Supported Decision-Making

A Guide to Independence

For Individuals with Disabilities & the Elderly



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If you need this Guide in an alternative format, please contact the Protection & Advocacy Project.

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The North Dakota Supported Decision-Making Project

In 2017, after learning about the "Supported Decision-Making" (SDM) model, the North Dakota Protection & Advocacy Project (P&A) helped form a steering committee to develop a SDM program in North Dakota with a grant funded by the ND State Council on Developmental Disabilities. The ten members, representing communities of the young and the elderly, people with various types of disabilities, and agencies with diverse agendas, met for over a year to study this model.

The committee reviewed other states' Supported Decision-Making models and met with national and state leaders who shared knowledge, resources, and recommendations. The committee also collected information from other states pursuing or implementing SDM either legislatively or through legal processes.

Locally, the committee gathered input from additional stakeholders across the state via Interactive Video Conferences (IVN) meetings. Participants from local communities could ask their questions and provide their ideas for the future SDM model. Public media (radio, TV, newspaper) was also used to create awareness and seek responses.

The committee continually sought responses, concerns, and suggestions, to enhance the program development process. It was unclear whether the SDM model would be accepted by clinicians, banks, or other providers. After much deliberation, the group found that in many states a legislative statute was used to provide that necessary validity. The committee decided to pursue legislation. P&A's legal staff drafted a proposal that was presented to the stakeholders. Revisions continued until members came to agreement.

The next step was to find a sponsor for the bill and work with the legislator to guide it through the legislative process. A House Representative supported the bill and assisted P&A in finding eleven more legislators to endorse this program. The bill was received strong endorsement, with 86 yeas & 6 nays in the House Chamber and unanimous support in the Senate Chamber. The Governor signed the bill into law on March 19, 2019.

EVERYONE has the right to make choices and EVERYONE needs a little help.

Jenny Hatch Story

In 2013, the Jenny Hatch case received national attention when she became the first person in the country to have a court order the use of supported decision-making instead of a guardianship for a person with a disability. The previous year, Jenny Hatch, a 29-year-old woman with Down Syndrome, was placed under guardianship, and lost her right to do many things she loved including seeing her friends and using her cell phone and laptop. With the help of Quality Trust for Individuals with Disabilities, Jenny won back her right to make her own decisions using supported decision-making. She now lives and works where she wants and has the friends she chooses. Jenny has been the inspiration for supported decision-making laws across the United States, including here in North Dakota.



To learn more about Jenny Hatch's story, you can visit <u>The Jenny Hatch Justice</u> <u>Project</u>¹ to read her words and listen to her tell her story.

¹ A project of Quality Trust for Individuals with Disabilities

What is Supported Decision-Making?

Supported Decision-Making is...

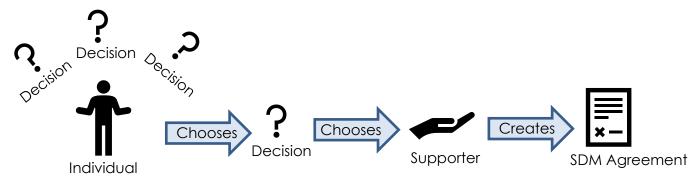
- a flexible alternative to guardianship and can provide more opportunities for independence. Many elderly individuals or individuals with disabilities can manage their own affairs with assistance and guidance from a Supporter whom they trust.
- often defined as "Supports and Services" that help an older adult or an adult with a disability make his or her own decisions by relying on trusted friends, family members, professionals, and others.
- a process for making well-informed voluntary decisions by methods less restrictive than guardianship or conservatorship and that allows individuals to make their own decisions and stay in charge of their lives, while receiving the help and assistance they need.

How does Supported Decision-Making Work?

All people need and use support to make important life decisions (where to work, which friends or family members to spend time with, and help with medical or financial decisions). Using the SDM model, older adults and people with disabilities choose someone they trust - often a friend, family member, or professional, to serve as their "Supporter."

There are three components in the Supported Decision-Making process:

- 1) The Individual
- 2) The Supporter
- 3) The Supported Decision-Making Agreement



The Individual selects a Supporter to help make decision(s):

- from someone they trust; and
- with whom they can discuss choices and decisions.

The **Supporter** can help the Individual to:

- understand the options, responsibilities, and consequences of their decisions,
- obtain and understand information relevant to their decisions, and
- communicate their decision to the appropriate people.

