

2019 HOUSE HUMAN SERVICES

HB 1378

2019 HOUSE STANDING COMMITTEE MINUTES

Human Services Committee Fort Union Room, State Capitol

HB 1378
1/23/2019
31206

- ☐ Subcommittee
☐ Conference Committee

Committee Clerk Signature : Elaine Stromme
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Explanation or reason for introduction of bill/resolution:

Relating to supported decision making, a process for making well-informed, voluntary decisions by methods less restrictive than guardianship or conservatorship.

Minutes:

Attachments: 1-14

Chairman Weisz: opened the Hearing on HB 1378.

Representative Jeffery J. Magrum: Introduced HB 1378. (Testimony #1)

Judy DeWitz, a Disabilities Advocate with the North Dakota Protection and Advocacy Project (P&A)
In support of HB 1378. Testimony # 2

Rep. Rohr: On page 4 when you say that the percentage of guardianship is going up the 2802 is just adult guardianship? If you break that down, what percentage would be kids?

Judy Dewitz: This is all adults.

Rep. Rohr: What percentage would be children?

Judy Dewitz: I don't have that information. The information that I have here came from the Supreme Court Guardianship Program. That is where my numbers came from.

Chairman Weisz: As a supporter do I have the ability to sign a lease for an apartment for that person or who has the legal authority, can I write checks on their account? Can I purchase things for them or can I only advise them?

Judy Dewitz: The individual still makes their own decisions, so all those would be done by the individual, not the supporter, the Supporter is providing them information so they can make the decision whether to sign that lease or not. The plus part of this, if someone has a supporter helping them and they want to go to the doctor or to the bank to get some information. They might not believe them. That is the reason we put it into statute They do need a statute to carry weight that this is a true agreement.

Rep. Skroch: These people that you visualize being these decision makers, these assistances who do you picture them being? Would they be family members? Or Social Services Workers?

Judy Dewitz: Family Members or friends, it might be a professional the family knows.

Rep. Skroch: Then how would they be compensated? Would they be able to utilize any state dollars? Money from a social security check?

Judy Dewitz: There is no money changing hands this is a voluntary type situation.

Rep Skroch: In the story you shared with us about the girl with down syndrome that lost her privileges That disturbs me a bit, because guardians are supposed to allow for to stay in the wards control as possible. Just as a follow up to that, in ND I think we have more private guardians then we do corporate. In some states they have more of a State guardianship program. So I am wondering if the same situation should occur here if we have to be concerned about private guardianships as we do about Corporate Guardianships.

Judy Dewitz: I am not that familiar with how to compare them. I would prefer having our attorney address the question. I worked on the intake line for Protection Advocacy for several years and we would get calls from guardians or from folks who had guardians and there was often a difference of opinion. If we can help people, make their own decisions in the long run they will be safer. If we can help them find out what is the right thing to do for them. Rather than have someone else say you will do this or you will not do that. Involving them in the decision making seems to make a better life for this person if they can make their own decisions.

Representative Fegley: I was appointed for a individual who had mental problems, I asked the judge what my authority was and he said," Everything, but you can't tell him no." Does the judge control this process or who appoints an individual as an advisor?

Judy Dewitz: The individual themselves decides who the supporter is, there is no judge at all involved At all in this. The agreement does have to be witnessed so that it is considered to be a legal type of agreement, by a notary public or two witnesses', that it was an agreement that was agreed to by both parties.

David Boeck, a State employee and a lawyer for the Protection & Advocacy Project. Testimony #3 One of the questions previously asked was if the supporter could sign a lease for an individual in general the answer is no, because the individual has to make the decision who still has the legal competence of course the individual could authorize them to sign a lease.

Rep. Rohr: Can an individual do this without this bill in place?

David Boeck, Yes.

Rep. Rohr: If this bill would pass, is there any data that would be kept to be sure that we have accomplished the goal of less guardianship required or corporate. Is there any method that this is working for the state?

David Boeck: The state Court Administrators Office keeps track of the number of guardianships in ND.

Rep Skroch: On the second page of your testimony, you say that ND guardians have unnecessary broad decision making authority who gives a guardian that authority?

David Boeck: A court does. A person says this person is not competent to make responsible decisions, and so the guardian needs to make them and they don't articulate any difference between 'any kind of decisions.

Rep Skroch: Isn't it true that before any decision is made there is a hearing in a courtroom, and isn't it true that before that hearing there is a home visit by some usually appointed by the court and maybe operates out of a County Social Service office, and there is quite an in-depth investigation before that takes place, and then the court determines which of the rights and powers of that individual can be assumed by the guardian?

David Boeck: Yes, there are hearings, there is an individual appointed by the court, not by the Social Service office but the individual has to be either a Social Worker or a nurse. There is also an attorney appointed by the court for the individual's best interests.

Rep. Skroch: I think there might be some variances in guardian's authority and that, but in many specific cases, all powers stay in the hands of the ward unless necessarily need to be taken over by The guardians. I think that there is a little gray area here, and maybe needs a little more study.

Representative Porter: Inside of this proposed piece of legislation we are putting a sample decision making agreement form into the century code. I am uncomfortable putting a sample form into the century code. Isn't that best left to the courts and attorneys and the individuals to figure out or even associations and groups what form best works for them, rather than putting a sample form inside of the law?

David Boeck: That is a good point. We do have a form, not a required form, but it helps individuals who don't have a lawyer.

Representative Porter; I understand that the form is not a sample form but an actual form that can be used. This one lists as a sample agreement. The advanced directive one is a legal document that can be signed and copied, pasted and used. Is your opinion that this is the one?

David Boeck: The Advanced Directive Form is not required either. There are many Health Care Organizations that have their own version, some follow the exact statutory form but the purposed legislation is that the form could be fashioned for the proposed individual.

Representative Porter

Inside of the general provisions of chapter 30.1-26 where it talks about the alternate resource plan and it also talks about the least restrictive form of intervention. Is this piece an offshoot of that or is this a stand-alone separate situation? What I have heard so far is that these are the least restrictive forms, the plan is supposed to provide the least restrictive form, is this separate or added on?

David Boeck: The petitioner states that there are no alternative resource plans that would work in place of Guardianship, but there is no real examination of what could be used, this would create an alternative that would be considered by courts or petitioner's.

