Evaluation:

Vision Exam:

Neurological Exam:

Orthopedics:

Specialist:

**Clothing sizes:**  Shirt/dress \_\_\_  Shorts/pants \_\_\_  Shoes \_\_\_  Socks \_\_\_

**Adapted Clothing:** (Example: shorten/take in pants, use Velcro fasteners, etc.).

Indicate where obtained \_\_\_\_\_

***Favorite Routines***  
*Emergency Back-Up Plan*

Best way to wake up/what to avoid: \_\_\_\_\_

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Favorite breakfast foods/routines/what to avoid: \_\_\_\_\_

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School start time: \_\_\_\_\_ School: \_\_\_\_\_

School lets out: \_\_\_\_\_ Transportation: \_\_\_\_\_

Job start time: \_\_\_\_\_ Job: \_\_\_\_\_

Employer: \_\_\_\_\_ Phone: \_\_\_\_\_

Sports/Fitness: \_\_\_\_\_

Favorite after school/evening I routine/what to avoid: \_\_\_\_\_

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Favorite Lunch/supper foods/routine/what to avoid: \_\_\_\_\_

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---

Homework arrangements (if any): \_\_\_\_\_

Play activities: \_\_\_\_\_

Approved Friends: \_\_\_\_\_

---





***Environmental Needs***  
*Emergency Back-Up Plan*

**A safe environment for our child has . . . .**

	List or describe special items, needs and situations	Not a problem	Keep out of reach	Keep out of sight	Keep locked/lock up Do not have in house	Bring/keep with at all times
<b>Foods</b>						
<b>Sharp objects</b>						
<b>Small objects</b>						
<b>Cleaning supplies</b>						
<b>Windows/doors</b>						
<b>Tools/electrical</b>						
<b>Medications</b>						
<b>Cords and strings</b>						
<b>Special equipment</b>						
<b>Special products</b>						
<b>Pets/animals</b>						
<b>Other</b>						

## ***Person Centered Planning - Budget***

Once you have created a support plan you will need to gather the resources to carry it out. This involves making an individual budget. Once your budget is approved you can begin to find and direct the supports you need. As your child grows he will assume a more active role in building a budget. Your case manager will help you create the budget.

### **Part Three: Building an individual budget**

- 1. Determine the costs of self-directed in-home supports**
  - In-home supports
  - Training for family and/or care providers
  - Temporary relief for the family
- 2. Determine the costs of disability related supports/skilled supports**
  - Skilled supports (therapy, therapeutic recreation, individual/family counseling)
  - Transportation
  - Materials and Supplies (special equipment, home modifications, vehicle adaptations, dietary supplies, adaptive clothing)
- 3. Determine the costs for administrative services** (support brokerage, fiscal agent, background checks)
- 4. Negotiate the budget and submit for approval**
- 5. Review the budget quarterly**

#### **Support Definitions**

This section describes the services that may be listed in the budget. Materials include questions and criterion used to determine what supports or services may be needed to achieve outcomes or address emergency back-up plans.

#### **Budget Forms**

The DD Case Manager provides these budget forms. The forms are included so that you can see what must be considered in budgeting and how the forms look. You may fill out these forms on your own, or ask a case manager for assistance.

# Self-Directing Supports



## ***Getting Started***

Once the plan has been developed, you can begin to self-direct supports to achieve your goals. Self-directing supports involves nine important steps.

1. Consider the goals and supports in the plan
2. Consider the budget you have created
3. Find someone to provide any formal supports included in the budget
4. Find someone to provide any informal supports included in the plan
5. Train family members and support providers as needed
6. Decide if your child and family are satisfied with your child's progress
7. Meet to discuss how the plan is going and make revisions

This section provides information to help you carry out the plan. You can direct the plan yourself or ask your support broker for help. Remember you do not have to carry out the plan on your own. You have the support of friends, neighbors, your fiscal agent, case manager, caregivers and professionals who will work together to provide your child with a meaningful life. Feel free to add new information to this section as you gain experience. You will update the plan as needed to meet your child/families' changing needs.

### **Resources in this section:**

#### **Planning worksheets**

These simple checklists can be used to help record plans, track progress and keep other team members in the loop. Families are encouraged to include simple pictures to help children visualize goals. Families are free to design forms that work for them, to keep a simple checklist by the phone or to use no forms at all.

#### **Youth involvement checklists**

These checklists can help you involve a teen with a disability in planning. Teens gain valuable experience by being consulted about schedules, the kind of people they like to have work for them and the community activities that they would like to try out or be involved in.

## *Planning Worksheets*

These simple checklists can be used to help record plans, track progress and keep other team members in the loop. Families are encouraged to include simple pictures to help children visualize goals. Families are free to design forms that work for them, to keep a simple checklist by the phone or to use no forms at all.

The examples below describes how plans can be used to track progress towards goals.

An example of formal supports for a two year old boy with CP.

Goals	Formal or informal	Supports	
Ryan will walk around the living room without help	Formal/Informal Physical Therapy	Describe the support:	Physical therapy- training family to do stretches daily and providing therapy at the center one time per week
		State the purpose:	Help Ryan relax and gain strength for walking
		Responsible:	Mary Carson – Therapist Jack Carson – Ryan’s Dad Sue Carson’s – Ryan’s child care provider
		Due/Review Dates:	Check on progress monthly.

An example of informal supports for a ten year old girl with Down syndrome.

Goals	Formal or informal	Supports	
Sue will be called by friends from her special education class	Formal/Informal	Describe the support:	Set up a calling tree and give Sue a script to follow that will be kept by the phone. Set up a calling time.
		State the purpose:	To help Sue make friends and gain self confidence and phone skills
		Responsible:	Jennifer Parks – Sue’s teacher Molly Halstad – Sue’s mother Rene Halstad – Sue’s big sister
		Due/Review Dates:	All items to be in place in two weeks. Monitor progress quarterly

Name: \_\_\_\_\_

Date: \_\_\_\_\_

Review Date and Comments:

Goals	Formal or informal	Supports	
	Formal/Informal	Describe the support:	
		State the purpose:	
		Responsible:	
		Due/Review Dates:	
	Formal/Informal	Describe the support:	
		State the purpose:	
		Responsible:	
		Due/Review Dates:	
	Formal/Informal	Describe the support:	
		State the purpose:	
		Responsible:	
		Due/Review Dates:	
	Formal/Informal	Describe the support:	
		State the purpose:	
		Responsible:	
		Due/Review Dates:	
	Formal/Informal	Describe the support:	
		State the purpose:	
		Responsible:	
		Due/Review Dates:	
	Formal/Informal	Describe the support:	
		State the purpose:	
		Responsible:	
		Due/Review Dates:	

## ***Youth Involvement Checklist***

Look at the list of activities below. Which steps can your son or daughter do? Read the steps to/with your son or daughter. Decide which steps they might like to complete. Watching is OK for a while. Doing just part of a step is OK too. Gradually give them more to do as they gain confidence.

---

### **Decide who will come to the meeting**

- Point to pictures of friends, relatives and neighbors
- Name people who are important to him/her
- Deliver an invitation to a professional
- Choose who he/she wants to be in his circle of support
- Follow a picture/word script to call and invite someone to attend
- Ask someone to complete the planning forms
- Fill out part/all of the form to list team members

---

### **Get ready for the meeting and make people feel comfortable**

- Smile and greet people as they arrive
- Pass out cookies or drinks
- Bring paper or tablets to people who need them
- Turn off the TV or music during the meeting
- Bring something to look at if discussion gets longer than interest
- Help to clean up before people arrive
- Find out if a meeting place is available

---

### **Start the meeting and talk about your life**

- Welcome everyone and thank them for coming
- Call people by name.
- Ask someone to take notes (Use words or pass a pencil/tablet)
- State the purpose of the meeting "Help me plan my life."
- Show pictures of self doing favorite and important activities
- Invite the group to talk about dreams and strengths
- Take turns. Ask for comments "What do you think about that?"
- Ask the note taker to list dreams, strengths
- Ask the group to help you describe a perfect day and worst nightmares
- Ask the note taker to write your story on a chart so all can see
- Take a short break when needed. Ask everyone if they would like more cookies

---

### **Write goals that will lead to a wonderful and meaningful life**

- Ask the group to think and talk about what is important to you
- Look at pictures of other goals for children or adults to get ideas
- Look at pictures/think about stories that tell what is important to you
- Ask the group to suggest some goals
- Ask the note taker to write down the goals
- Ask the note taker to draw a picture by each goal
- Listen and see if the group gets quiet
- Ask other people if they think that would be a good goal
- Invite someone to say what would be a better goal
- Ask your friends if they think that would be a good goal
- Ask people to say why
- Decide which goals you like best
- Ask the group if everyone can tell when the goal is met

---

### **Make a plan that will help you reach your goals**

- Read/ask someone to read each goal out loud
- Invite the group to think of ways to make that dream come true
- Ask the note taker to write down each idea
- Decide what ideas will really work
- Ask people who is willing to help you
- Find out where you can get more help to meet a goal
- Give each person something important to do
- Ask the group to think about what might go wrong
- Ask the group to think about how to solve problems
- Ask the note taker to list what each person will do, when they will do it
- Be sure to make a list of what YOU will do
- Ask the group to talk about safety
- Use the safety checklist to plan for emergencies
- Ask the note taker to record your plan on the forms

---

### **Make a budget to get and manage money for your goals**

- Put up a picture of each new goal. Ask someone to draw the picture for you with a marker or draw one yourself
- Look at or think about the supports you need
- Decide if the team will need money to pay for a support
- Ask the team if someone can volunteer or help out
- Offer to trade something or help others to get the help you need
- Ask the case manager to write out the budget for you

*Picture Guide to Person-Centered Planning - Part I*

 <p>Decide who will come to the meeting</p>	<p>Point/Choose</p> 	<p>Name/Tell</p> <p>Bob Mary Sue Chuck Dan</p>
 <p>Get ready and make people feel comfortable</p>	<p>Smile/Welcome</p> 	<p>Pass/Share</p> 
 <p>Start the meeting and talk about your life</p>	<p>Welcome/Begin</p> <p>Hi! Thanks for Coming</p>	<p>Show/Tell</p> 
	<p>Dream/Imagine</p> 	<p>Ask/Write</p> 

*Picture Guide to Person-Centered Planning - Part II*

 <p>Write goals for a wonderful life</p>	<p>Think/Look</p> 	<p>Point/Suggest</p> 
	<p>Listen/Question</p> 	<p>List/Write</p> 
 <p>Make plans to reach your goals</p>	<p>Read/Think</p> 	<p>Plan Steps</p> 
	<p>Do/Choose</p> 	<p>Plan for Safety</p> 
 <p>Budget money to pay for the plan</p>	<p>Picture/Think</p> 	<p>Bargain/Trade</p> 
	<p>Write/List</p> 	<p>Balance/Approve</p> 

## ***Using Community Services***

You will find formal/informal supports to help your child. Formal supports can be found by:

1. Asking your support broker if an existing service is available to provide the support
2. Looking on the web to see if other similar supports exist
3. Working with a community support provider to modify or individualize a service
4. Creating or building new supports with help from your support circle

Informal supports can be found by:

1. Asking neighbors and friends
2. Talking with other families who are raising children with similar needs
3. Visiting with a trusted provider, physician or teacher
4. Using the yellow-pages
5. Asking at your church, temple, or mosque
6. Checking the local library or newspaper

### **Resources in this section:**

#### **Using the web to find out what's available**

This guideline contains information about some of the most commonly used databases in North Dakota. You may feel empowered or have a better sense of control if you can learn to search for at least some information on your own.