The Supporter cannot make the decision. The Individual makes the final decision.

A written **Supported Decision-Making Agreement** between **the Individual** and **the Supporter** defines the assistance the Individual is requesting and the help the Supporter is providing.

Individual → Supported Decision-Making Agreement ← Supporter

- The form is signed, dated, and requires witnesses or a notary public.
- This document can help doctors, bankers, lawyers, and other third parties to understand and accept the decisions of the person with a disability.

The Principals of Supported Decision-Making

- 1) People with disabilities have the right to make decisions about things that impact their lives.
- 2) People with disabilities are presumed to have the capacity to make their own decisions and give informed consent, when needed.
- 3) People with disabilities have the right to be supported in making decisions.
- 4) People with disabilities have the right to choose who will provide them decision-making support, what types of decisions they want support to make, and how this support will be provided.

There is no "one size fits all" in supported decision-making. It is about working with an individual to identify if help is needed, where help is needed, and then how any needed help can be provided. This will look different for every individual.

Supported decision-making should be considered when a person can take part in the decision-making process. Supported decision-making recognizes the individual's independence (autonomy), presumes the individual is capable of making decisions (capacity), and preserves the individual's right to make decisions (self-determination) while recognizing that the individual may need assistance in making decisions.

Capacity, when it comes to decision-making, is not "all or nothing." A person may be capable of:

- making some decisions, but not others;
- making some decisions at some times, but not others;
- making decisions only if they get help understanding the decision to be made (informed consent).

Informed consent is an important consideration in decision-making. There are three components to informed consent, all of which are necessary:

- 1) information to the Individual,
- 2) understanding by the Individual, and
- 3) choice by the Individual.

Supported Decision-Making Law in North Dakota

North Dakota supported decision-making laws can be found at <u>North</u> <u>Dakota Century Code Chapter 30.1-36</u>. These laws:

- define important supported decision-making terminology,
- list what information is confidential,
- discuss liability of a Supporter,
- set out legal requirements and presumptions for supported decision-making, and
- talk about termination of an agreement.

Supported Decision-Making Agreement Requirements

The Individual and his/her Supporter can use the sample Supported Decision-Making Agreement template produced by the North Dakota Protection & Advocacy Project, or any other form consistent with the requirements found at N.D.C.C. Chapter 30.1-36. A version of the template can be found <u>here</u>.

Completing the Supported Decision-Making Agreement does not require going to court, having an attorney, or paying a fee.

The Supported Decision-Making Agreement is a written, signed, dated, and witnessed understanding between an Individual and a trusted adult (Supporter) who agrees to aid with decision-making to maximize the Individual's ability to make informed, voluntary choices.

For the agreement to be valid, the Agreement needs to be witnessed by a notary public or two qualified adults. Witnesses must:

- not be a party to the agreement,
- be at least eighteen years of age,
- be competent,
- not be an employee or agent of a Supporter in the agreement, and
- cannot be a creditor of the named Individual.

On the Supported Decision-Making Agreement:

- the Individual can specify what kinds of decisions he/she wants help making, and
- whether he/she wants the Supporter to be able to access his/her private health and education records.

The Individual can have multiple Supporters to help with different kinds of decisions. It is recommended the Individual fill out a separate agreement with each Supporter. Multiple agreements are allowed.

The Supported Decision-Making Agreement...

May **NOT** be used as evidence of incapacity or incompetence.

Does **NOT** give a Supporter the ability to act as a surrogate decisionmaker.

The Individual or the Supporter should keep the original form. Copies can be provided to professionals who work with the Individual, such as doctors, teachers, service providers, and others. People who receive a copy of the Supported Decision-Making agreement cannot be held to criminal or civil liability or professional misconduct as long as they act in good faith to what is in the agreement.

Having a Supported Decision-Making Agreement does not guarantee that someone can provide informed consent. The Individual with a disability still needs to demonstrate that he/she has the capacity to make a particular decision. The Supporter's role is to help the Individual understand and communicate what is needed to provide informed consent.

Does **NOT** give a Supporter the authority to sign documents on behalf of the Individual.