Representative Damschen : I think that the person filling out this form certainly needs some support. (read line 18 of David Boeck's testimony) The supportive decision making does not relieve a person of legal obligations to provide services to an individual with a disability. So is the helper assuming legal obligations by entering into this agreement?

David Boeck: What that refers to is the rights under the Human Rights Act or the Americans with Disabilities Act those don't go away just because of the supportive decision making agreement. An individual will still have an obligation to make access to documents accessible to individuals who have Disabilities.

Representative Damschen : Wouldn't it be better to have power of attorney?

David Boeck: The difference in a Power of Attorney, it is a document that gives an agent decision making authority, this would not take away the rights of the individual to make decisions.

Representative Tveit : I am a trustee I am a power of attorney for a completely competent individual In just knowing the questions that come before me from that individual and the decision making I help her with I would be scared to sign this document. Number one as a volunteer number two it looks like any decision making you would do as this advisor would put you in jeopardy. My question is who would challenge that?

David Boeck: The liability of a supporter is addressed in one of the provisions of the bill, (page 2 lines 24 to 26). The supporter is well protected for acts under good faith

Representative Fegley: This **whole** process of having someone come in and advise who is outside the judge's process under guardianship for a conservator. Is that correct?

David Boeck: That is correct. There wouldn't be a judge involved.

Representative Fegley So I see this is a contract between two individuals and somewhere in the process there is going to have to be an education process to tell people that this is available.

David Boeck: Yes.

Representative Skroch: There certainly could be opportunities of abuse that develop in these relationships. Where there is abuse who would investigate this?

David Boeck: I don't see this as really affecting who would bear the burden of proof. There is an Adult protection agency.

Representative Tveit: You said that this could be handled without this law. Why would we spend the time putting something into legal jargon and enforcing it? For what reason?

David Boeck: The reason is to put things in a language that the individual could understand, and that they could pick a person they trust.

Representative Tveit: Why then would we have to put this into a law?

David Boeck: Some states have this as a document but not part of the law.

Julianne Horntvedt, Director of the North Dakota State Council on Development Disabilities.
Testimony # 4 In support of.

Representative Porter: Do you think that this would increase confusion?

Julianne Horntvedt: If this bill goes through, we would do a lot of training throughout the state Educating the medical world and the banking world so they know this is a real document, and it is ok to use.

Representative Porter: Wouldn't this be the same as HIPA, a federal program? Isn't this just common practice?

Julianne Horntvedt: You are right this wouldn't supersede HIPA . It is to come into a room so you have more power, so this person is here to support me. Having this document as an alternative to guardianship will really help people.

Representative Porter: Are there any reported cases? Or are their problems that people need this extra weight? I have never heard there was a problem.

Julianne Horntvedt: There are people in the room that can answer that question for you.

Representative Skroch: If this bill would be passed, how would this be funded? And what module would you use for a common instruction?

Julianne Horntvedt: We have funded this through Protection and Advocacy, which is a sister organization to us. We would have in person trainings, phone trainings. It would probably be another year or 2 of training. Testimonies handed in #'s 5,6,7,8,9.

Matthew McCleary, the Youth Coordinator for North Dakota Federation of Families for Children's Mental Health. (NDFFCMH) In support of: Testimony # 10

Kirsten Dvorak, Executive Director of the Arc of ND, Testimony #11

Representative Porter: It seems to me we don't have a problem.

Kirsten Dvorak: People that don't have their parents around, this is where it would be helpful.

Representative Rohr: So both of you would have to sign over health information via HEPA Laws.

Kirsten Dvorak: That is correct.

Trevor Vannett: Testimony # 12

Julianne Horntvedt: I was asked by Shelly Peterson to let you know she supports this bill. But she wasn't able to be here today.

Vicki Peterson, A Family Consultant for Family Voices of ND. Testimony # 13
Guardianship costs a lot of money, about 5 to 6 thousand dollars. I have been asked to leave meetings that my son goes to, I am the parent.

Representative Tveit: I have a grandson with autism, but I believe you could still have this form filled out without legislation.

Vicki Peterson: If you don't pass this bill the paper doesn't hold any weight. So they don't have to recognize this paper.

Roxane Romanick: Designer Genes of North Dakota: In support of HB 1378. Testimony handed in: # 14. No oral statement given.

Opposed? Seeing none.

The Hearing is closed on HB 1378.

2019 HOUSE STANDING COMMITTEE MINUTES

Human Services Committee
Fort Union Room, State Capitol

HB 1378
1/29/2019
31729

☐ Subcommittee
☐ Conference Committee

Committee Clerk Signature Nicole Klamann Typed by: Elaine Stromme

Explanation or reason for introduction of bill/resolution:

Relating to supported decision making, a process for well informed, voluntary decisions by methods less restrictive than guardianship or conservatorship

Minutes:

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Chairman Weisz: Opened the Hearing on the HB1378.

Representative Schneider: Moved for an amendment 19.0884.03001.

Representative Porter: seconded

Voice Vote: Amendment Passed

Representative Dobervich: Moved Do Pass as Amended

Representative Ruby: Seconded

A Roll Call Vote was taken Yes – 9 No – 4 Absent 1

Do Pass as Amended Carries.

Representative Schneider will carry HB 1378.