#### **A list of community service providers**

This resource lists licensed providers that serve children, adults and families in ND. Because this information is constantly changing families are advised to use web information to keep updated. This resource is found in the appendix.

#### **A guide for building generic services**

This guide offers helpful suggestions for starting a new or informal service in your neighborhood or community. These checklists provide information about how families can find both formal and informal supports for their child. Information includes practical suggestions for developing generic supports as well information from the world-wide-web.

## ***Using the web to find out what's available in North Dakota***

- The Arc, Upper Valley  
<http://www.thearcuppervalley.com/>
- Blue Cross Blue Shield  
<http://www.noridian.com>
- Child Care Resource and Referral  
<http://www.ndchildcare.org/>
- Division of Medical Genetics  
<http://www.medicine.nodak.edu/genetics>
- Early Intervention  
<http://ndearlyintervention.com/>
- Families Need to Know  
<http://www.ndcpd.org/projects/n2k>
- Family Voices  
<http://www.geocities.com/ndfv/>
- Federation of Families  
<http://www.ffcmh.org/>
- Freedom Resource Center  
<http://macil.org/freedom>
- Job Services of North Dakota  
<http://www.sharenetworknd.com/>
- Health Steps (SCHIP)  
[www.state.nd.us/childrenshealth/](http://www.state.nd.us/childrenshealth/)
- Lutheran Social Services – Special Needs Adoption  
<http://www.lssnd.org/index.asp>
- North Dakota Academy of Pediatrics  
<http://www.ndaap.org/>
- North Dakota Center for Persons with Disabilities  
<http://www.ndcd.org/>
- The ND Center for Rural Health  
<http://www.med.und.nodak.edu/depts/rural/>
- ND Child Care Resource and Referral  
<http://www.ndchildcare.org/splash/>
- North Dakota Children Special Health Services  
<http://lstate.nd.us/humanservices/services/>
- North Dakota Department of Human Services  
<http://state.nd.us/humanservices/>
- North Dakota Department of Insurance  
<http://www.state.nd.us/ndins/>
- ND Department of Public Instruction  
<http://www.dpi.state.nd.us/speced>
- North Dakota Disabilities Advocacy Consortium  
<http://www.nddac.org/>
- The Family Connections Conference  
[www.conted.und.edu/connections](http://www.conted.und.edu/connections)
- North Dakota Family to Family Support Network  
<http://www.med.und.nodak.edu/depts/rural/family/>
- North Dakota Interagency Program for Assistive Technology  
<http://www.ndipat.org/>
- North Dakota Public Health Units  
[www.health.state.nd.us/localhd/](http://www.health.state.nd.us/localhd/)
- North Dakota Web Server  
<http://www.discovernd.com/>
- Path Inc (Therapeutic Foster Care)  
<http://www.pathinc.org>
- Pathfinders Family Center  
<http://pathfinder.minot.com/>
- Protection and Advocacy  
<http://www.ndpanda.org>

## ***A Guide for Building Services In Rural Communities***

What if there is not a special service that does just what you need? You can build the service you need by working with other people in your community. How?

### **Who are the people in your neighborhood?**

Nearest farm or ranch  
Greenhouse  
Gas station  
Truck stop  
School  
Clinic or hospital  
Pharmacy  
Fast food place  
Bowling alley  
Churches  
4-H leaders  
Village team

County Extension  
Service  
Parent resource center  
Nursing home  
Newspaper office  
Grocery Store  
Scout leaders  
Future Farmers of  
America  
Radio or TV station  
Community Theater  
Library

Bar or steak house  
Boat ramp or canoe  
rental  
Lumber Yard  
Public health nurse  
Senior Companions  
Human service center  
Boys/Girls Club  
Book group  
Homemakers club  
Church youth group

### **How can we get together or get to know each other?**

#### **Get Information**

Ask around  
Check the local  
newspaper  
Listen to the radio  
Read a bulletin  
Check out any  
advertisements

#### **Check it Out!**

Show up  
Make a visit  
Make an appointment  
Ask for a tour  
Look on the web  
Get an invitation

#### **Share Who You Are**

Go for a walk/be seen  
Sell or give away crafts  
Share a hobby at school  
Volunteer at church  
Write an article  
Bake something  
Donate or recycle  
Join a choir/be in a play  
Hang out at the coffee shop

## ***Hiring and Managing Support Staff***

Sometimes you may need someone to come into your home and care for your child when you are gone. Or you may want someone to help your child when you are at home but busy with your other children. Or you may need someone who can take your child into the community or care for your child temporarily at his or her home. You may decide to recruit and hire a caregiver to work with your child. Families make several important decisions when looking for in-home or community support. You will decide:

1. What job you want the care giver to do for your child and family
2. What skills the care giver will need to meet your child's health and safety needs
3. How to obtain a background check of potential caregivers
4. How to find and hire the right person for the job
5. What laws you must follow in recruiting and hiring a caregiver
6. What training is needed for care givers, family and friends to support your child
7. How many hours of support your child or family will need
8. What resources and supports are available to help you manage the employee
9. How you will evaluate employee performance and resolve problems as they arise.
10. How you will make sure that the caregiver is paid, the right amount, on time.
11. How you will communicate with the caregiver and your fiscal agent

Resources in this section provide families with basic information to help get started in recruiting, and supervising caregivers.

### **Fiscal Agent roles and responsibilities**

Your fiscal agent will help you pay workers and comply with laws that you must follow in hiring, paying or firing a caregiver. Your fiscal agent cannot do everything. This guide shows what responsibilities are yours and what the fiscal agent can do for you.

### **Family and caregiver roles and responsibilities**

Know your responsibilities in training and directing an independent provider or caregiver. Handle boundaries when employing family and friends.

### **Finding a caregiver**

This resource shows you how to advertise a job or let people know you are hiring. It has suggestions for creating a simple job description and spreading the word about the job using newspapers, church bulletins and word-of-mouth.

### **Using an employment agency**

This guideline describes services available through ND Job Services. They can help a lot.

### **Interview guide**

This resource lists common questions that you might ask in an interview. It lets you know what questions are legal and which ones are not.

### **Evaluating employee performance**

Start out on the right foot. Plan to give feedback frequently and in a positive manner. Follow some simple suggestions from families who have done this kind of thing before.

### **Frequently asked questions**

Read questions that most families had when hiring their own caregiver for the first time.

### **Preventing abuse and neglect**

You will have your own ideas about what abuse or neglect may be for your child. What can a caregiver do to discipline your child? How will you know if your child has been neglected or abused when you are not present? How can you tell if your child is unhappy because a limit was set by the caregiver or responding to abuse? What will you do if a caregiver reports *your* behavior as abuse? Read these important guidelines to help you address this sensitive and important area.

## ***Fiscal Agent Responsibilities***

### **What are Fiscal Agents?**

A fiscal agent pays employees and keeps your accounting records. This leaves you free to direct supports. The fiscal agent eliminates many headaches for families who don't want to be a bookkeeper. The fiscal agent makes sure that your records and payroll follow the rules. There are some things you should know about a fiscal agent.

### **A Fiscal Agent IS NOT:**

- The agency that is funding your budget
- The decision maker about employee duties or schedules
- Someone who provides or directs support services

### **The Duties of a Fiscal Agent Include:**

- Act on behalf of the person/family receiving support and service to report payroll to the state.
- Make payments as approved by the person's budget
- Generate paychecks on a timely basis to your employees according to all federal and state laws
- Conduct background checks and keep the information on file
- Process all employment records
- Withhold, file, and deposit all state and federal taxes according to the IRS and Department of Labor

## *Family/Caregiver Roles and Responsibilities*



You may choose either an Independent or Agency provider when self-directing supports.

<b>Agency providers:</b>	People who work for an agency
<b>Independent Providers:</b>	People who work independently

If you choose an agency provider the agency does the work of hiring, training and supervising the individual. If you decide to hire an Independent provider, **you** are responsible for finding, hiring, training, supervising and evaluating employees.



This can seem overwhelming but wait. You are not alone. You can get help from your fiscal agent. The fiscal agent will help you with the more difficult parts of worker management.

### **Family**

- Make plans for your child's support needs
- Identify training for independent providers
- Create a job description
- Find/interview potential providers
- Make the decision to hire someone
- Schedule in-home support in advance
- Train workers or arrange for training
- Sign pay records to verify services
- Attend to any injuries workers may suffer
- Report incidents of neglect or abuse

### **Fiscal Agent**

- Conduct provider background checks
- Make sure a fair wage is paid
- Collect paperwork from new workers
- Pay workers on schedule
- Submit payroll taxes on time; and
- Pay premiums for worker's compensation insurance on time.
- Keep time records of the dates and hours worked and money paid
- Complete an Immigration and Naturalization Service Form 9 (I-9) to assure eligibility to work in the USA.
- Submit other tax forms (e.g., IRS Forms W-3)
- Withhold federal unemployment taxes (FUTA), if required
- Withhold state income tax from worker's pay,
- Issue IRS form W-2 to all in-home support workers and submit it to the proper authorities by February 1 of the year following the work year

### **Case Manager**

- Assist families in setting up a budget
- Assist families in locating training resources
- Assist families in the planning process
- Report incidents of neglect or abuse

### **Providers**

- Come to work on time
- Implement the person-centered plan
- Exercise good judgment on the job
- Avoid injury and follow safety rules
- Submit payroll records on time
- Keep skills up to date as needed
- Use the emergency backup plan as needed
- Maintain good working relations with children and families
- Report incidents of neglect or abuse



## *Finding a Caregiver*

### **Begin with People You Know**

#### **Use Word of Mouth**

This is a powerful tool! Tell everyone you know you are looking for someone to provide in-home support. Some people you may tell are neighbors, relatives, your child's teachers, principals, para-educators and child care providers. These people may be interested in the job, or know of someone who would be great!

#### **Lean on your Family**

Self-directed dollars may **NOT** be used to reimburse a relative living in the home to provide support. Any other relatives who:

- *are of legal age to work*
- *live outside of the family home*

can be hired as an independent provider. Many families rely on relatives to provide support. It would be nice to be able to pay someone and give something back.

If you plan to hire and pay a relative please take some time to think about how this might impact your relationship. Can both you handle the new roles? There is no right or wrong answer but it is important to think about family dynamics. A paid position can provide a job for a relative. It can also create some special problems. Will you fire them if they don't do a good job? What happens if you disagree about the best way to proceed?

#### **Consider teachers or para-educators**

Many special education teachers and para-educators in ND provide in-home support to families. These individuals may also be an important source of care during the summer or after school. Often this relationship is supportive and works well. It is important to think about what you might do if things go wrong. What happens if you disagree with something that is happening at school? Will you still feel that you can bring it up? Or what happens if you disagree about the best way to proceed? Will you fire them if they don't do a good job?

### **Get the Attention of Your Community**

#### **Newspapers**

This is also a good way to let people know that you have an open position for an in-home support provider. Placing a classified ad in the Sunday edition of a daily paper may be the best way to reach a large number of people. You might have to screen more callers this way. Make sure you have a clear job description that is as informative as possible. A well-organized ad is much more appealing than just a phone number. Here is a simple example

**Wanted:** In-Home Caregiver for 12-year-old boy with disabilities. Duties include personal care in home, companionship, and taking child to social events from time to time using local transit service. No lifting is required. For more information, call 555-1111.