Terminating a Supported Decision-Making Agreement

Supported Decision-Making Agreements can be Terminated by the:			
	Individual notifying Supporter	Supporter notifying Individual	Court
Orally	Х		
Through an assistive technology (AT) device	Х		
By any other act showing intent	Х		
In writing	Х	Х	
By any additional method specified in the SDM Agreement	Х	Х	Х
Convicting Supporter of a crime involving abuse, neglect, or exploitation			Х
Issuing a restraining order to protect the Individual from the Supporter			Х
Determining that the Supporter lacks capacity to make or communicate responsible decisions concerning matters affecting the health or safety of the Individual			Х

Reliance on Agreement

Any third person receiving a copy of the Supported Decision-Making Agreement shall rely on the Agreement, unless the third person:

- has cause to believe the Individual is being abused, neglected, or exploited by the Supporter;
- has actual knowledge or notice the Supported Decision-Making Agreement is invalid or has been terminated.

A third person is not subject to criminal or civil liability and has not engaged in professional misconduct for an act of omission, if the act or omission is done in good faith, and in reliance on a Supported Decision-Making Agreement.

An entity, custodian, or organization that discloses personal information about an Individual to a Supporter who has written authorization to access, collect, or obtain, or to assist an Individual to access, collect, or obtain that information, is immune from any action alleging the entity, custodian, or organization improperly or unlawfully disclosed information to the Supporter unless the entity, custodian, or organization:

- Had actual knowledge or notice that the Individual had revoked the authorization; or
- Had actual knowledge or notice the Supported Decision-Making Agreement is invalid; or
- Knowingly or recklessly disclosed information beyond the scope of the authorization.

A third person is not protected from charges of professional misconduct and is not immune from liability for:

- Acting inconsistently with the known expressed wishes of an Individual; or
- Failing to provide documents, records, or other information to either an Individual or a Supporter who has written authorization for lawful access to or copies of the information.

A Supported Decision-Making Agreement does not relieve a person of legal obligations to provide services to an Individual with a disability.

Advice for Individuals

Making My Own Choices

Self-determination is making your own choices. You make decisions every day.

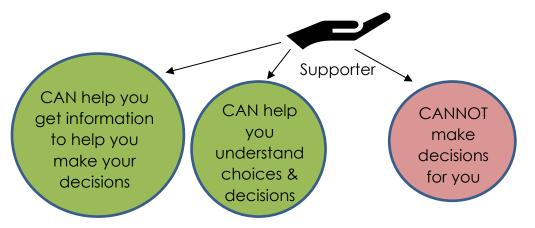
You choose things like:

- What to wear
- Where to work
- Which friends or family members to spend time with
- And more!

All people need help to make important decisions. You have the right to make your own choices, even if you need help. Your right to make choices should not be taken away just because you need help.

Choosing a Supporter

Supported Decision-Making means choosing someone you trust to help you make a decision. Your Supporter can be someone like your parents, a family member, a good friend, a neighbor, or a service provider.



Your Supporter CANNOT make decisions for you.

Your Supporter CAN:

- help you understand your choices and decisions and
- help you get and understand information to help you make your decisions.

With Supported Decision-Making, **you** make your own choices with help. This lets you be more independent. You can choose to listen or not listen to the advice of your Supporter. You can also get advice from other people you trust. You are in charge.

Who Might Make a Good Supporter?

Picking a good Supporter is very important. You might have your own beliefs about who would be a good Supporter for you. Consider these qualities.

Good Supporters:

- Believe that you have the right to make your own decisions;
- Support you in speaking for yourself;
- Like to listen to what other people think and are interested in others;
- Are patient;
- Respect the privacy of others, especially your privacy;
- Are able to put aside their own opinion, values, and influences;
- Know you and what is important to you;
- Listen to you and communicate in the way you want;
- Help when there is a problem.

Steps to Follow When Choosing a Supporter...

 \checkmark Think of people in your life that you trust.

- ✓ Think of decisions you need help making. Your Supporter can help you choose things like where to live, where to work, what medical help you want, and more.
- \checkmark Choose people you trust to help you make decisions.
- ✓ Ask them to be your Supporter. You can change your mind and say you do not want this person to support you whenever you want.
- ✓ Complete a written plan...the Supported Decision-Making Agreement.