DP 1/29/19

19.0884.03001
Title.04000

Adopted by the Human Services Committee

January 29, 2019

PROPOSED AMENDMENTS TO HOUSE BILL NO. 1378

Page 5, remove lines 20 through 30

Page 6, remove lines 1 through 31

Page 7, remove lines 1 through 30

Page 8, remove lines 1 through 31

Page 9, remove lines 1 through 31

Page 10, remove lines 1 through 28

Renumber accordingly

Date: 4/29/19
Roll Call Vote #: 7

2019 HOUSE STANDING COMMITTEE
ROLL CALL VOTES
BILL/RESOLUTION NO. HB 1378

House Human Services Committee

☐ Subcommittee

Amendment LC# or Description: 19.0884.03001

Recommendation: ☒ Adopt Amendment
☐ Do Pass ☐ Do Not Pass ☐ Without Committee Recommendation
☐ As Amended ☐ Rerefer to Appropriations
☐ Place on Consent Calendar
Other Actions: ☐ Reconsider ☐

Motion Made By Rep. Schneider 14:09 Seconded By Rep. Porter

Representatives	Yes	No	Representatives	Yes	No
Robin Weisz - Chairman			Gretchen Dobervich		
Karen M. Rohr - Vice Chairman			Mary Schneider		
Dick Anderson					
Chuck Damschen					
Bill Devlin					
Clayton Fegley					
Dwight Kiefert					
Todd Porter					
Matthew Ruby					
Bill Tveit					
Greg Westlind					
Kathy Skroch					

Total (Yes) _____ No _____

Absent _____

Floor Assignment _____

If the vote is on an amendment, briefly indicate intent:

Motion to Amend Carries

Date: 4/29/19
Roll Call Vote #: 2

**2019 HOUSE STANDING COMMITTEE
ROLL CALL VOTES
BILL/RESOLUTION NO. HB 1378**

House Human Services Committee

☐ Subcommittee

Amendment LC# or Description: _____

Recommendation: ☐ Adopt Amendment
☒ Do Pass ☐ Do Not Pass ☐ Without Committee Recommendation
☒ As Amended ☐ Rerefer to Appropriations
☐ Place on Consent Calendar
Other Actions: ☐ Reconsider ☐ _____

Motion Made By Rep. Dobervich Seconded By Rep. Ruby

Representatives	Yes	No	Representatives	Yes	No
Robin Weisz - Chairman	X		Gretchen Dobervich	X	
Karen M. Rohr – Vice Chairman	X		Mary Schneider	X	
Dick Anderson					
Chuck Damschen		X			
Bill Devlin		X			
Clayton Fegley	X				
Dwight Kiefert	X				
Todd Porter	X				
Matthew Ruby	X				
Bill Tveit	X				
Greg Westlind		X			
Kathy Skroch		X			

Total (Yes) 9 No 4

Absent 1

Floor Assignment Rep. Schneider

If the vote is on an amendment, briefly indicate intent:

REPORT OF STANDING COMMITTEE

HB 1378: Human Services Committee (Rep. Weisz, Chairman) recommends **AMENDMENTS AS FOLLOWS** and when so amended, recommends **DO PASS** (9 YEAS, 4 NAYS, 1 ABSENT AND NOT VOTING). HB 1378 was placed on the Sixth order on the calendar.

Page 5, remove lines 20 through 30

Page 6, remove lines 1 through 31

Page 7, remove lines 1 through 30

Page 8, remove lines 1 through 31

Page 9, remove lines 1 through 31

Page 10, remove lines 1 through 28

Renumber accordingly

2019 SENATE HUMAN SERVICES

HB 1378

2019 SENATE STANDING COMMITTEE MINUTES

Human Services Committee Red River Room, State Capitol

HB 1378
3/6/2019
Job #33319

- ☐ Subcommittee
☐ Conference Committee

Committee Clerk: Justin Velez and Alicia Larsgaard
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Explanation or reason for introduction of bill/resolution:

Relating to supported decision making, a process for making well-informed, voluntary decisions by methods less restrictive than guardianship or conservatorship.

Minutes:

Attachments: 8

Vice Chairman O. Larsen: Opened the hearing on HB 1378.

(02:14-03:12) Representative Jeffery J. Magrum, District 28: Introduces HB 1378. Please see attachment #1 for testimony.

(03:23-14:15) Judy DeWitz, Disabilities Advocate with the North Dakota Protection and Advocacy Project: Testifying in support of HB 1378. Please see Attachment #2 for testimony.

(14:13) Senator Anderson: Explain if the person is making their own decisions, such as myself and my wife steps in, can I carry her wishes to the court or the hospital or does she still have to be there to make the decision?

Judy DeWitz: She can go with you if you want her to, but you are still the person in charge. If you want that supporter to go with you, you can. If you want that supporter to speak for you, you can but you're the person in charge.

Senator Anderson: The only time that supporter can speak for me is if they also carry this agreement to the court, hospital, etc. That gives the court the ability to accept it, correct?

Judy DeWitz: Yes, that is the reason it was put in there. It wasn't always, because the person was afraid someone was being taken advantage of. There was also the concern of would the supporter take advantage of the person. We want protection and want the people to have a positive life. We also wanted the third party to feel protected. If people think something is going to go wrong, they won't work for us.

Senator Hogan: 30-40 years ago you would have family or neighbors that would do this informally. This is a formal process for building a support network for people who are alone correct?

Judy DeWitz: Yes, it is formalized. It is on paper.

Madam Chair Lee: They can sway that person pretty easily in many cases and I am not sure if I want to formalize that agreement.

Senator Hogan: It is the liability. At the same time, with the shortage of guardianships, people are in that limbo land. It would be helpful for them to have someone to work with them.

Judy DeWitz: Right that is correct. I am not trying to short change this issue but we do have to get through this stuff before our noon caucus and we have another bill to hear.

(19:10-23:11) David Boeck, State employee and a lawyer for the Protection and Advocacy Project: Testifying in support of HB 1378. Please see Attachment #3 for testimony.

(23:35-26:00) Vicki Peterson, Family consultant for Family Voices of ND: Testifying in support of HB 1378. Please see Attachment #4 for testimony.

(26:30-27:20) refer to recording Please see Attachment #5 for additional testimony.

(28:18-32:52) Kirsten Dvorak, Executive Director of the Arc of North Dakota: Testifying in support of HB 1378. Please see Attachment #6 for testimony. Please see Attachment #7 for additional supporting testimony from Roxane Romanick, Executive Director of Designer Genes of ND.

(33:45-34:12) Matthew McCleary, Youth Coordinator for North Dakota Federation of Families for Children's Mental Health (NDFFCMH): Testifying in support of HB 1378. Please see Attachment #8 for testimony.

Madam Chair Lee closed the hearing on HB 1378.

2019 SENATE STANDING COMMITTEE MINUTES

Human Services Committee
Red River Room, State Capitol

HB 1378
3/6/2019
Job #33325

☐ Subcommittee
☐ Conference Committee

Committee Clerk: Justin Velez and Alicia Larsgaard
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Explanation or reason for introduction of bill/resolution:

Relating to supported decision making, a process for making well-informed, voluntary decisions by methods less restrictive than guardianship or conservatorship.