## Print advertising

Other print media that you may want to check out include:

- Free newspapers with business advertisements and coupons
- College newspapers
- Bulletin boards at colleges, grocery stores, churches, child care centers

You may want to make a flyer or announcement and place it around town to advertise the position. You must follow North Dakota labor laws regarding advertising. This simply means the ad cannot discriminate based on:

- Sex
- Race
- Color
- National origin
- Religion
- Age (40 years of age or older)
- Disability
- Family status
- Marital status
- Public assistance
- Lawful activity

Flyers don't have to be fancy! Color paper stands out on a bulletin board full of other ads. Many computers have programs that will set up a pattern and all you have to do is put in your own information. Color printers make the finished product more appealing.

Get creative – If you are looking for in-home support for your child, you could include a picture of your child, and show your child participating in an activity he or she enjoys (remember – do not include their name or address). Sometimes a simple paper plate that has the edges cut with your phone number written on each slip to be torn off is great. Use your imagination and come up with an appealing product that is sure to catch a prospective employee's eye!

**Privacy:** A word about privacy. Be careful about sharing written information that might reveal the location of your vulnerable child to people who prey on the innocent. Keep your child's name and your name and address out of written advertisements. One family we know received a call in the middle of the night from someone in another state who had seen their ad in the home town paper. This person knew their name, phone number, where they lived and the name and age of their child. What he had to say was scary.

## Agencies

**Job Service North Dakota Job Services** can help you find the right person. Call your local Job Service Center and discuss your needs. They will help and guide you through the rest. Call (800)-482-0017 or visit the website at: <http://discovernd.com/jsnd/>

## Service Agencies

Another option to include are service agencies such as:

- **Home Health Service Network**
- **County Social Services**
- **Public Health Nurses**
- **Childcare Centers:**
- **Universities or Community Colleges**

## Advertisements

You may be able to place an individual ad on the campus bulletin board or at a department where it will be seen by students.

Before you post ads, be sure to get permission from the locations you wish to place them.

Some suggestions you may consider are:

- Post office
- Grocery store
- Clinics
- Banks
- Restaurants
- Gas Stations
- Churches
- Schools (your child's and/or the high school)
- Community day cares
- Human Service Center
- Community colleges
- Special Ed offices
- Nursing Homes
- Senior citizen center

One family used the following flyer at a community college to find a student worker.

***Wanted:*** A student to provide in-home support for a 14 year old girl with Down syndrome. Transport to student dorm, apartment or home. Occasionally take our daughter to a sporting event, the library, mall etc. Provide age-appropriate supervision and support. References required. Excellent opportunity to gain experience with a youth who has special needs. If interested, contact: Name, Address, Phone, email

Right next to this ad they placed one that showed a daughter's perspective.

***Wanted:*** A college student with a car who can stay with me sometimes when my parents are gone or pick me up after school and be a friend. Someone who likes to watch movies, eat good snacks and if possible has a cat. I need a friend who will help me if I join a school club this year. I like people who smile a lot and don't boss me around too much. I like basketball games and getting books on tape at the library. I want someone who can help me grow up and still remembers how to be a kid. If this sounds like you, please call or email my mom.

## *Using an Employment Agency*

Whether you live in a larger city in North Dakota or on a farm near a rural community, if you have access to the Internet OR a phone you can contact the regional Job Service office to help you locate a worker to provide in-home support.

### JOB SERVICE LOCATIONS

- [Beulah](#)
- [Bismarck](#)
- [Devils Lake](#)
- [Dickinson](#)
- [Fargo](#)
- [Fort Yates](#)
- [Grafton](#)
- [Grand Forks](#)
- [Jamestown](#)
- [Minot](#)
- [New Town](#)
- [Oakes](#)
- [Rolla](#)
- [Valley City](#)
- [Wahpeton](#)
- [Williston](#)

Go to: <http://www.jobsnd.com/> OR Call: **1-800-366-6888** toll free

Job Services will assist you to post a position, search the resumes of candidates in your area that may be a match for the job you are creating and conduct a virtual search so that you are notified when new potential employees log into the system. They can help you write a clear job description. Job Service also has books, computers and brochures designed to help you write your own description. When you post your position or hire through Job Service, you must pay at least minimum wage. Job Services can also help you set the wage based on past postings. If you are interested in having Job Services help you find the right person to provide in-home support, call your local Job Service Center and discuss your needs. They will help and guide you through the rest.

Another option to consider are service agencies such as:

- Home Health Service Network (Aging Services),
- County Social Services
- Public Health Nurses
- Special Education Units or Cooperatives
- Churches or Houses of Worship
- Childcare Centers

If they are not able to provide service for you, they may be able to refer you to another agency or individual.

## *Interviewing and Hiring*



### **Screen Workers**

If you receive more than one response to an ad you can screen the callers. Ask some simple questions up front. This will help you decide if the caller is worth a full interview. Sample questions include:

- Where do you live (Decide if the person lives near enough to you to be helpful)
- Do you have a reliable means of transportation?
- Tell them a little bit about the job (Describe any lifting or personal care requirements briefly but clearly).
- Describe the pay rate (Your fiscal agent can help you set a rate).

If the response to each question or statement is positive then you might go ahead and set up an interview. Create an application that the person can fill out so that you have contact information. Ask the person to bring their driver's license to the interview if they will be transporting your son or daughter. Ask them to bring names and phone numbers of references. Also get a phone number in case you need to reschedule. Some families set up a simple script to keep by the phone at home and or at work.



### **Interview Workers**

Next set up a simple interview. Even if you plan to hire a relative it is important to sit down together and visit about your expectations. Remember you cannot hire a relative who lives in the same house with your family.

Consider where you will interview the potential employee. Most people choose to do the interview in their home. This is where the actual work will be done. It is easiest to explain work duties. Other families prefer to meet at a neutral site such as a local café or coffee shop. They feel this is a safer location to meet someone they don't know well. If you meet in a public place, decide how much information you can share in a location where others may overhear. The choice is up to you.

Before you start, think about ways to involve your son or daughter in the interview. Even a person with limited awareness can play an important part in the interview. You may be able to see how someone reacts to the person who needs support. Are they uncomfortable? Do they seem at ease and interact with the individual? Reactions can help you determine who would be the best person to provide support for your loved one.



## Photos

Take pictures of your son or daughter doing important activities. Ask your child to show the pictures to the person you interview. This is another way for your child to be involved. These pictures can help create a more realistic idea of what the potential employee will actually be doing. Older children and youth may be able to think up simple questions that they would like to ask. This way, they will have a part in choosing the care provider who will be working with them. By the time a young person is 16, he or she should be given an opportunity to conduct the interview.

If you plan to meet with more than one person, remember to keep questions the same for each interview. It is important to be fair! Ask follow-up questions but make sure they are not illegal. It is a good idea to have someone do the interview with you. Another person can help you make decisions, and make sure your questions are really helpful and consistent. Plan on about 30 minutes for an interview.

There are some questions that you should not ask during an interview. Laws on discrimination determine what questions are legal. Decide if the questions you are asking will really help you judge the applicant's ability to do the job.

This seems very formal. You may want to just visit and ask what you want. You could do this, but it may lead to illegal or inconsistent questions. It is important to judge every potential employee fairly and give everyone an equal chance.



## Background Checks

You must check the background of each person you hire. If you are using public dollars to self-direct supports. Contact your fiscal agent and ask him or her to complete a background check for any candidates that you believe might do a good job. The cost of the background check is considered to be an administrative cost and does not come out of the budget set up for your child.



## Questions to Avoid

Sometimes questions are used to rule out workers because of his or her age, sex, religion or a disability. This is illegal. These questions are off-limits to ask **before** someone is hired. They might be used to discriminate against someone even if that is not what you intend to do.

Of course you will have concerns about the person's ability to do the job. The best way to handle that is to clearly describe what will be required in your job description and as you visit with the individual. These questions are only examples.

- ⊗ What is your age or date of birth?
- ⊗ Have you ever been arrested?
- ⊗ Have you ever had any convictions other than a traffic ticket?

- Are you available for Saturday and Sunday work?
- Do you have children under the age of 18?
- How many children do you have? What ages are your children?
- What arrangements can you make for the care of your minor children?
- What country are you a citizen of? Where were you born?
- How is your credit rating? Do you own your own home? Do you own a car?
- Have you ever had a fidelity bond refused to you?
- What is your eye color? What is your hair color?
- Do you have friends or relatives who work for me?
- Have you ever had wages garnished?
- What is your height and weight?
- Did you receive an honorable discharge from the military?
- What is the lowest salary that you will accept?
- What is your maiden name?
- What is your marital status?
- Are you "Mr., Miss, or Mrs.?"
- Do you belong to any organizations?
- What is your political party?
- Do you have a prior married name?
- What is your race?
- What is your sex/gender?
- What is your spouse's employment?
- Are you widowed, divorced or separated?
- Can I see a photograph?
- Do you have a disability that would stop you from doing things on the job?
- What is your sexual preference?



### **Conduct an Interview**

When you interview the worker you may both be a little nervous. This is normal. Do your best to put each person at ease. Choose a quiet place so you can listen and concentrate. Tell the applicant the order in which things will happen. Make sure you have copies of forms with you. Being organized and prepared will send the message that caring for your child is important work.

People may have questions concerning your child's disabilities as well as about the job. They may not use "people first" language. Decide how much you are comfortable discussing. Be willing to face questions in a matter of fact way. Sample Interview questions include:

- Do you have any questions about the job?
- Is there anything that would prevent you from performing the tasks outlined in the job description (this question is legal)?
- Tell me a little bit about yourself. How do other people describe your work?
- Why did you decide to apply for this job? What interests you about the work?
- What experiences/skills/qualities do you have that would make you a good choice?
- What strengths do you have?

- What did you dislike most about previous jobs that you have had?
- Are you willing to follow detailed instructions about meeting my child's support needs?
- Tell me what you will do/not do to respect our right to keep personal information about our child's care private?
- When could you start?

Finish the interview process by visiting about the schedule. When do you need someone to come into your home and/or take your child out into the community? Set up a sample schedule and check to see that the person you have interviewed will be available.



### **Keep Records**

Keep records of your interviews. Have the person fill out an application. Remember, this is a real job. Be sure to take notes during the interview. Memories are not always good. You can buy or make a simple written application. Printed forms are expensive. Make your own form or copy the sample in this book. We recommend that you check any references. Ask the worker to sign a reference waiver form. A sample of this form is also included. Finally, follow up with a letter to anyone decide not to hire. Remember that these forms are examples. Keeping records is your responsibility.

## ***Evaluating Employee Performance***

It is a good idea to think about evaluating a worker's performance. How will you let them know they are doing a good job? If you decide to fire a worker, what proof do you need that you did not discriminate against them?

A written evaluation is NOT **required** under North Dakota law. It is **highly recommended**.

Observe and give feedback when things are going well. That is the best way to let an employee know what you expect and how satisfied you are. If you do this, the employee can see if any improvement is needed. Let the employee know that you appreciate the work that is being done. Use low-key, approachable manner. Invite the worker to give his or her input and feedback as well. Check with the caregiver to see if there are any concerns, needs or comments in between evaluations. Work for great employee-employer communication!

Decide how you will conduct annual evaluations. You can make a form or checklist that can be filled out once in a while. Use the job description that you wrote when you hired the caregiver. Make a list of responsibilities that should be completed, and how well they have been met. Meet with the employee and the person with a disability. Decide together how well things are going. Let him/her provide feedback and comments.