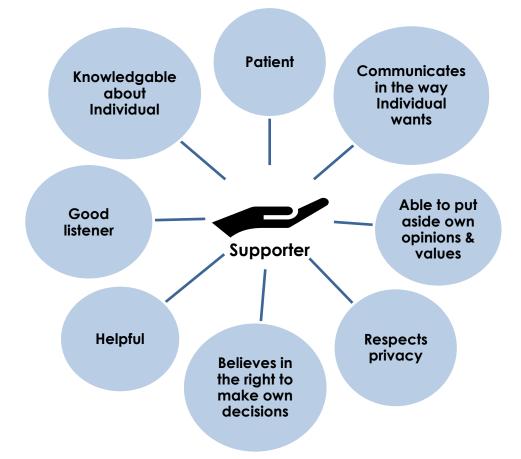
Advice for Supporters

Being a Supporter is hard work. The relationship between the Individual and Supporter is one of trust. It works best when the Supporter knows and understands the Individual's preferences and values.

A Supporter could be someone who helps the Individual do other things in their life, like a family member, advocate, friend, or in some cases, even a service provider. The Individual can have more than one Supporter and can have a lot of people working together to help them make decisions.

Supporters may find information, help the Individual consider consequences, and communicate the decision on behalf of the Individual. Supporters must put aside their own opinions, values, and influences to ensure the Individual is the one deciding. Supporters must be very careful not to unduly influence the Individual and should keep in mind that the Individual is exercising his or her right to seek the opinion of Supporters and to use their help in decision-making.

While no two Supporters are alike, there are some things that good Supporters have in common.



Tools for Supporters to use with Individuals

- Remember you are only giving advice to the Individual...the Individual is the decision-maker!
- Provide plain language materials or information in visual or audio form;
- Provide extra time to discuss choices;
- Create lists of pros and cons;
- Create reminders for appointments and due dates;
- Help the Individual visit places and try out different choices to see what Individual likes;
- Role-play activities to help Individual understand choices;
- Go to appointments with the Individual to take notes and help the Individual to remember and discuss options;
- Help the Individual use assistive technology for bills and/or payments
- Help communicate the Individual's choices to others (with the Individual's permission).

Supported Decision-Making and Guardianship

Supported Decision-Making is a less restrictive alternative to legal guardianship. Guardianship is when the court grants a person or entity legal authority to make decisions for an individual. These decisions can be limited to certain areas or extend to all aspects of an individual's life. Guardianships can be temporary or permanent, and they are always court ordered. Guardianships, by their very nature, strip an individual of their primary decision-making rights. They are generally inflexible and require court action to be changed.

Supported decision-making and other guardianship alternatives should be considered prior to establishment of a legal guardianship.

This guide should facilitate conversations about an Individual's decision-making capacity and assist in establishing a SDM Agreement between an Individual and his or her Supporters.

Other Alternatives to Guardianship...

- **Medical Directives:** Written statements allowing you to make arrangements ahead of time and express your desires for specific medical treatments during instances when you cannot communicate consent.
- **Power of Attorney:** You give someone else permission to make some decisions for you, but you keep your right to make decisions without this person, e.g., medical, school, money, or other decisions.
- **Durable Power of Attorney:** You give someone else permission to make decisions for you even if you become incapacitated and unable to handle matters on your own.
- Mental Health Advance Directives: Document outlining mental health care instructions for treatment and care and a decision-maker who can make those decisions.
- Fiduciary or Representative Payee: If you receive SSI, other social security, or benefits, someone will keep track of and manage your money.
- Joint Bank Account: An account you and someone else share. You and the other person can both put money in and take money out.
- **ABLE Account:** A special bank account you have control over. You can save money in an ABLE Account and still get all of your Medicaid or SSI benefits.
- **Special Needs Trust:** A trust is an account where you and others save money for your benefit, and you will not lose your Medicaid or SSI benefits.

Guardianship Resources

For more information about guardianship, contact: Rose Nichols Guardianship Monitoring Program North Dakota State Court System 600 E Boulevard Avenue, Mailstop 180 Bismarck ND 58505-0530 701-328-2212 guardianshipmonitor@ndcourts.gov

North Dakota Courts has a Legal Self Help Center with information on this process, as well as, the rights of the proposed incapacitated person:<u>https://www.ndcourts.gov/legal-self-help/adult-guardianship</u>.

This site has information and free fillable forms for starting and maintaining guardianships. There is also online training for guardians.