Minutes:

Attachments: 0

Madam Chair Lee: Called the committee to order on HB 1378.

Senator Anderson: Moved a Do Pass on HB 1378.

Senator Hogan: Seconded.

Madam Chair Lee: Any Discussion?

A Roll Call Vote Was Taken. 6 yeas, 0 nays, 0 absent.

Motion Carried.

Senator Anderson will carry the bill.

Date: 3/6/19
Roll Call Vote #: 1

2019 SENATE STANDING COMMITTEE
ROLL CALL VOTES
BILL/RESOLUTION NO. 1378

Senate Human Services Committee

☐ Subcommittee

Amendment LC# or Description: _____

Recommendation: ☐ Adopt Amendment
☒ Do Pass ☐ Do Not Pass ☐ Without Committee Recommendation
☐ As Amended ☐ Rerefer to Appropriations
☐ Place on Consent Calendar
Other Actions: ☐ Reconsider ☐ _____

Motion Made By Anderson Seconded By Hogan

Senators	Yes	No	Senators	Yes	No
Sen. Judy Lee	X		Sen. Kathy Hogan	X	
Sen. Oley Larsen	X				
Sen. Howard C. Anderson	X				
Sen. David Clemens	X				
Sen. Kristin Roers	X				

Total (Yes) 6 No 0

Absent 0

Floor Assignment Sen. Anderson

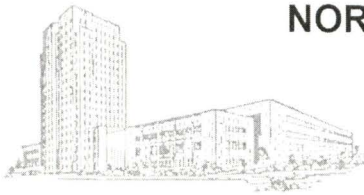
If the vote is on an amendment, briefly indicate intent:

REPORT OF STANDING COMMITTEE

HB 1378, as engrossed: Human Services Committee (Sen. J. Lee, Chairman)
recommends **DO PASS** (6 YEAS, 0 NAYS, 0 ABSENT AND NOT VOTING).
Engrossed HB 1378 was placed on the Fourteenth order on the calendar.

2019 TESTIMONY

HB 1378



NORTH DAKOTA HOUSE OF REPRESENTATIVES

STATE CAPITOL
600 EAST BOULEVARD
BISMARCK, ND 58505-0360



#1 HB 1378
1-23-19
P1.

Representative Jeffery J. Magrum

District 28
P.O. Box 467
Hazelton, ND 58544-0467
C: 701-321-2224
jmagrum@nd.gov

COMMITTEES:

Judiciary
Political Subdivisions

"Click here to type date"

Good morning chairman and committee members.

For the record I am Jeff Magrum representing district #28 which is south central North Dakota east of the Missouri River.

I stand before you to introduce HB1378 on behalf of the Protection & Advocacy Project.

HB1378 is a bill for Supported Decisionmaking.

#2
HB 1378
1-23-19

Human Services Committee
Representative Robin Weisz, Chairman
House Bill 1378
January 22, 2019

Chairman Weisz and members of the Committee:

I am Judy DeWitz, a Disabilities Advocate with the North Dakota Protection and Advocacy Project (P&A). The Protection & Advocacy Project is an independent state agency that acts to protect people with disabilities from abuse, neglect, and exploitation, and advocates for the rights of people with disabilities.

P&A supports House Bill 1378, a process for making well-informed, voluntary decisions by methods less restrictive than guardianship or conservatorship. Supported Decisionmaking allows individuals to make their own decisions and stay in charge of their lives, while receiving the help and assistance they need.

All people need and use support to make important life decisions. Using this model, older adults and people with disabilities choose someone they trust, often a friend, family member or professional, to serve as their “supporter.”

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.

However, the supporter CANNOT make a decision for the individual; the individual makes the final decision.

Before selecting a supporter, the individual decides what decisions for which he or she needs assistance and the supporter is then selected to help. A Supported Decisionmaking Agreement between the individual and the supporter is made in writing using a form which defines what type of assistance the individual is requesting and what the supporter has permission to do. The form is signed, dated and requires witnesses or a notary public.

While this model might not work for everyone, Supported Decisionmaking is an alternative to guardianship, is flexible, and can change with the needs of the individual to provide more opportunities for independence. Many people with disabilities can manage their own affairs with assistance and guidance from a supporter whom they trust.

Supported Decisionmaking is not a new concept. ND providers and self-advocates learned about this model from in-state colleagues and across the country. The ND State Council on Developmental Disabilities (SCDD) provided a grant to P&A to coordinate a project to research, study, and bring together stakeholders to consider implementation of Supported Decisionmaking in ND.

- A ten-member Steering Committee, representing a cross section of the population – from young people to the elderly, those working with individuals with various types of disabilities, and those who represent agencies with diverse agendas, was selected to coordinate and collaborate on the project. The members have met 12 times in the past year, reviewing,

studying, and learning ways, Supported Decisionmaking can provide individuals support to make their own choices.

- The Steering Committee sought and received resources and recommendations from the *National Resource Center for Supported Decision-making*. This is a partnership of state and national leaders who are actively involved in the implementation and use of Supported Decisionmaking.
- Supported Decisionmaking models in other states were studied, along with enabling legislation:
 - On September 1, 2015, *Texas* was the first state to enact a Support Decision-Making Law. Since then, *Delaware, Tennessee, Wisconsin and Alaska* have also enacted state statutes.
 - On August 14, 2017, the *American Bar Association's* (ABA) House of Delegates adopted Resolution 113, "urging state, territorial, and tribal legislatures to (1) amend their guardianship statutes to require that supported decision making be identified and fully considered as a less restrictive alternative, before guardianship is imposed, and (2) require that decision-making supports that would meet the individual's needs be identified and fully considered in proceedings for termination of guardianship and restoration of rights."
 - More than 20 states are currently providing presentations and trainings and are planning for further implementation in their states.