It is important to include the person with a disability whenever possible. The person with a disability may be well taken care of, but may not get along with the employee, or be frustrated with the person if they do not understand their wants and needs. Ask your family how they feel things are going. It is important to have feedback from all people involved in the home to make sure things run as smoothly as possible.

Simple checklists can be used to reflect the needs and feelings of your son or daughter about caregiver support. This teaches decision making and problem solving skills.

<b>This is how I feel when Beth . . .</b>			
Comes to visit			
Helps me with my chores			
Makes me do my home work			
Takes me to her house			
Fixes my favorite foods			
Helps me in the bathroom			
Uses my communication book			
Plays outdoors with me			
Helps me at bedtime			
Makes me eat healthy meals			

Using some kind of feedback chart is especially important with young people who may not be able to tell you everything they experience or feel. For an older child the checklist may look a little different.

	Going really well	We could make some changes	We need to fix this
Meals			
Baths			
Schedule			
Transportation			
Communication			
Transfers			
Choice & control			
Helping out			

Most people have a natural tendency to avoid conflict. Because of this you may hold back and be afraid of getting angry or emotional if there is a problem with performance. It is possible to give critical feedback without becoming *confrontational!* It will be important for you to find out your skills in dealing with these issues. Conflict is part of human relationships.

### Good Communication

Good communication skills help us to have good relationships with other people. Part of good communication is the willingness to be an active listener.

Active listening means paying attention to what the other person says and not just thinking about what you want to say. Active listening can help to resolve problems before they get out of hand. Active listening involves these steps.

- **Show the person you are attending** by facing them and looking at them.
- **Use open, approachable body language.** Avoid frowns, glares and sarcasm.
- **Avoid interruptions.** Pick a time when your child is safe and cared for by others to start a conversation.
- **Restate the message** – show the other person that you heard what was said by briefly restating the key message that they seemed to be communicating.
- **Name the feeling in what you hear.** Acknowledge frustration and concerns.

### Handling Conflict

Once you decide to solve a problem or resolve a conflict you must begin by making an assertive request. The rule is to address conflicts as early as possible in the relationship. Don't let things build up. If you have, limit your comments to asking for one change at a time. Show enough respect and concern for the other person to limit what you give out to what you could take.

- Take one thing at a time
- Provide privacy
- Allow space
- Be concise
- Take responsibility for yourself (Say "I'm tired when I get home and toys aren't put away," rather than "You left the toys out again.")
- End with appreciation

These steps can help us move away from the strong emotions we may feel. We can be objective and careful in our communication with one another. This is difficult to do if the other person is behaving badly. Focus on the outcome you want.

### **Follow Up**

Once you have brought up a problem, it is your responsibility to monitor or follow up. This may involve:

- Thanking the person for their cooperation if your comments were well received
- Thanking the person for improvement and repeat your requests for needed changes
- Document your conversations by writing down a brief note and dating it
- Check to make sure that what you want is fair and doable
- Review your communication style. If there is room for improvement take the first step in starting over
- If what you want is fair and doable, if your communication is appropriate, repeat your request and stress that you need changes to be made
- Ask a case manager to meet with you to review your plans and make suggestions
- Write out a plan of correction. Put in dates and timelines. Describe what you want done and how to do it briefly. Without making threats indicate that failure to make the changes will result in immediate dismissal
- Make back-up plans in case your final attempts to work things through are not successful

You have the right and choice to fire independent providers who are not meeting your needs. You have the right to terminate services with an agency provider if they are not meeting your needs. Firing someone or terminating a service is a final step in resolving a conflict. If you are using the services of an Agency provider and you are not satisfied, approach the service coordinator or single point of contact for help in resolving conflicts. As the legal guardian for your son or daughter (under the age of 18) you may request changes in services on his or her behalf.

If there are any employee complaints or performance problems, be sure to keep records about the incident! You may wonder why keeping records is so important. If you ever need to participate in an unemployment hearing, the records will be firm documentation of what has been done to try and fix the situation, what has not been done, and the complaints that were made. If you have to fire an employee for not doing their job properly and they think it is because of discrimination, you will have strong evidence proving that it was actually lack of performance.

## *Abuse and Neglect*



**At home we set limits for our children.** We say no, we teach right from wrong, we encourage children to learn new skills and do what we need to do to teach our children to behave. This job is harder when children have special needs. Children with special needs may repeat mistakes or bad behavior more often. It may take longer for some children to “get it”. Children with disabilities are also more vulnerable. They can easily be tricked or abused by other people.

### **What is abuse or neglect?**

#### **Physical abuse**

Using force on a child in a way that causes injury or risk of injury. Examples include: Shaking a fist at a child, spanking, shaking the child, burning them with cigarettes, grabbing them by the arm and squeezing, hitting, biting or scratching a child to “teach them a lesson” or “show them what it feels like,” or pushing a child.



#### **Psychological abuse**

Using negative words or actions to control a child’s behavior in a way that causes emotional harm. Examples may include shutting a child in a room or closet, constantly yelling at or scolding a child, glaring at them and getting “in their face” in an angry way, ignoring the child’s need for attention or closeness, using words to intimidate, reject or excessively discipline or control a child. Taking actions that over time will cause the child to think badly about themselves or experience delays in growth and development. Abuse can also occur when an older or young sibling takes advantage of a child with special needs by intimidating or excessive blame or rejection. Abuse can also occur when a child with special needs is allowed to torment a sibling.

#### **Sexual abuse**

Touching a child in inappropriate or sexual way by a teenager or adult. Talking to a child about sexual acts, showing pornography or explicit photographs or leaving those around where they can be found and viewed by a child or teenager. Sexual abuse includes incest, fondling and giving children sexual information that they cannot resist or handle.



### **Physical Neglect**

Placing a child in a situation where their basic needs for care, support and supervision are not met. Examples include leaving a young child (age 8 or younger) home alone, letting your toddler roam the neighborhood without supervision, not giving your child warm clothes, coats or mittens to wear in the winter, sending children to school in dirty or torn clothing, not feeding your child or giving them adequate nutrition, not teaching your child to bathe or keeping them clean so that body odor or the scent of urine causes them to be rejected by others, not giving your child the medication they need or making sure they go to school.

Physical neglect can also occur when families do not carry out recommendations for therapy or treatment without an adequate reason or when they do not allowing a child enough time to eat or keep a child restrained within a mobility device with no chance for a break. Neglect can occur when families do not provide a child with some alternate way to communicate if they cannot send messages by speaking or understand language. Physical neglect occurs when a parent forces a child to sleep in urine soaked sheets because "he wet the bed and should know better," or when the washer and dryer break down and laundry is not done for weeks.

Physical neglect occurs when parents do not fill a prescription or get medical or dental treatments for health problems that if left untreated could present a danger for the child. Educational neglect happens when parents do not send a child to school or do not check to make sure their teenaged child is in class or actually goes to school when they are working.

### **Lack of Supervision**

Parents are responsible to provide adequate child care and supervision for their child in their absence. This does not mean that you take a child to the bathroom with you. It does mean that parents do not let a child play outside without supervision until they are eight years old. Families must keep the child in site or make sure they are at a neighbor's house. Also it means that families cannot make an older brother or sister who is younger than twelve into a substitute parent and leave a small child alone with that school-aged son or daughter. Children may act as caregivers when they reach the age of twelve. A child with mental retardation may not be capable of self protection or able to show good judgment when left alone at home, even after they reach the age of twelve. Supervision means that you do let your older child play in the neighborhood in the summer or after school as long as they can do so without excessive fighting or bothering others. It means knowing where they are and who they are with and teaching them safe ways to check in with you.

## Neglectful Home Setting

Parents are responsible to provide a clean, warm/cool, safe home for children. Neglect includes broken glass (that is not swept up), spoiled food, feces, drugs, inadequate sewage or garbage disposal, inadequate or unsafe heat, excessive heat during the summer, chemicals that are not locked up when children are small, guns that are not locked up or adequately stored, rodents or other environmental risks to children. A neglectful home setting may also include not providing children with adequate mobility device or a way to exit quickly in case of an emergency, or not providing smoke detectors or having a fire extinguisher in the house.

## Abuse, anger and behavior

Your child may be at risk if you or a caregiver become frustrated or angry. Children with disabilities sometimes learn slowly. They make more mistakes and do the wrong thing. When children repeat behaviors that we do not like, it is easy to lose control. Sometimes anger and frustration lead to abuse. You can take positive action to prevent abuse and neglect.



## Problem-solving

Problem solving helps families and caregivers take a step back and decide what is happening and how to help. Solve problems by using 6 important steps.

Be Assertive  
Manage Anger  
Handle Conflict  
Deal with Stress  
Cope with Change  
Work for Prosperity  
Enjoy a happier life  
Improve Self Esteem  
Master Relationships

1. Talk about the problem with others
2. Name the problem. Be sure you know what the real problem is
3. Think of several ways that you might solve the problem
4. Choose the best steps so that everyone wins
5. Make a plan and carry it out
6. See what happens and tell other people

## Some families find it helpful to

### Make Lists

You can make a list of any behavior problems that make life difficult in living with a child with special need. Decide on one priority behavior that you hope the child can learn to stop and one behavior they might use in similar situations instead. Example: Perhaps you want your child to ask permission before raiding the cupboard for food.

### Use Charts

Instead of getting mad, it is helpful to use tally marks to count behaviors. This gives parents some other way to respond. When a behavior occurs you can say "I guess we'll have to count that one."

### Keep Schedules

You can make a picture schedule to help your child with special needs predict what will happen and when

**Phone a friend**

Contact the ND Family to Family Network. Ask a veteran parent what might work when a child is at risk

**Make a Video**

You can borrow a video camera and make a tape of your child so you can show a doctor, teacher or therapist what you see at home.

**Prevent Abuse**

You can take action that will make abuse or neglect less likely to occur.

# How?

**Use Self Control**

Count to 10, walk away, take deep breaths, count behaviors or do chores to calm down

**Be Watchful**

Look for actions or events that might place your child at risk (example, be aware of resentful feelings or sudden changes in your child's behavior, do background checks on potential caregivers, even family members).

**Be Well**

Give yourself and your child an active, busy life with opportunities for friendship and community involvement. This helps to prevent problems and relieve stress.

**Manage Anger**

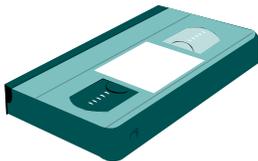
Some families need a formal program to learn to recognize the signs of anger and new ways of thinking about and responding to others.

**Talk with a Doctor**

Visit with your family doctor. The doctor sees many families whose children have challenging behaviors. Ask for ideas that may help.

**Training**

Get information that will help you respond to your child in positive ways.

**Video**

You might watch a video about teaching children good behavior or about managing anger. Ask your child's school or doctor or library to help you find a video.

**Online**

Look online and find a slide presentation, or book you can use.

## Home visitor

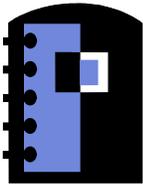
Invite a professional to come to your house and show you how to discipline without harming a child.

## Class

Ask a local university if they have a class that caregivers or family members can take to learn new strategies for coping with stress or responding to behavior

## Behavior Intervention

Most families find it helpful to learn special ways to respond to problem behaviors that children may learn. This special training should include ideas that families can use at home, in the car and when out and about in the community.



### Spot Trouble

Write down events that place your child at risk so that problems can be identified and solved.

## Log or journal

Some families find it handy to keep a spiral notebook to exchange information with caregivers or teachers. It is OK to write down good things too.