Supported Decision-Making Agreement

Template for North Dakota

The following format is not mandatory, but any Supported Decision-Making Agreement template must be substantially equivalent as described in North Dakota Century Code: <u>N.D.C.C. Chapter 30.1-36</u>

Supported Decision-Making Agreement

This is a Supported Decision-Making Agreement of the following Named Individual:

Name:	Da	te of Birth:	
Address:			
Phone: (work)	(home)	(cell)	
Email:			
I am voluntarily entering into this Agreement with the following Supporter whom I have chosen, and we agree will help me make some decisions. My Supporter does not have authority to make decision(s) for me.			
Supporter's Name:		Date of Birth:	
Address:			
Phone: (work)	(home)	(cell)	
Email:			
Relationship to me:			

My Supporter will help me, as I request, by:

- 1. Collecting records, documents, and other information so I can consider them to better understand the issues;
- 2. Organizing my records, documents, and other information so I can more easily understand the issues;
- 3. Identifying choices available to me and how each choice might lead to advantages and disadvantages;
- 4. Showing me ways to compare the advantages and disadvantages of each available choice;
- 5. Telling other people my decision(s) when I ask my Supporter to tell them; and,
- 6. Explaining how I am using the decision-making process, as allowed under N.D.C.C. Chapter 30.1-36, to the court in any proceeding to help me create or modify a guardianship or conservatorship.

I understand that:

- I must be at least eighteen years old to make an effective Supported Decision-Making Agreement;
- This Supported Decision-Making Agreement is effective only if I understand its meaning and what the Agreement does;
- I can have more than one Supported Decision-Making Agreement with different Supporters at the same time. I understand that a separate SDM Agreement is recommended for each Supporter.

This Agreement takes effect as soon as the Agreement is signed by me, my Supporter, and a notary public or the required witnesses.

The Agreement may be terminated:

- By the Named Individual giving notice to the Supporter orally, in writing, through an assistive technology device, or by showing specific intent to terminate the Agreement;
- By the Supporter providing written notice of resignation to Named Individual; or
- As to a specific Supporter when one or more of the following occurs:
 - a) A court has convicted the Supporter of a crime involving abuse, neglect, or exploitation.
 - b) A restraining order has been issued by a court to protect the Named Individual from the Supporter.
 - c) A court has determined the Supporter lacks capacity to make or communicate responsible decisions concerning residential or educational matters, medical treatment, legal affairs, or vocational, financial, or other matters affecting the health or safety of the Named Individual.

A Supported Decision-Making Agreement may be terminated by any additional method specified below.

Some areas I want my Supporter to help me decide:

(Initial those that apply)

Healthcare - Managing my physical health and mental health

- Yes _____ No _____ When to seek healthcare
- Yes _____ No _____ Which health care professionals to consult
- Yes ____ No ____ Which health care professionals to use for treatment purposes
- Yes _____ No _____ Which, if any, legally, available, over the counter or prescribed medications to take
- Yes _____ No _____ When to provide a signed authorization, so my Supporter may see my private health information under the Health Insurance Portability and Accountability Act (HIPAA)

Residence - Managing my home

- Yes ____ No ____ Where I live
- Yes _____ No ____ Who I live with
- Yes _____ No _____ What I need to live independently

Finances - Managing my money and property

- Yes _____ No _____ How much money I save and how to save it
- Yes _____ No _____ How much money to spend and how I spend it
- Yes _____ No _____ Whether to have a representative payee
- Yes _____ No _____ How and when to pay legitimate bills

Education - Getting an education or other training

- Yes _____ No _____ Whether to get additional education
- Yes _____ No _____ Where to get additional education
- Yes _____ No _____ Assistance in determining goals of additional education
- Yes _____ No _____ Choosing support services

Legal Affairs - Getting legal advice

Yes ____ No ____ Whether to get legal representation Yes ____ No ____ Whether to get help with suspicious offers

Vocation	- Finding	a job
Yes	_ No	Assistance in determining employment decisions
Yes	_ No	Additional training to get employment and to advance in employment
Yes	_ No	Choosing support services for employment, as needed

This list is not exclusive or does not identify all areas the Named Individual might request support from the Supporter. Other areas in which I would like assistance from my Supporter are:

Areas I DO NOT want my Supporter to help me with are: (if any)

Signatures of Named Individual and Supporter

Named Individual's Signature

I am at least 18 years of age and I understand the nature and effect of this Agreement. I have chosen the Supporter listed on this page to help me make some decisions.