- Recognizing the importance of many ideas and viewpoints, input was requested from anyone who would like to contribute their thoughts or expertise to the project.
 - So that stakeholders throughout the state could participate, a series of 5 Interactive Video Network (IVN) presentations and conversations were held.
 - To further provide awareness and collect input, 15 community presentations were offered.
 - To provide ease access to programs and knowledges about Supported Decisionmaking programs and activities, the P&A website www.ndpanda.org has been updated.
- Statistics regarding guardianship were gathered:
 - Guardianship numbers are growing. As of February 2016, there were 2,802 adult guardianship cases in ND. By July 2018 the number had risen to approximately 3120 active cases.
 - There are waiting lists for corporate guardians. One agency reported:
 - they currently are providing guardians to 466 people,
 - have 122 individuals on the waiting list for a guardian,
 - and the waiting list is growing, remaining on the list for more than a year.

Why is Supported Decisionmaking important for older adults and people with disabilities?

- People with disabilities face long-standing biases about perceived abilities, including decision-making; but most people can make at least some decisions about their lives.
- Decision-making is a learned skill that requires encouragement and practice. Let's give a person a chance to learn how to make decisions before taking rights away.
- Research shows us that maximizing choice and control (self-determination) in a person's life increases positive outcomes in health, happiness, and safety through stronger relationships and better ability to recognize and resist abuse.

Thank you. I'd be happy to answer any questions the Committee may have.

#3
HB1378
1-23-19

House Human Services Committee
Sixty-Sixth Legislative Assembly of North Dakota
House Bill No. 1378
January 22, 2019

Good morning, Chairman Weisz and Members of the House Human Services Committee. I am David Boeck, a State employee and a lawyer for the Protection & Advocacy Project. The Protection & Advocacy Project is an independent state agency that acts to protect people with disabilities from abuse, neglect, and exploitation, and advocates for the disability-related rights of people with disabilities.

I have served as staff for the Steering Committee that wrote HB 1378 through a grant from the North Dakota Council on Developmental Disabilities. As well, I participated in the IVN (Interactive Video Network) presentations to stakeholders.

Nearly everyone can make and communicate legitimate choices of one kind or another. Only very small categories of individuals cannot. Examples include an individual in a coma, an individual incapable of rational thought, an individual incapable of communicating. Many choices can be made with very little capacity for independent thinking and very little capacity for communication.

North Dakota's guardianship laws are well written and require an individual to be afforded the right to live with the benefit of "alternative resource plans." Most families, lawyers, and judges are

not aware of supported decisionmaking arrangements, so they do not consider them as alternative resources.

Many North Dakotans think of guardianship and conservatorship as generous ways of assuring a good life for their impaired children, parents, or grandparents. In recent times, professional guardians serve those unable to rely upon relatives as guardians.

Supported decisionmaking has proven in other states and nations to be an effective means of restoring an impaired individual to enjoying some control over the individual's life. Many individuals with disabilities who have a guardian could make well-informed, voluntary choices ... if provided some decisionmaking support.

In North Dakota, guardians with unnecessarily broad decisionmaking authority are far too common. There are not enough potential guardians (relatives or professional guardians) to satisfy the demand for guardians.

Use of supported decisionmaking agreements would help to address the shortage of qualified guardians in the State. If North Dakota had supported decisionmaking, the demand for new guardians would be less.

Individuals using supported decisionmaking would no longer be labeled "wards." Many impaired individuals using supported decisionmaking would not fall victim to the common experience of

becoming depressed due to feeling the loss of legal identity, self-esteem, and value as a person.

Many individuals able to benefit from supported decisionmaking would have greater self-fulfillment, greater satisfaction with life, and greater happiness.

The Legislative Council has put the working group's draft into proper legislative format but I could probably address any questions you have on details of the bill. Thank you.

#4
HB 1378
1-23-19

House Human Service Committee

January 22, 2019

Testimony in favor of HB1378

Members of the Committee,

My name is Julianne Horntvedt and I live in Bismarck. I am the Director of the North Dakota State Council on Developmental Disabilities and we helped fund this project through Protection and Advocacy through a grant.

Supported decisionmaking promotes self-determination, control, and autonomy. It fosters independence.

We all engage in supported decisionmaking. We consult with family or friends, colleagues or classmates, mechanics or mentors before we make decisions. We may seek support to decide whether to go on a blind date, buy a used car, change jobs, renew a lease, or undergo cataract surgery. We confer and consult with others, and then we decide on our own.

People with disabilities may need assistance making decisions about living arrangements, health care, relationships, and financial matters. But they do not necessarily need a guardian to make those decisions for them. A trusted network of supporters can field questions and review options to help the person with the disability make their own decisions. Supporters are selected by the person with the disability. They can be family members, co-workers, friends, and past or present providers. The individual should select supporters who know and respect his or her will and preferences, and who will honor the choices and decisions the individual makes.

Though supported decisionmaking is just gaining a foothold in the United States, this concept has been evolving in other countries for more than a decade. Several countries have long found that everyone – including individuals with disabilities – has legal capacity to make decisions. This concept was further advanced when the United Nations Convention on the Rights of People with Disabilities voted in 2006 to adopt Article 12 which states that “persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life” and that “[all] parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.”

Thank You,
Julianne Horntvedt

#5
HB 1378
1-23-19

House Human Service Committee

January 22, 2019

Testimony in favor of HB1378

Members of the Committee,

My name is Carol Becker and my husband, Allen, and I live in Minot. My husband, Allen, has a sister who has a guardian, but we feel that she would be better served with supporters to help her make decisions because she would be able to learn this way. With guardians, she can't learn because someone is always making decisions for her.

Thank You,
Carol Becker
701-240-8400

#6
HB 1378
1-23-19

House Human Service Committee

January 22, 2019

Testimony in favor of HB1378

Members of the Committee,

My name is Cynthia Kyle and I live in Fargo. I support this bill because a supporter is someone to work with you to help make decisions together, rather than a guardian who makes decisions for you. I really think a supporter would help compromise and communicate with a person, instead of being watched over by a guardian.

Thank You,
Cynthia Kyle
701-540-3435

#7
HB1378
1-23-19

House Human Service Committee

January 22, 2019

Testimony in favor of HB1378

Members of the Committee,

My name is Jillian Schaible and I live in Bismarck. I think it's important for people with disabilities to make their own decisions and involve who they choose in their life. This may not be something I need, but I want the option for other people.