## Report

If you accept funds to self-direct supports you must agree to record incidences of possible abuse or neglect. This does not mean that you need to report the time your child was out of clean laundry because you had the flu. It does mean that you agree to report serious problems that might place a child at risk or could lead caregivers to abuse or neglect a child.

The following people **MUST** report abuse or neglect **NO MATTER WHAT!**

- Families whose children receive self-directed supports
- Caregivers hired by the family
- Case managers
- Other professionals such as therapists, teachers, doctors or clergy

**WHAT SHOULD YOU DO if you suspect that your child has or may be abused or neglected?**

**Call the ND Protection and Advocacy Project:  
1-800-472-2670 in an emergency.**

Or contact your regional office. The phone and email contact information for regional offices is included in the appendix or can be found online at:

<http://www.ndpanda.org/offices/office.html>

Jot down and share a quick report telling the name and address, sex, age and location of the person at risk. Describe the problem and if the person is in a life threatening situation. Include when and where the abuse may have occurred, witnesses or people who may be aware of what happened, the person responsible (even if that is YOU) and any other action taken to protect your child. Think about who, what, when, where, how and why. A copy of the state form used to report abuse and neglect is found in the appendix.

## **WHAT HAPPENS WHEN AN ABUSE/NEGLECT REPORT IS MADE?**

Staff from the P & A project will consider the information. If a child is at risk they will contact the Child Protective Services (SPS) team in your county. Either P & A or CPS or both will investigate the report. They will take steps to make sure your child is safe. They may want to talk to other people who can tell them about your child and his or her history. They may visit your child, interview your family and talk to others who may know what is going on.

Unless your child is in danger and cannot be protected at home, the goal will be to keep your family together. If your child is in immediate danger at home the social worker will seek a court order to have the child removed. The police will be contacted if the investigators think that a child has been sexually abused, has a serious body injury or is the victim of a crime.

Providing information that is accurate and given in good faith keeps people who report immune from any civil or criminal liabilities that may happen as a result. Caregiver's may report anonymously and may be asked for more information so they can be contacted during an investigation.

Often the P & A staff will find that NO ABUSE OR NEGLECT OCCURRED and they can help bring your family services or assistance to prevent future abuse or neglect.

YOUR REPORT is a cry for help, a request for investigation and follow up. It is NOT an accusation and you do not need to be SURE before you call. If you think "Maybe I should call, DO!

The information you give is confidential and not used to prosecute a reporter.

## Get Family Support

You can invite a trained caregiver into your home or ask them to take your child into the community so that your family gets the support they need. You can ask a specialist to work with a family member in a supportive way. Trained caregivers or specialists may provide:

**Care** - Help to meet the physical demands of caring for your child

**Respite** - A break that allows you to attend to other children or tasks

**Community Support** - Support to allow a young person to make friends or enjoy recreational events without constant supervision from a parent

**Sibling support** - Activities that allow a brother or sister to get needed attention or support as the sibling of a person with a disability

**Family or individual therapy** - Counseling that helps families to strengthen relationships and learn strategies for controlling thoughts and feelings and solving problems

## Get Community Support

Use the resources in your community to help you give your child a good life and cope with the challenges of parenting a special needs child.

- Library
- YMCA
- After school program
- Church
- Social clubs (boy or girl scouts)
- Theater
- Sports
- Concerts
- Stores or Malls
- Dairy Queen

## How Do You Know if Abuse is Real?

We love our children. Our hearts break if we think anything might happen that would put them in harms way. It is important to know that most abuse is done by someone the individual knows (a family member or trained caregiver) and not a stranger.

- Abuse happens more often to people with disabilities.

Anyone you hire as a trained caregiver must report any possible signs of abuse or neglect. If you accept funds for self-directing supports, you must agree to report problems too.

Examples of abuse may include

- Screaming at your child frequently
- Scolding often or shaming your child
- Spanking your child
- Forcing your child into or out of a room (except in an emergency)
- Humiliating your child



Abuse damages your child's sense of control over what happens to him or her. Abuse can cause

- shame
- anger
- physical harm
- emotional harm

Abuse teaches children that their body and wishes will not be respected and they do not deserve to be treated well. People with disabilities react to abuse by expressing

- anxiety
- anger
- depression
- fear

Often children or even youth cannot tell someone if they have experienced abuse. Many behaviors that signal discomfort may have a physical cause. For example a child who suddenly protects his or her genitals could have a urinary tract or yeast infection. Trained caregivers are required to report information that is a cause for concern. Professionals who are experienced in determining if abuse has occurred can then help your family investigate and problem solve.

#### **Verbal changes in behavior to report**

- Complaints about poor treatment
- Telling about a specific time when sexual abuse occurred
- Suddenly talking about sexual acts with unusual knowledge
- Unexpectedly talking about sexual topics
- Unexpected crying/screaming for a long time or in the presence of one person

Remember, a typical 5 year old may ask where babies come from. Sometimes children with DD do not clearly understand roles and rules. It would not be unusual for a young teenage girl with moderate disabilities to ask their teacher or a caregiver to marry them when they are feeling happy or excited. The youth may not be clear about what to say instead. We should show greater concern if a young child suddenly begins to ask for tight hugs and to rub people in private areas.

#### **Non-verbal changes in behavior to report**

A child who experiences trauma such as a death, divorce, a reaction to a medication, an undetected illness or an abusive incident may change their behavior suddenly. If the child has been abused, they may not know how to talk about the situation or who they can trust. The perpetrator may have told them he or she would repeat the behavior or hurt them or someone they love if they told. There is no one list of behaviors that consistently prove that abuse has occurred. Over time, people who investigate abuse have observe many behaviors that afterwards were a clue that helped supporters figure out what was going on and put a stop to the problem, whatever the cause. Report the behaviors listed below so that someone can help with problem solving and help you decide if the child is at risk.

- Suddenly begin to ask for help, cling to a caregiver or imitate the behavior of a much younger person
- Shows sudden mood changes such as irritability, rage, anger, apathy or fear by crying, snapping at others, blowing up unexpectedly or withdrawing from activities they used to enjoy
- Abruptly take on a new “bad boy or bad girl” role by shoplifting, gossiping or stealing
- Show a sudden change in appetite, eating too much or too little; stealing food
- Refuse to bathe or show an unusual desire to be clean; show reduced interest in self-care
- Demonstrate sudden changes in bowel and bladder habits
- Begin to masturbate for long periods of time in a driven way with little satisfaction
- Take to wearing many layers of clothing or clothing that is revealing; fear of undressing; stripping
- Become very concerned about being touched.
- Become suddenly or unusually fearful of being alone, being with a certain person, being touched, going to a particular place or of specific objects
- Suddenly showing a very close, intense relationship with an adult, especially someone who does not treat them well. Going out of there way to avoid certain people.
- Problems with concentration, memory, and attention that are unusual for this child.
- Difficulty with complex tasks (more than 2 steps) that previously were no problem for that person. Having no energy and avoiding work or school.
- Nightmares, sleep problems, and early morning awakening with no known cause
- Staying in their room, avoiding recess or contact with classmates or friends, looking sad, losing interest in usual activities, or commenting on being sick or wanting to die.

### **Possible physical signs of abuse**

- Unexplained cuts, bruises, burns, or bites on a child’s body that are unusual for him.
- Marks on areas of the body that would be difficult to injure by accident.
- Blood or semen on clothing, bedding, towels, or furniture.
- Changes in how the person walks, bleeding in anal and genital areas.
- Missing, torn or stained clothing that suggests assault.
- Poor hygiene, for young women who typically have good hygiene
- A sudden or unexplained preference for shabby, torn, or poorly fitting clothes
- A urinary tract infection or complaints of discomfort
- Frequent complaints of hunger and obvious weight loss/gain in a short period
- Unusual or unexplained sexually transmitted diseases, trauma to the anal/genital area or pregnancy.

### **Harmful situations or materials**

Report any current or past behavior, words, actions that you observe regarding people who provide support.

- Aggression, hostile, angry, disrespectful, uncaring or insensitive statements made to yourself or others
- Previous history of abusing others or sexual abuse.
- Alcohol or drug abuse.

- Negative statements that devalue yourself and others, such as referring to people as retards, idiots or dummies
- Threats to harm the person; "He'll catch it when he gets home."
- Finding humor in the pain and suffering of the individual or others; Laughing when the individual struggles to walk or fit in
- Seeming preoccupied with sex, hitting on other caregivers in a way that is not appreciated, having pornographic materials in the home of the child with a disability
- A caregiver who seeks to be alone with a child in a way that is unusual or inappropriate

Deciding whether or not abuse actually occurred is not your job. Incidences should be reported even if another caregiver or family member is involved and expresses tearful regret when their behavior is observed. Record what you see and share that information with the case manager who can help.

## ***Training Family and Friends***

You will be responsible for training family members and friends or caregivers to care for your child. You can provide the training yourself or call on therapists or specialists working with your family to conduct the training. As you plan for training you will consider:

1. Training for yourself and immediate family members
2. Training for independent caregivers
3. Training for licensed or certified providers (Example: a new physical therapist is familiar with safe lifting techniques but has never lifted or moved *your* child)
4. Training for community members

Consider the following. Review the people who will carry out your plan. For each person consider if he or she will need:

1. Certification or licensure
2. General background information or training
3. Specific training to care for your child
4. General orientation procedures
5. Access to safety equipment or resources

### **Resources in this section**

#### **Planning Checklist**

This checklist provides you with a list of items to consider in planning training that may be needed for caregivers who are supporting your child.

#### **Training Guidelines**

This guide provides general information on setting up a training program. It includes suggestions for writing down important information and problem solving situations that can come up when training another person. Family friendly examples of how to prevent common problems are included. This section includes forms and examples of ways to track or document training provided to caregivers and communities.

#### **Training Resources**

A list of modules and training resources that families can use to consider training for caregivers or family members is included in the Appendix.

**Training Planning Checklist for \_\_\_\_\_ Date: \_\_\_\_\_**

**People who support my child need certification in/as:**

- |  |  |
|--|--|
| <input type="checkbox"/> CPR/First aid                     | <input type="checkbox"/> Massage therapy                   |
| <input type="checkbox"/> Medication administration         | <input type="checkbox"/> Physical or occupational therapy  |
| <input type="checkbox"/> Lifeguard/swimming instruction    | <input type="checkbox"/> Speech or Language therapy        |
| <input type="checkbox"/> Therapeutic riding instructor     | <input type="checkbox"/> Individual or family counseling   |
| <input type="checkbox"/> Therapeutic behavior intervention | <input type="checkbox"/> Orientation and mobility training |
| <input type="checkbox"/> Sign language interpreter         | <input type="checkbox"/> Certified nursing assistant       |
|  | <input type="checkbox"/> Nursing                           |

**People who support my child need general information about:**

- |  |   |
|--|---|
| <input type="checkbox"/> Reporting events or abuse/neglect | <input type="checkbox"/> Orientation and mobility training                |
| <input type="checkbox"/> Lifting/transferring techniques   | <input type="checkbox"/> Seizure management                               |
| <input type="checkbox"/> Behavior intervention             | <input type="checkbox"/> Managing specific disabilities (Example: autism) |
| <input type="checkbox"/> Age – appropriate intervention    |   |

*List who will provide the information and how it will be available to caregivers*

**People who support my child need orientation to:**

- Become familiar with my home, neighborhood or nearby community
- Locate and be familiar with my child's emergency back-up plan
- Other: \_\_\_\_\_

**The community will need training to support my child or family:**

\_\_\_\_\_ Teach people living nearby to communicate with your child. (Example: friends and neighbors who also use sign language).