(Print Name)	(Signature of Named Individual)	(Date)
Consent of Supporter		
My relationship to the	Named Individual is:	
l agree to act as a Suppunder this Agreement.	porter for the Named Individual fo	r decision-making
(Print Name)	(Signature of Supporter)	(Date)
Notary Public or Statement of Witnesses		
This document mus	st be either:	
Notarized	OR	
 Witnessed by two qualified adult witnesses who verify the signing of a Supported Decision-Making Agreement. 		
Each witness must:		
1. Not be a party to the Agreement;		
2. Be at least eighteen (18) years of age;		
3. Be competent;		
4. Not be an employee or agent of the Supporter in the Agreement;		
5. Not be a creditor of the Named Individual.		

Option 1: Notary Public for Verification of Named Individual's Signature

State of	
County of	_
(Named Individual) acknowled	(date) ges his/her signature on this document or ected the person signing this document to behalf.
	_ Signature of Notary (stamp)
My commission expires:	_ Title of office

Option 1: Notary Public for Verification of Supporter's Signature

State of		
County of	-	
Signed in my presence on (Supporter) acknowledges his/h acknowledges that he/she dire on the Supporter's behalf.	ner signature on this do	cument or
	_ Signature of Notary	(stamp)
My commission every	_ Title of office	
My commission expires:		26

Option 2: Two Witnesses for Verification of Named Individual's Signature

Witness one:		
In my presence on(date),		
(Named Individual) signed this document. I acknowledge the Named Individual's signature on this document or acknowledge that the Named Individual directed the person signing this document to sign on the Named Individual's behalf.		
(Signature of Witness #1)		
(Address)		
Witness two:		
In my presence on(date),		
(Named Individual) signed this document. I acknowledge the Named Individual's signature on this document or acknowledge that the Named Individual directed the person signing this document to sign on the Named Individual's behalf.		
(Signature of Witness #2)		
(Address)		

Option 2: Two Witnesses for Verification of Supporter's Signature

Witness one:
In my presence on(date),
(Supporter) signed this document. I acknowledge the Supporter's signature on this document or acknowledge that the Supporter directed the person signing this document to sign on the Supporter's behalf.
(Signature of Witness #1)
(Address)
Witness two: In my presence on(date),
(Supporter) signed this document. I acknowledge the Supporter's signature on this document or acknowledge that the Supporter directed the person signing this document to sign on the Supporter's behalf.
(Signature of Witness #2)
(Address)

Supported Decision-Making Committee

2018-2019

COMMITTEE MEMBER	AFFILIATION
Judy DeWitz, Project Dir.	P&A Project
Teresa Larsen	P&A Project
David Boeck	P&A Project
Steven L. Beard	Advocates Leading Their Lives (ALL)
Mike Chaussee	AARP
Kirsten Dvorak	The Arc of Bismarck
Lori Garnes	ND Center for Persons with Disabilities
Julie Horntvedt	State Council Developmental Disabilities
Matthew McCleary	Youth Move BeyoND
Shelly Peterson	Long Term Care Association
Vicki Peterson	Family Voices of ND
Rebecca Rosenkranz	P&A Project

North Dakota Protection & Advocacy Project

The Protection & Advocacy Project (P&A) is an independent State agency that protects and advocates for the rights of people with disabilities within established priorities.

P&A serves eligible individuals, of all ages with all types of disabilities, at no cost. P&A also advocates for individuals to receive disability-related assistive technology devices and services.

P&A works exclusively for the person with a disability. P&A's efforts focus on the expressed wishes of the client, within his or her legal rights.

P&A believes that people with disabilities should be empowered to advocate on their own behalf to the extent possible and should have the greatest opportunity to shape his or her personal destiny.

Services provided by P&A shall promote client control in decisionmaking. P&A focuses on the empowerment of people with disabilities in order to foster independence, productivity, and integration into the community. Administrative Office: Protection & Advocacy Project 400 E. Broadway, Suite 409 Bismarck, ND 58501 Phone: (701) 328-2950 Toll Free: 1-800-472-2670 E-mail: panda@nd.org www.ndpanda.org

North Dakota Supported Decision-Making Information

The North Dakota Protection & Advocacy Project appreciates information and support from Disability Rights Texas's *The Right to Make Choices: A Supported Decision-Making Toolkit for People with Disabilities and Their Supporters* (January 2018 Edition).

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