Thank You,
Jillian Schaible
701-220-0238

House Human Service Committee

January 22, 2019

Testimony in favor of HB1378

Members of the Committee,

My name is Cindy Dahlgren and my husband, Jay, and I live in Grand Forks. I support this bill because it is a great alternative to guardianship for individuals who don't need guardianship but do need guidance.

Thank You,
Cindy Dahlgren
701-741-6926

#8
HB 1378
1-23-19

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1-23-19

House Human Service Committee

January 22, 2019

Testimony in favor of HB1378

Members of the Committee,

My name is Darrel Wahl and I live in Minot. I support this bill because I have always been my own guardian, so I have been able to make my own decisions. I have people in my life who help me with choices, so I use supporters. I believe getting guidance through supporters is a great alternative to guardians.

Thank You,
Darrel Wahl
701-838-3737

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P1

HB 1378 Testimony
House Human Services Committee
Representative Weisz, Chairman
January 22, 2019

Chairman Weisz and members of the committee, my name is Matthew McCleary. I am the Youth Coordinator for North Dakota Federation of Families for Children's Mental Health (NDFFCMH), which is a parent-run organization focused on the needs of children and youth with emotional, behavioral, and mental health needs and their families. I am also the peer support Project Coordinator for Mental Health America of North Dakota (MHAND), which is a consumer-run organization whose mission is to promote mental health through education, advocacy, understanding, and access to quality care for all individuals.

On behalf of both NDFFCMH and MHAND, I am testifying in support of HB 1378. Supported decision making is an alternative to guardianship, but is not meant to be a replacement for guardianship. Supported decision making formalizes what many people do every day: consult with trusted sources in order to make a decision. In supported decision making, the supporter does not make decisions on behalf of an individual, they just help make sense of it all.

- There are many groups who can benefit from supported decision making, but I will highlight one: youth with disabilities who are college-bound. The journey to college is exciting and fraught with complex decisions and many small tasks to complete just to continue being a college student. How do I apply to college? How do I get financial aid? How do I get housing or a meal plan? How do I sign up for classes? How many classes should I sign up for? What do I do if I am failing a course? What are these forms and why do I have so many of them?

When I made my transition to adulthood as a student with a disability, I was blessed to have a strong support network to help with understanding the world of higher education. But I was still away from home and there were many times I had a lot of questions about what to do, how to do it, and what the ramifications of each choice would be. Despite

these challenges, I thrived in college. While I often made contacts with my parents and my Vocational Rehabilitation case manager, I was mostly able to adapt to my environment without much additional assistance. But my experience is not going to be like other people's experiences. My brother, who also has a disability, did need a guardianship. The decision was not taken lightly and although it was the correct decision, it was no less devastating to him and his sense of independence and dignity. However, many people in North Dakota are unnecessarily in a guardianship and could use supported decision making instead.

People with disabilities often need additional supports to make it more likely that they succeed in life, but we also want to have supports that function as naturally as possible. Many of the youth I work with could use additional supports as they enter college, but they do not require guardianships. When they are going off to college, what they may need is someone to make things more understandable. Often it may be difficult for another person besides the student to be involved in those conversations between student, faculty, administrative support, or anyone else in higher education. I happen to think that instilling that level of independence for a young person is a good thing, but sometimes it is not as helpful as we may think it is. Perhaps we forget the important details, maybe if the steps to solving a problem are complicated, we do not know how to do them. That is why it is useful for some people with disabilities to be able to have a supported decision making agreement and have a supporter help them out. Just as sometimes it is helpful to have someone else with you during a medical appointment, it can be helpful to have someone with you in an appointment at the college level.

Bringing supported decision making to North Dakota may also improve self-determination among youth with disabilities. Although special education has improved the fortunes of millions of people with disabilities, we have never given self-advocacy and self-determination its due. A national study of post-school outcomes for students with disabilities in the mid-2000s found that only 12% of special education students were leaders in their own post-school plans. Several years ago a study from Minot State University found that only 19% of North Dakota special education teachers have utilized

student-led planning at least once—which means those teachers could be using it with all of their students, or just one. If supported decision making is spread throughout North Dakota and people become aware that more people with disabilities can make their own decisions, perhaps it is possible that services such as special education can encourage and better prepare youth with disabilities to exercise their own decision making skills.

Formalizing supported decision making ensures that our institutions recognize when vulnerable populations use a process many of us use every day and provides North Dakotans more alternatives to guardianship. I urge this committee to support HB 1378 and bring supported decision making to North Dakota.

Thank you for your time and I will answer any questions you have.

Matthew McCleary
Youth Coordinator
North Dakota Federation of Families for Children's Mental Health
Email: mmccleary@ndffcmh.com
Phone: (701) 222-3310



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1-23-19

House Health and Human Services

HB 1378

January 22, 2019

Chairman Weisz, and members of the committee, my name is Kirsten Dvorak. I am the executive director of The Arc of North Dakota, which includes all six Arc chapters in the state: Bismarck, Bowman, Dickinson, Fargo, Grand Forks, and Valley City. Our mission is to improve the quality of life of people with intellectual and developmental disabilities and actively support their full inclusion and participation in the community.

The Arc believe all individuals with intellectual and/or developmental disabilities (I/DD) have the right to recognition as persons before the law and to enjoy legal capacity on an equal basis with individuals who do not have disabilities in all aspects of life (United Nations Convention on the Rights of Persons with Disabilities (UN CRPD), 2006). The personal autonomy, liberty, freedom, and dignity of each individual with I/DD must be respected and supported. Legally, each individual adult or emancipated minor is presumed competent to make decisions for himself or herself, and each individual with I/DD should receive the preparation, opportunities, and decision-making supports to develop as a decision-maker over the course of his or her lifetime.

The primary goal in assisting individuals with I/DD should be to assure and provide supports for their personal autonomy and ensure equality of opportunity, full participation, independent living, and economic self-sufficiency (Americans with

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1-23-19

Disabilities Act, 1990, section 12101 (a)(7); Individuals with Disabilities Education Act, 2004, section 1400 (c)(1)). Each individual adult and emancipated minor is legally presumed competent to make decisions for himself or herself and should receive the preparation, opportunities, and decision-making supports to develop as a decision-maker over the course of his or her lifetime. All people with I/DD can participate in their own affairs with supports, assistance, and guidance from others, such as family and friends. People with I/DD should be aware of and have access to decision-making supports for their preferred alternatives.