\_\_\_\_\_ Advise community workers of the need for special services. Examples:

- An accessible park or playground in the community
- Signs or lights for a child with sensory impairments
- Accepting service animals in local restaurants
- How to welcome our child in activities available to the public
- After school or summer recreational programs for teens with disabilities

\_\_\_\_\_ Train emergency personnel on how to evacuate or rescue your child

**Training Planning Checklist** for \_\_\_\_\_ Date: \_\_\_\_\_

	People who support my child need specific instruction to:	Decide <i>who</i> will provide the training and <i>how</i> (Example Who: parents, therapist, youth, How: write out directions, make videotape, show/practice)
<b>Health</b>		
<input type="radio"/>	Give his/her medications	
<input type="radio"/>	Help my child to manage symptoms of illness	
<input type="radio"/>	Follow special health procedures	
<input type="radio"/>	Use special health equipment	
<input type="radio"/>	Respond to seizure behavior	
<input type="radio"/>	Other	
<b>Mobility</b>		
<input type="radio"/>	Lift and transfer my child	
<input type="radio"/>	Help my child move about (use walker, cane etc)	
<input type="radio"/>	Transport my child in a vehicle	
<input type="radio"/>	Other	
<b>Routines</b>		
<input type="radio"/>	Assist my child with the daily routine	
<input type="radio"/>	Assist my child to wake up or get to sleep	
<input type="radio"/>	Assist my child with feeding, diet or meals	
<input type="radio"/>	Assist my child to dress/bath/shave/care for menses	
<input type="radio"/>	Involve my child in play/recreation activities	
<input type="radio"/>	Other	
<b>Relate</b>		
<input type="radio"/>	Communicate with my child	
<input type="radio"/>	Gain my child's trust and cooperation	
<input type="radio"/>	Understand my child's likes and dislikes	
<input type="radio"/>	Other	
<b>Behavior</b>		
<input type="radio"/>	Help my child contact others/make friends	
<input type="radio"/>	Respond to refusals/frustration behavior	
<input type="radio"/>	Carry out his/her behavior intervention plan	
<input type="radio"/>	Respond to fearfulness or sensitivity	
<input type="radio"/>	Respond to repeated behaviors	
<input type="radio"/>	Assist my child to relax after a stressful episode	
<input type="radio"/>	Other	
<b>Safety</b>		
<input type="radio"/>	Prevent my child from wandering	
<input type="radio"/>	Help my child avoid high risk behavior	
<input type="radio"/>	Assist my child to use special equipment	
<input type="radio"/>	Other	

# Leadership Training Opportunities for ND Families

## The North Dakota Family Connections Conference



This annual conference is sponsored by over 15 ND family support agencies. It offers joint training on early intervention, education, health, mental health, disability issues, family support and community development. The conference gives educators, providers and family members an opportunity to meet with ND policymakers to talk about issues that challenge families of special needs children in ND. To register call 1-866-579-2663 <http://www.conted.und.edu/connections/> or call Cathy Haarstad at 1-800-233-1737

## Common Ground Training

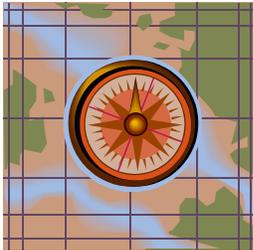
### Common Ground Training



Focus on the Child

"Common Ground Training" acknowledges the importance of people being able to work together." The workshop provides both information and skill-building activities to help you feel confident in working with others and advocating for children. CGT helps educators, providers and families to find common ground in meeting a child's individual needs. The workshop covers information about different types of conflicts and how to resolve problems by working together. For more information contact Jim Jacobson at 1 (800) 472-2670

## Navigating the System



Many ND families find the array of services and supports to be bewildering. No matter what their child's disability or unique needs may be, families need to learn the skills required to successfully access systems and obtain services. This training offers families an overview of the educational, finance, health care, recreation, mental health and social service programs available in ND. For more information, contact Kathleen Twite at the ND Family-to-family network by calling toll free to **1 (888) 434-7436** or visit the web site at <http://www.med.und.nodak.edu/depts/rural/family/>

## Veteran Family Training



This training teaches veteran families to mentor other families whose children have similar disabilities. Many parents who have completed the training said that the program has been very instrumental in reducing their own isolation and helping them come to terms with issues related to parenting a special needs child. For more information, contact Kathleen Twite call **1 (888) 434-7436** or visit the web site at <http://www.med.und.nodak.edu/depts/rural/family/>

## Partners in Policymaking



This intensive leadership program assists people with disabilities and parents of children with disabilities in developing advocacy skills. The program analyzes disability issues and builds skills that participants use to influence legislation, create systems change, and obtain appropriate supports and services for themselves, family members, and other North Dakotans. Funded primarily by the State Council on Developmental Disabilities, there is no cost to selected participants. For more information, contact Joyce Smith at Dakota Center for Independent Living at 222-3636 or 1-800-489-5013.

## Collaborative Family Training



This training conducted by the director of special education provides families with basic information about the special education law and process. The training helps to establish positive relationships and give participants insight into how families can participate as an equal partner in the planning process. Training for regional teams who wish to implement the program is available. For information contact Cindy Wilcox at (701) 777-6315 or email [cindy\\_wilcox@und.nodak.edu](mailto:cindy_wilcox@und.nodak.edu)

## Parents as Teachers



Parents receive home visits by certified parent educators, trained in child development. These visitors, help parents understand what to expect in each stage of their child's development. They offer practical tips on ways to encourage learning, manage challenging behavior, and promote strong parent-child relationships. Group meetings: Parents get together to share their experiences, common concerns and success. For more information contact: Parents as Teachers, NDSU PO Box 5057, Fargo ND 58105. Phone: 701-231-6374 or 1-800-267-4401/ Program Coordinator 701-231-6372. E-mail - [Kim.Hemberger@ndsu.nodak.edu](mailto:Kim.Hemberger@ndsu.nodak.edu).

## Parent-School-Community Partnerships



This workshop shows families and educators how to increase parent/family involvement in the school environment. Training brings together a small group of parents, school officials and community members as they write goals, objectives and action plans to build partnerships. For more information call 1-800-245-5840 or on the web at <http://www.pathfinder@minot.com/index2.html>

## NDCPD CD Casts



These 3 hour workshops help families access the latest research. The training takes place totally online. Participants receive a CD in the mail with a power point presentation and handouts. Parents who register may call the number provided and listen to an expert presenter review the slides and discuss the topics. Although there is a cost to participate, families may join their local school personnel (possibly at no cost) for a session or save on travel costs by joining the CD cast from their office or home. For more information contact Mary Mercer at 1-800-233-1737.

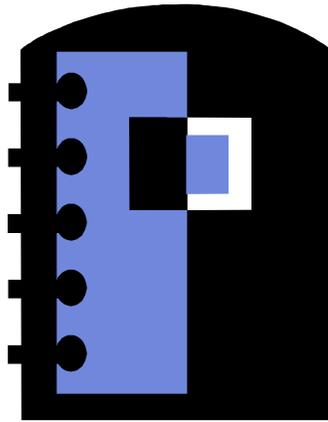
## NDCPD Community Training Modules

### Developmental Disabilities Modules Coursework



Parents who wish to earn a degree (non teaching) in Developmental Disabilities can take courses online for credit through Minot State University leading to an associate's degree in Developmental Disability. Over 14 modules covering seizures, job development, sexuality, and a variety of other topics are available. For more information contact Mary Mercer at 1-800-233-1737 or check out the course contents on the web at [www.ndcpd.org](http://www.ndcpd.org).

# APPENDIX



## ND Community Providers

The Arc of Bismarck  
1211 Park Avenue  
Bismarck, ND 58504  
Contact: Mike Schwab  
Phone: (701) 222-1854  
Fax: (701) 222-1854  
E-Mail: [arcbis@midconetwork.com](mailto:arcbis@midconetwork.com)

Arc of Cass County, The  
215 N. University Drive  
Fargo, ND 58102  
Contact: Janell Malpert  
Phone: (701) 293-8191  
Fax: (701) 293-3095  
E-Mail: [arccassnd@yahoo.com](mailto:arccassnd@yahoo.com)  
URL: [www.arccassnd.com](http://www.arccassnd.com)

The Arc of Dickinson  
P.O. Box 1421  
Dickinson, ND 58601  
Contact: Connie Kathrein  
Phone: 701-483-4272

The Arc, Upper Valley  
PO Box 12420  
Grand Forks, ND 58201  
Contact: Dianne Shepard  
Phone: (701) 772-6191  
E-Mail: [thearc@arcuv.com](mailto:thearc@arcuv.com)  
URL: <http://www.thearclink.org>

Caregiver Support Program  
P.O. Box D  
Fort Yates, North Dakota 58538  
Contact: Fritz Eagleshield Jr.  
Phone: (701) 854-4364  
Fax: (701) 854-4250  
E-Mail: [nfe@westriv.com](mailto:nfe@westriv.com)

Catholic Charities North Dakota  
5201 Bishops Boulevard, Suite B  
Fargo, ND 58104-7605  
Phone: (701) 235-4457  
Fax: (701) 356-7993  
E-Mail: [fargo@catholiccharitiesnd.org](mailto:fargo@catholiccharitiesnd.org)  
URL: [www.catholiccharitiesnd.org](http://www.catholiccharitiesnd.org)

Community Living Services, Inc.  
111 N University  
Fargo, ND 58102  
Contact: James Berglie  
Phone: (701) 232-3133  
Fax: (701) 478-4140  
E-Mail: [clsberglie@hotmail.com](mailto:clsberglie@hotmail.com)

Community Options, Inc  
3831 Lockport St., Suite B  
Bismarck, ND 58503  
Contact: Beth Johnson, Program  
Administrator  
Phone: (701) 223-2417  
Fax: (701) 223-2843  
E-  
mail: [Bryan.CORESINC@Midconetwork.com](mailto:Bryan.CORESINC@Midconetwork.com)

Dakota Center for Independent Living,  
Inc.  
3111 E. Broadway Avenue  
Bismarck, ND 58501  
Contact: Bob Gomez  
Phone: (701) 222-3636  
Fax: (701) 222-0511  
E-Mail: [dcil@dakotacil.org](mailto:dcil@dakotacil.org)  
URL: [www.dakotacil.org](http://www.dakotacil.org)

Dakota Center for Independent Living  
40 1st Avenue West Park Square Mall  
Dickinson, ND 58601  
Contact: Kim Johnson  
Phone: (701) 483-4363  
Fax: (701) 483-4361  
E-Mail: [dcil@ndsupernet.com](mailto:dcil@ndsupernet.com)  
URL: [www.dakotacil.org](http://www.dakotacil.org)

Easter Seals Goodwill ND, Inc  
PO Box 1206  
Mandan, ND 58554  
Contact: Marilyn Bender  
Phone: (701) 663-6828 Ext 301  
E-Mail: [mbender@btinet.net](mailto:mbender@btinet.net)

Family to Family Network  
Center for Rural Health  
School of Medicine and Health  
Sciences  
Grand Forks, ND 58202-9037  
Contact: Family Intake Specialist  
Phone: 1-888-434-7436  
Fax: (701) 777-2353  
E-Mail: [NDF2F@medicine.nodak.edu](mailto:NDF2F@medicine.nodak.edu)  
URL: [medicine.nodak.edu/crh](http://medicine.nodak.edu/crh)

