

Decision Making



Decision-Making

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

1. What outcomes and priorities your family has (example: staying together)
2. What supports can help you meet your child's disability-related needs
3. Which support option may be the best match for your family
4. How much assistance you need to help you plan and manage supports
5. 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 . . . ?

1. Living in a rural community without support providers?
2. Used to running a small business or coordinating activities?
3. Someone who enjoys making decisions and directing services?
4. Interested in recruiting and hiring your own care providers?
5. Someone with the time to take on a new role as long as support is available?
6. 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 on 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.

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

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

1. Meet health and safety needs
2. Stay together
3. 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
What is this support option?	The Family Subsidy program reimburses families of children with DD for allowable excess costs (e.g. child care, therapy, and equipment) related to a child’s disability .	Family Support Services provides families of children having DD with in-home and/or community-based support to assist the family in meeting the needs of a child and prevent unwanted out-of-home placement.	Self-Directed Supports helps families self-direct services needed to carry out a family support plan. Supports include: self-directed in-home supports or disability related supports (skilled supports, materials and supplies, transportation) or employment supports .
What is this program designed to do?	<ul style="list-style-type: none"> • Keep families together • Prevent unwanted institutionalization 	<ul style="list-style-type: none"> • Keep families together • Prevent unwanted institutionalization 	<ul style="list-style-type: none"> • Keep families together • Prevent unwanted institutionalization • Increase family choice and control
Who is eligible?	Families of children with DD who: <ul style="list-style-type: none"> • are ages 0 to 22 and • receive case management services • may need a specially trained care-giver for excess child care 	Families of children with DD who: <ul style="list-style-type: none"> • are any age (birth –adulthood) • are ages 0-21 for the family-care option • receive case management services • need a specially trained care-giver • would be eligible for services in a special group home (ICF/MR) if a family could no long provide them 	Families of children with DD who: <ul style="list-style-type: none"> • are ages 3 through adulthood for SDS • are ages 3 to 21 for disability related supports • are ages 21 and older for employment supports • receive case management services • need a specially trained care-giver • would be eligible for services in a special group home (ICF/MR) if a family could no long provide them
How is need determined?	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 person-centered care plan 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 budget to fund the minimum amount of services needed to maintain the child in the family. The budget supports only those formal supports that are needed but not available through informal or generic community supports.

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

Questions	Family Subsidy	Family Support Services	Self Directed Supports
<p>How is this option different than the other services?</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 both Family Subsidies to pay for excess costs related to therapy or equipment (but not excess child care) and Family Support Services.</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>What are the potential benefits of this option?</p>	<ul style="list-style-type: none"> • Families get help with excess costs related to their child's disability • Paperwork is minimal when the number of hours is small. 	<ul style="list-style-type: none"> • Families get relief from stress • Families have new ways to involve their children in the community • Families have more time to spend with other children • The work of directing services is turned over to a trained provider • Families have the benefit of health care and services available through Medicaid 	<ul style="list-style-type: none"> • Families choose their own direct support workers. • Families do the work of self-directing services • Families get support to plan and set up supports • Families have choice and control in self-directing services instead of relying on someone else • Support is available in remote rural communities • Families have the benefit of health care and services available through Medicaid
<p>What costs do we have?</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
What roles and responsibilities do we have?	<ul style="list-style-type: none"> • Think about family needs • Sign contract • Keep track of an submit receipts • Complete paperwork on time • Review needs quarterly • Complete annual satisfaction survey annually 	<ul style="list-style-type: none"> • Apply for Medicaid • Schedule support within the hour limits set by the DHS • Orient new providers to child/home • Complete satisfaction survey annually 	<ul style="list-style-type: none"> • Apply for Medicaid • Develop a person-centered plan • Develop an emergency back-up system • Hire support workers if needed • Train support workers • Direct the fiscal agent to pay bills or write checks • Evaluate worker performance • Complete satisfaction survey annually
What roles and responsibilities does the case manager have?	<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.</p>	<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.</p>	<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"> • Provide families with training to self-direct services • Provide families with training to understand the person centered planning process.
What support is available to help us use this option?	<p>A detailed manual describing how to hire and direct support workers and manage employer responsibilities under this plan is available from your case manager.</p>	<p>Licensed providers help families assess needs, recruit and hire support workers, conduct employee evaluations and manage payroll responsibilities.</p>	<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>
What is the application process?	<p>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.</p>	<p>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.</p>	<p>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.</p>

Questions	Family Subsidy	Family Support Services	Self Directed Supports
<p>What else should I know about this option?</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?

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

Remember:

1. You can get family support *and* family subsidy (but not in-home support and excess child care)
2. Self directed supports are not available for children under age 3
3. You must apply for Medicaid to get family support or self-directed supports
4. 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 only 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

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

Exercise choice and control

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

Plan for the future

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

Solve Problems

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

Reduce risks

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