Supported Decision-Making agreements can provide the Person with the support they need or want to maintain a personal autonomy, liberty, freedom, and dignity in their life. Supported Decision-Making agreements may be the tool that the Person needs to live the life of their choosing and live a independent life in their communities.

The Arc of North Dakota asks for a do pass on HB 1378

Kirsten Dvorak, Executive Director
222-1854

House Human Service Committee

#12
HB 1378
1-23-19

Testimony in favor of HB1378

Members of the Committee,

My name is Trevor Vannett and I live in Bismarck. I support this bill because it will help youth turning 18 have another option besides a guardianship. When I turned 18, I didn't have any other option except guardianship. I wasn't able to learn how to do things because I didn't have Supported Decisionmaking. This will be another option for people.

Thank You,
Trevor Vannett
701-955-0000

#13

HB 1378

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pg 1.

House Bill 1378

House Human Services

Tuesday, January 22nd, 2019

Chairman Representative Weisz and Members of the House Human Services Committee;

My name is Vicki Peterson and I am a Family Consultant for Family Voices of ND.

Family Voices of ND is the Family to Family Health Information Center in ND

I am before you in support of House Bill 1378, Supported Decision Making.

Supported Decision Making is an alternative to Guardianship, an important alternative. Supported Decision Making is the process of a person with any type of disability requesting the support to make life decisions from another trusted person (s) in agreement that does not hinder the self-determination in making those choices. Supporters help gather information, compare options and help with the communication on those decisions.

Under law, all adults have the right to make decisions, whether they have a disability or not. Certain circumstances dictate that there is a need for someone else to make life decisions for someone else. This is still true today, but we must recognize, and give opportunity to the individual person the right to have an agreement to support their decisions and the right and responsible choices for their life.

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P 2.

I am a parent of a child with an intellectual disability and autism. Everyday he is supported in making decisions for himself. Decision Making is a learned skill. He learns this in school, at home and in his community. My son is 16 years of age and so I will have to be making decisions on guardianship very soon and looking at all the options for my son. I am also a family consultant that offers trainings for parents and young adults on guardianship and alternatives to that process. In my trainings, we discuss Supported Decision Making and what that process may look like for a young person. These choices are never easy and should not happen quickly. Supported Decision Making has been one area that we discuss plenty on. Many caregivers have responded by saying this option would fit best for their child as they enter the adult world. We discuss that persons gain experience over time that could increase their potential for making responsible decisions. Changes in their functional skills may also change over time. Supported Decision making may also be used with other alternatives to guardianship as well such as Power of Attorney. They are used to compliment each other , not take away from each other.

Persons with self-determination are typically healthier, more well adjusted and better able to recognize abuse and resist abuse(*Wehmeyer, Palmer, Rifenbark, & Little 2014; Powers et al., 2012; Khemka*). Syracuse University did a survey in 2016(*Quality Trust for Persons with Disabilities*) and found that Supported Decision Making has made the client have more confidence, happier, and try more things in their life they would otherwise not.

On August 14, 2017, the American Bar Association adopted Resolution 113, urging states to:

(1) amend their guardianship statutes to require that supported decision making be identified and fully considered as a less restrictive alternative, before guardianship is imposed, and

(2) require that decision-making supports that would meet the individual's needs be identified and fully considered in proceedings for termination of guardianship and restoration of rights.

Supported Decision Making will be giving the validity it deserves by putting this in statute. Making Supported Decision Making a law will retain the persons rights to make their own decisions. If it is law , it defines what a supporter is and what assistance the supporter can offer. By adding Supported Decision Making to the law establishes the legal framework for helping and supporting the Person to other agencies and professionals.

I want to thank you for your time and consideration for House Bill 1378.

Vicki L Peterson

vickiasdc@bis.midco.net

701-258-2237

701-527-2889

HB 1378
House Human Services
Tuesday, January 22, 2019

Chairman Weisz and Members of the House Human Services Committee:

My name is Roxane Romanick and I'm representing Designer Genes of ND, Inc., as their Executive Director. Designer Genes' membership represents 220 individuals with Down syndrome that either live in our state or are represented by family members in North Dakota. Designer Genes' mission is to strengthen opportunities for individuals with Down syndrome and those who support them to earn, learn, and belong.

I am here today to ask for a "do pass" on HB 1378. Adults living with Down syndrome will benefit for a broader continuum of supports for help with decision-making and are grateful for the work of the task force that has moved this bill forward. While the concept of "dignity of risk" sounds good in theory, many of us, as parents and siblings, worry about the vulnerabilities that come with living with an intellectual disability. Typically, family members and/or loved ones of individuals with Down syndrome turn to guardianship as the only alternative. For many of us, this step feels counterintuitive to the work of independence, growth, and inclusion during childhood and adolescence.

Creating intentionality around making decisions and providing education to individuals with Down syndrome and other intellectual disabilities is important, but so often can be neglected. Individuals with Down syndrome are often victims to lowered expectations and do not have the opportunity to "learn" because people believe they can't. Given the opportunity and needed accommodations, making choices about options and desires is possible. Jenny Hatch, a young woman with Down syndrome, who challenged her guardianship and was granted the opportunity to live with people she chose versus a group home her parents chose, was one such individual. She was one of the sparks needed to move the supported decision-making option forward.

Here is a text that I received from my daughter who lives with Down syndrome two days ago: "Mom, I will be working on my scholarship by myself with my friend, Hannah. Do you think I should use my Minot State address or our home address? Don't worry about this, I have it taken care of. Can you send the login to my bank account, so I can see how much money I have?" I shudder to turn over the possibility of up to a \$5000 scholarship application over to her, but I am also exceedingly proud of the display of independence that she's exhibiting. Elizabeth deserves the supported decision-making option in ND and no one should assume that she needs a guardianship just because she was born with a diagnosis of Down syndrome.

Formally recognizing supported decision-making in ND will help us to think with more intention around supporting individuals with Down syndrome and other intellectual disability to make decisions, even those individuals who do have guardianship. I foresee additional training and education for both decision-makers and supporters. Thank you for your time. I'd be willing to answer any questions.