Family Voices of North Dakota  
PO Box 163  
Edgeley, ND 58433  
Contact: Donene Feist  
Phone: (701) 493-2634  
Fax: (701) 493-2635  
E-Mail: [feist@daktel.com](mailto:feist@daktel.com)  
URL: [www.geocities.com/ndfv/](http://www.geocities.com/ndfv/)

Fargo Housing & Redevelopment  
Authority  
325 Broadway  
PO Box 430  
Fargo, ND 58102  
Phone: (701) 293-6262  
Fax: (701) 293-6269  
E-Mail: [jille@fargohousing.org](mailto:jille@fargohousing.org)

Freedom Resource Center  
For Independent Living  
2701 9th Ave SW  
Fargo, ND 58103  
Contact: Chuck Stebbins  
Phone: (701) 478-0459  
Fax: (701) 478-0510  
E-Mail: [freedom@freedom.org](mailto:freedom@freedom.org)  
URL: [www.macil.org/freedom](http://www.macil.org/freedom)

Friendship, Inc.  
801 Page Dr  
Fargo, ND 58103  
Friendship, Inc.-Grafton  
554 W. 12th Street  
Grafton, ND 58237  
Contact: Don Brunette  
Phone: (701) 235-8217  
Fax: (701) 235-7538  
E-  
Mail: [DonBrunette@catholichealth.net](mailto:DonBrunette@catholichealth.net)  
URL: [www.friendship-inc.com](http://www.friendship-inc.com)

Greater Grand Forks Business  
Leadership Network  
3551 South 20th Street  
Grand Forks, ND 58201  
Contact: Diane Werness  
Phone: (701) 775-3356  
Fax: (701) 772-5266  
E-Mail: [success@rrv.net](mailto:success@rrv.net)  
URL: [www.usbln.com](http://www.usbln.com)

Hope, Inc  
830 South 48th Street  
Grand Forks, ND 58201  
Contact: Jim Steinke  
Phone: (701) 772-3344  
Fax: (701) 772-5284  
E-Mail: [jsteinke@iphope.com](mailto:jsteinke@iphope.com)  
URL: [www.hopeinonlin.org](http://www.hopeinonlin.org)

Independence Inc.  
300 3rd Avenue SW  
Minot, ND 58701  
Contact: Stephen Repnow  
Phone: (701) 839-4724  
Fax: (701) 838-1677  
E-Mail: [agency@independencecil.org](mailto:agency@independencecil.org)

Independent Living Program  
1325 11th St S  
Fargo, ND 58103  
Contact: Dawn Peters  
Phone: (701) 235-7341  
Fax: (701) 235-7359  
E-Mail: [dpeters@lssnd.org](mailto:dpeters@lssnd.org)  
URL: [www.lssnd.org](http://www.lssnd.org)

Interagency Program for Assistive  
Technology (IPAT)  
PO Box 743  
Cavalier, ND 58220  
Contact: Judie Lee  
Phone: (800) 265-4728  
Fax: (701) 265-3150  
E-Mail: [jlee@polarcomm.com](mailto:jlee@polarcomm.com)  
URL: [www.ndipat.org](http://www.ndipat.org)

Knife River Group Homes, Inc.  
508 3rd Avenue NW  
PO Box 392  
Hazen, ND 58545  
Contact: Marilyn Jensen  
Phone: (701) 748-6627  
E-Mail: [krgh@westriv.com](mailto:krgh@westriv.com)

L.I.S.T.E.N. Inc.  
1407 24th Ave. S. # 100  
Grand Forks, N.D. 58201  
Contact: Charlie Brenseth  
Phone: (701) 746-7840  
E-Mail: [listen@wiktel.com](mailto:listen@wiktel.com)  
URL: [www.wiktel.net/listen](http://www.wiktel.net/listen)  
Lutheran Social Services of North  
Dakota  
Grand Forks Program Center  
412 Demers Avenue  
Grand Forks, ND 58201  
Contact: Theresa Flitter  
Phone: (701) 772-7577  
Fax: (701) 772-5001  
E-Mail: [tflitter@lssnd.org](mailto:tflitter@lssnd.org)  
URL: [www.lssnd.org](http://www.lssnd.org)

MVAW  
PO Box 1030  
605 27<sup>th</sup> Street SE.  
Minot, ND 58703  
Contact: Neil Sharpe  
Phone: (701) 852-1014  
Fax: 701-852-1139  
E-Mail: [nscharpe@mvaaw.org](mailto:nscharpe@mvaaw.org)  
URL: <http://www.mvaaw.org/>

North Dakota Association for the  
Disabled  
1913 South Washington Street  
Grand Forks, ND 58201  
Contact: Patti Burke or Jerri Hietala  
Phone: (701) 775-5577  
Fax: (701) 795-6630  
E-Mail: [jhietala@ndad.org](mailto:jhietala@ndad.org)  
URL: [www.ndad.org](http://www.ndad.org)

North Dakota Association for the  
Disabled  
3114 1st Avenue W  
PO Box 1503  
Williston, ND 58801  
Contact: Leslie Stastny  
Phone: 701-774-0741 or 1-800 - 532-  
NDAD  
Fax: (701) 774-1045  
E-Mail: [lstastny@ndad.org](mailto:lstastny@ndad.org)  
URL: [www.ndad.org](http://www.ndad.org)

Open Door Center  
209 2nd St SE  
Valley City, ND 58072  
Contact: Mary Simonson  
Phone: (701) 845-1124  
Fax: (701) 845-1175  
E-Mail: [opendoorctr@hotmail.com](mailto:opendoorctr@hotmail.com)

OPTIONS, Interstate Resource  
Center for Independent Living  
318 3RD St. NW  
East Grand Forks, MN. 56721  
(2 out of 3 services selected)  
Disability Services, Independent Living  
Skills

OPTIONS, Interstate Resource  
Center for Independent Living  
318 3RD St. NW  
East Grand Forks, MN. 56721  
Contact: Judy Moen  
Phone: (218) 773-6100  
Fax: (218) 773-3692  
E-Mail: [options@myoptions.info](mailto:options@myoptions.info)

OPTIONS, Interstate Resource  
Center for Independent Living  
200 Bjornson Drive  
PO Box 761  
Cavalier, ND 58220  
Contact: Revel Sapa  
Phone: (701) 265-4618  
E-Mail: [options3@polarcomm.com](mailto:options3@polarcomm.com)

Pride Inc  
PO Box 4068  
Bismarck, ND 58501  
Contact: Barbara Murry  
Phone: (701) 258-7838  
Fax: (701) 258-7911  
E-Mail: [prideinc.org](mailto:prideinc.org)  
URL: [www.prideinc.org](http://www.prideinc.org)

Progress Enterprises, Inc.  
1601 Hwy 20 N  
Jamestown, ND 58402  
Contact: Roger Koenig  
Phone: (701) 252-6994  
Fax: (701) 252-8153  
E-Mail: [roko@csicable.net](mailto:roko@csicable.net)

Quentin Burdick Job Corps Center  
1500 University Avenue West  
Minot, ND 58703  
Contact: Rae Schobinger  
Phone: (701) 857-9611  
Fax: (701) 837-5547  
E-Mail: [schobir@jcdc.jobcorps.org](mailto:schobir@jcdc.jobcorps.org)  
URL: [burdickjobcorps.com](http://burdickjobcorps.com)

Rehabilitation Consulting and Services  
117 1st ST E  
Dickinson, ND 58601  
Contact: Kari Lyon Shea  
Phone: (701) 227-7600  
Fax: (701) 227-7618  
E-Mail: [88lyok@state.nd.us](mailto:88lyok@state.nd.us)

Supported Employment Program  
117 1st St. E.  
Dickinson, North Dakota 58601  
Contact: Kim Buck  
Phone: (701) 227-7600  
Fax: (701) 227-7618  
E-Mail: [88buck@state.nd.us](mailto:88buck@state.nd.us)

Rehab Services, Inc.  
1421 2nd Avenue SW  
Minot, ND 58701  
Contact: Jay Klabunde, Assistant  
Director  
Phone: (701) 839-4240  
Fax: (701) 838-2621  
E-Mail: [rsi@minot.com](mailto:rsi@minot.com)  
URL: [www.minotrehabservices.com](http://www.minotrehabservices.com)

Success Unlimited  
3551 South 20th Street  
Grand Forks, ND 58201  
Contact: Diane Werness  
Phone: (701) 775-3356  
Fax: (701) 772-5266  
E-Mail: [success@rrv.net](mailto:success@rrv.net)  
URL: [www.dressforsuccess.org](http://www.dressforsuccess.org)

Three Affiliated Tribes  
477 Employment Training Program  
PO Box 597  
New Town, ND 58763  
Contact: Leo Cummings  
Phone: (701) 627-4756  
Fax: (701) 627-2520  
E-Mail: [program477@hotmail.com](mailto:program477@hotmail.com)

Tribal 1-21 Vocational Rehabilitation  
404 Frontage Road  
New Town, ND 58763  
Contact: Mavis Young Bear  
Phone: (701) 627-2688  
Fax: (701) 627-4024

Western Sunrise Inc.  
211 2nd Ave West  
Williston, ND 58801  
Contact: Victoria Scheldrup  
Phone: (701) 577-0267  
Fax: (701) 774-4620  
E-Mail: [uffda@nemontel.net](mailto:uffda@nemontel.net)

Workforce Investment Act  
3315 University Drive  
Bismarck, ND 58504  
Contact: Debbie Painte  
Phone: 701-255-3285 ext. 1232  
E-Mail: [dpainte@uttc.edu](mailto:dpainte@uttc.edu)  
URL: [uttc.edu](http://uttc.edu)

# Developmental Disabilities Modules/Coursework

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\*Certification Requirements

\*\* Electives

These modules are available through the ND Center for Persons with Disabilities. They can be taken online or on campus at Minot State University. To order a copy, contact:

Mary Mercer  
Community Staff Training Program  
500 University Avenue W.  
Minot, ND 58707  
1-800-233-1737  
[Mary.mercer@minotstateu.edu](mailto:Mary.mercer@minotstateu.edu)

## **Sp.Ed.101 Introduction to DD Services (3 SH)**

- \*895.39 Supporting Individuals with Disabilities in the Community
- \*895.03 Legal Issues & Developmental Disabilities
- \*895.40 Team Planning
- \*895.41 Working with Families OR \*895.42 Job Coach Training Manual

SPED101: Introduction to Developmental Disabilities

## **Sp.Ed.111 Health Care in DD I (3 SH)**

- \*895.06 Medications Training
- \*895.07 CPR (Cardiopulmonary Resuscitation)
- \*895.08 First Aid
- \*\*895.45 Nutrition
- \*895.46 Sexuality and DD
- \*\*895.47 Oral Hygiene & Dental Care
- \*\*895.48 Control of Infection & Communicable Disease
- \*\*895.49 Signs & Symptoms of Illness
- \*\*895.50 Nurse Assistant Training

SPED 111: Health Care in Developmental Disabilities I

## **Sp.Ed.112 Health Care in DD II (2 SH)**

- \*895.10 Seizures
- \*\*895.11 Positioning, Turning and Transferring

SPED 112: Health Care in Developmental Disabilities II

**Sp.Ed.120 Introduction to Behavior Management (3 SH)**

- \*\*895.51 Principles of Behavior & Basic Behavior Intervention Procedures
- \*\*895.52 Designing & Implementing Behavior Intervention Programs
- \*\*895.15 Writing Behavioral Objectives & Measuring Behavior

SPED120: Introduction to Behavior Intervention

**Sp.Ed.130 Organization of Leisure Time in DD (1 SH)**

- \*\*895.19 Recreation & Leisure Training

SPED130: Organization of Leisure Time in DD

**Sp.Ed.140 Human Development (2 SH)**

- \*\*895.21 Human Development (Condensed Version)
- \*\*895.22 Human Development I
- \*\*895.23 Human Development II

SPED140: Human Development

**Sp.Ed.221 Techniques of Behavior Management (2 SH)**

- \*\*895.55 Assessment and Setting Goals
- \*895.18 Achieving Goals

SPED221: Techniques of Behavior Management

**Sp.Ed.223 Dual Diagnoses: Mental Retardation & Psychopathology (1SH)**

- \*\*895.53 Dual Diagnoses

SPED223: Mental Retardation & Psychopathology

**Sp.Ed.225 Assisting People with Traumatic Brain Injury & their Families (2 SH)**

- \*\*895.56 Assisting People with Traumatic Brain Injury & their Families
- \*\*895.57 Beyond Brain Injury: A Manual for Supported Employment Providers

SPED225: Assisting People with Traumatic Brain Injury

**Sp.Ed.250 Developing Communicative Interaction (2 SH)**

- \*\*895.24 The Framework of Interaction & Communication
- \*\*895.25 Recognizing & Responding to the Many Forms of Communication
- \*\*895.26 Increasing Understanding
- \*\*895.27 Increasing Communication
- \*\*895.60 Interpersonal Communication

SPED250: Developing Communicative Interaction

## **Sp.Ed.255 Aging and DD (2 SH)**

- \*\*895.28 Introduction and Overview
- \*\*895.29 Medical and Health Issues
- \*\*895.30 Transitions & Social Adjustment
- \*\*895.31 Legal Issues
- \*\*895.32 Issues in Service Coordination

### SPED 255: Aging and Developmental Disabilities Services

## **Sp.Ed.296 Supervised Field Experience in DD (4 SH)**

### **A. Practica**

- a. Person-Centered Planning Process(895.40)\*
- b. Medication: Administration and Storage(895.06)\*
- c. Positioning, Turning and Transferring(895.11)\*\*
- d. Communication(895.24-27)
- e. CPR(895.07)\*
- f. First Aid(895.08)\*

### **B. Portfolio Products**

- a. Community Networking and Natural Supports(895.39 & 41 **OR** 39 & 42)\*
- b. Consumer Empowerment, Advocacy and Ethics(895.39; 03)\*
- c. Seizure Activity Documentation(895.10)\*
- d. Data Collection: ABC Recording; Frequency Recording(895.15 or 51/52)\*\*
- e. Writing Objectives (895.15)\*\*
- f. Achieving Goals and Objectives(895.18)\*
- g. Assessment and Setting Goals(895.55)\*\*
- h. Aging and Developmental Disabilities(895.28-32)\*\*
- i. Recreation/Leisure(895.19)\*\*

### **C. Observations\***

- a. Participant Empowerment
- b. Communication
- c. Assessment
- d. Community and Service Networking
- e. Facilitation of Services
- f. Community Living Skills and supports
- g. Education, Training and Self-Development
- h. Advocacy
- i. Vocational, Educational and Career Support
- j. Crisis Intervention
- k. Organizational Participation
- l. Documentation

## North Dakota Protection & Advocacy Project Offices

512 4<sup>th</sup> Avenue East  
Room 220  
P.O. Box 2472  
Williston, ND 58802-2472  
Phone: 774-4345  
Fax: 774-4302  
<mailto:panda@state.nd.us>

900 North Broadway  
Suite 210  
Minot, ND 58703-2379  
Phone: 857-7686  
Fax: 701-857-7687  
<mailto:panda@state.nd.us>

1401 College Drive  
Devils Lake, ND 58301  
Phone: 701-662-9026  
Fax: 701-662-9009  
<mailto:panda@state.nd.us>

311 S 4<sup>th</sup> St.  
Suite 112  
Grand Forks, ND 58201-4792  
Phone: 795-3800  
Fax: 795-3803  
<mailto:panda@state.nd.us>

1351 Page Drive  
Suite 303  
Fargo, ND 58103-3551  
Phone: 239-7222  
Fax: 239-7224  
<mailto:panda@state.nd.us>

311 1st Avenue South  
Jamestown, ND 58401-3373  
Phone: 253-3295  
Fax: 253-3245  
<mailto:panda@state.nd.us>

Wells Fargo Bank Building  
400 East Broadway  
Suite 409  
Bismarck, ND 58501-4071  
Phone: 328-2950  
Fax: 328-3934  
Toll Free: 1-800-472-2670  
<mailto:panda@state.nd.us>

135 Sims  
Suite 206  
Dickinson, ND 58601-5141  
Phone: 227-7444  
Fax: 227-7443  
<mailto:panda@state.nd.us>



# REPORT OF SUSPECTED CHILD ABUSE OR NEGLECT

ND DEPARTMENT OF HUMAN SERVICES  
 CHILDREN AND FAMILY SERVICES  
 SFN 960 (Rev. 09-2001)

Name of Child(ren)	Age or Birthdate	Identifying Information			
		Name of Parent(s)/Caretaker			
		Address	City	State	Zip Code
		Telephone Number			
		Name of Subject (Person(s) Suspected to be Causing Maltreatment)			
		Address	City	State	Zip Code
		Telephone Number			

Give nature and extent of the suspected abuse or neglect, including any information of previous abuse or neglect; family composition; and any other information which may be helpful in protecting the health and welfare of the child(ren). If additional space is needed, attach additional pages (**BE SPECIFIC. ANSWER; WHO, WHAT, WHERE, WHEN, WHY, HOW OFTEN**).

Name of Reporter	Address	City	State	Zip Code
Reporter's Relationship to Children	Telephone Number			
Signature of Reporter				Date

**AGENCY USE ONLY**

Date Received by Agency	Intake Social Worker	Source	Case Number
	Social Worker Assigned to Case	Date of Entry	

Received By:  Phone  Initial Category  
 In Person  Written  A  B  C

# Self Directed Supports Waiver

## Reporting suspected abuse, neglect or exploitation

### Who is required to report?

Under this policy, the following individuals having knowledge of or reasonable cause to suspect that an individual receiving self-directed supports is abused, neglected or exploited, must make a report of the circumstances:

- Consumers and/or family receiving self-directed supports
- Employees hired by the consumer and/ or family to provide supports
- Developmental Disabilities Case Manager and
- Any other professional or caretaker defined in North Dakota Century Code Chapter 50-35.1 and Chapter 25.01.3.04

### What should you do if you suspect there is abuse or neglect involving a person receiving self-directed supports?

- CONTACT the Protection and Advocacy Project

## What will happen after the report is made?

- Staff from the Protection and Advocacy Project will assess the report. If the "victim" is under the age of 18 years, P&A will contact Child Protective Services. Depending upon the age of the "victim" either P&A or CPS will investigate the presented report of abuse/neglect to take whatever steps are necessary to protect the person from the risk of further or potential harm.
- P&A and/or CPS will check for past or current reports and then contact persons who can give more information. They may visit the individual, the family, and talk to others who may have information pertinent to the report.
- Unless the person is in danger and cannot be protected in the home, the goal is to keep a family together. If the person is in immediate danger, the individual/child may be placed out of the home by order of the court. Law enforcement will be contacted during assessment of a report especially if there is reason to believe that a person has been sexually abused, has had a serious body injury or is the victim of a crime.
- Not all reports are determined to be abuse, neglect or exploitation. e.g., there may not have been enough information or evidence to support taking action; the person was not seriously endangered and/or a minimum level of care was being met. However,
- A report can often bring services and assistance to help prevent abuse and neglect and ultimately benefit the person receiving services.

Please do your best to provide the following information when you report:

- The name and address, sex, age, and present whereabouts of the individual of concern (victim/vulnerable person).
- Nature or extent of alleged abuse, neglect or exploitation.
- Whether the person is in a life-threatening situation now.
- How you know about the suspected abuse or neglect including:
  - What you saw, or what was said to you.
  - When it occurred (date/time)
  - Where it occurred (location)
  - Names of other witnesses or people who may be aware of what happened.
  - The name and relationship of the person(s) responsible for committing the suspected abuse, neglect or exploitation (alleged perpetrator)
  - Any action taken to treat, shelter or help the individual of concern (victim/vulnerable person).
  - Any other information you believe may be helpful.

## Remember-

- Your report is a request for further investigation and follow up, not an accusation.
- You do not need to be certain before reporting and you are not responsible for deciding if the incident actually happened. Waiting for "proof" may involve risk to the person you are concerned about. If you are unsure, or if you have the thought "Maybe I should call..." DO!
- Information you share is confidential.
- Providing information that is accurate and given in good faith provides immunity from civil or criminal liability which may otherwise arise from the report.
- You are not required to identify yourself when you make a report e.g., you can remain anonymous. However, being able to contact you later helps the worker to do a more thorough investigation. They may need to ask you for more information during the follow up process.
- Provide as much information as you can. The more information and details you provide, the easier it is for the person taking the report to assess the situation quickly.
- The purpose of the report and follow up is to help and protect the person from risk of further or potential harm and to provide them with appropriate services and support within the community.

## NDCC 25-01.3-01 Definitions of Abuse/Neglect/Exploitation.

### 1. **Abuse means:**

- a. Willful use of offensive, abusive, or demeaning language by a caretaker that causes mental anguish of any person with a developmental disability.
- b. Knowing, reckless or intentional acts or failures to act, which cause injury or death to a person with a developmental disability or mental illness or which, placed that person at risk of injury or death.
- c. Rape or sexual assault of a person with a developmental disability or mental illness.
- d. Corporal punishment or striking of a person with a developmental disability or mental illness.
- e. Unauthorized use or the use of excessive force in the placement of bodily restraints on a person with a developmental disability or mental illness.
- f. Use of bodily or chemical restraints on a person with a developmental disability or mental illness, which is not in compliance with federal or state laws and administrative regulations.

### 2. **Exploitation** (when committed by a caretaker, or relative of, or any person in a fiduciary relationship to the person with a developmental disability or mental illness) means:

- a. The taking or misuse of property or resources of a person with a developmental disability or mental illness by means of undue influence, breach of fiduciary relationship, deception, harassment, criminal coercion, theft or other unlawful or improper means.
- b. The use of the services of a person with a developmental disability or mental illness without just compensation.
- c. The use of a person with a developmental disability or mental illness for the entertainment or sexual gratification of others under circumstances that cause degradation, humiliation, or mental anguish to the person with the developmental disability or mental illness.

### 3. **Neglect means:**

- a. Inability of a person with a developmental disability or mental illness to provide food, shelter, clothing, health care, or services necessary to maintain the mental and physical health of that person. (Self neglect).
- b. Failure by any caretaker of a person with a developmental disability or mental illness to meet, either by commission or omission, any statutory obligation, court order, administrative rule or regulation, policy, procedure, or minimally accepted standard for care of persons with a developmental disability or mental illness.
- c. Negligent act or omission by any caretaker which causes injury or death to a person with a developmental disability or mental illness or which places that person at risk of injury or death.
- d. Failure by any caretaker, who is required by law or administrative rule, to establish or carry out an appropriate individual program or treatment plan for a person with a developmental disability or mental illness.
- e. Failure by any caretaker to provide adequate nutrition, clothing or health care to a person with a developmental disability or mental illness.
- f. Failure by any caretaker to provide a safe environment for a person with a developmental disability or mental illness.
- g. Failure by any caretaker to maintain adequate numbers of appropriately trained staff at a facility providing care and services for persons with a developmental disability or mental illness.