Roxane Romanick, Executive Director

701-391-7421

info@designergenesnd.com

NORTH DAKOTA HOUSE OF REPRESENTATIVES

STATE CAPITOL
600 EAST BOULEVARD
BISMARCK, ND 58505-0360

HB 1378
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#1 PS.1



Representative Jeffery J. Magrum

District 28
P.O. Box 467
Hazelton, ND 58544-0467
C: 701-321-2224
jmagrum@nd.gov

COMMITTEES:

Judiciary
Political Subdivisions

"Click here to type date"

Good morning chairman and committee members.

For the record I am Jeff Magrum representing district #28 which is south central North Dakota east of the Missouri River.

I stand before you to introduce HB1378 on behalf of the Protection & Advocacy Project.

HB1378 is a bill for Supported Decisionmaking.

That's using... "Supported Decisionmaking."

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#2 pg.1

Senate Human Services Committee
Senator Judy Lee, Chair
House Bill 1378
March 6, 2019

Chairman Lee and members of the Committee:

I am Judy DeWitz, a Disabilities Advocate with the North Dakota Protection and Advocacy Project (P&A). The Protection & Advocacy Project is an independent state agency that acts to protect people with disabilities from abuse, neglect, and exploitation, and advocates for the rights of people with disabilities.

P&A supports House Bill 1378, a process for making well-informed, voluntary decisions by methods less restrictive than guardianship or conservatorship. Supported Decisionmaking allows individuals to make their own decisions and stay in charge of their lives, while receiving the help and assistance they need.

All people need and use support to make important life decisions. Using this model, older adults and people with disabilities choose someone they trust, often a friend, family member or professional, to serve as their "supporter."

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.

However, the supporter CANNOT make a decision for the individual; the individual makes the final decision.

Before selecting a supporter, the individual decides what decisions for which he or she needs assistance and the supporter is then selected to help. A Supported Decisionmaking Agreement between the individual and the supporter is made in writing using a form which defines what type of assistance the individual is requesting and what the supporter has permission to do. The form is signed, dated and requires witnesses or a notary public.

While this model might not work for everyone, Supported Decisionmaking is an alternative to guardianship, is flexible, and can change with the needs of the individual to provide more opportunities for independence. Many people with disabilities can manage their own affairs with assistance and guidance from a supporter whom they trust.

Supported Decisionmaking is not a new concept. ND providers and self-advocates learned about this model from in-state colleagues and across the country. The ND State Council on Developmental Disabilities (SCDD) provided a grant to P&A to coordinate a project to research, study, and bring together stakeholders to consider implementation of Supported Decisionmaking in ND.

- A ten-member Steering Committee, representing a cross section of the population – from young people to the elderly, those working with individuals with various types of disabilities, and those who represent agencies with diverse agendas, was selected to coordinate and collaborate on the project. The members have met 12 times in the past year, reviewing,

studying, and learning ways, Supported Decisionmaking can provide individuals support to make their own choices.

- The Steering Committee sought and received resources and recommendations from the *National Resource Center for Supported Decision-making*. This is a partnership of state and national leaders who are actively involved in the implementation and use of Supported Decisionmaking.
- Supported Decisionmaking models in other states were studied, along with enabling legislation:
 - On September 1, 2015, *Texas* was the first state to enact a Support Decision-Making Law. Since then, *Delaware, Tennessee, Wisconsin and Alaska* have also enacted state statutes.
 - On August 14, 2017, the *American Bar Association's* (ABA) House of Delegates adopted Resolution 113, "urging state, territorial, and tribal legislatures to (1) amend their guardianship statutes to require that supported decision making be identified and fully considered as a less restrictive alternative, before guardianship is imposed, and (2) require that decision-making supports that would meet the individual's needs be identified and fully considered in proceedings for termination of guardianship and restoration of rights."
 - More than 20 states are currently providing presentations and trainings and are planning for further implementation in their states.

- Recognizing the importance of many ideas and viewpoints, input was requested from anyone who would like to contribute their thoughts or expertise to the project.
 - So that stakeholders throughout the state could participate, a series of 5 Interactive Video Network (IVN) presentations and conversations were held.
 - To further provide awareness and collect input, 15 community presentations were offered.
 - To provide ease access to programs and knowledges about Supported Decisionmaking programs and activities, the P&A website www.ndpanda.org has been updated.
- Statistics regarding guardianship were gathered:
 - Guardianship numbers are growing. As of February 2016, there were 2,802 adult guardianship cases in ND. By July 2018 the number had risen to approximately 3120 active cases.
 - There are waiting lists for corporate guardians. One agency reported:
 - they currently are providing guardians to 466 people,
 - have 122 individuals on the waiting list for a guardian,
 - and the waiting list is growing, remaining on the list for more than a year.

Why is Supported Decisionmaking important for older adults and people with disabilities?

- People with disabilities face long-standing biases about perceived abilities, including decision-making; but most people can make at least some decisions about their lives.
- Decision-making is a learned skill that requires encouragement and practice. Let's give a person a chance to learn how to make decisions before taking rights away.
- Research shows us that maximizing choice and control (self-determination) in a person's life increases positive outcomes in health, happiness, and safety through stronger relationships and better ability to recognize and resist abuse.

Thank you. I am happy to answer any questions the Committee may have.

“Supported Decisionmaking”

HB 1378

“Supported Decisionmaking” allows older adults and people with disabilities to make their own decisions and stay in charge of their lives, while receiving the help and assistance they need.

How does Supported Decisionmaking work?

The **“Individual”** works with a **“Supporter”** to...

- make significant decisions, and
- stay in charge of his/her own life.

The **“Supporter”** helps the **“Individual”** by...

- assisting in collecting and considering relevant information about the issue(s) to be decided,
- helping the Individual understand the options and potential consequences of a particular decision, and
- assisting the individual to communicate his/her decision to the appropriate people.
 - The Supporter has *no* authority to make the decisions for the Individual.
 - The Supporter is *only* allowed to assist the Individual as requested by the Individual.

The **Supported Decisionmaking Agreement** is...

- a written, signed, dated and witnessed agreement between the Individual and the Supporter in which the Supporter agrees to provide assistance with decisionmaking to the individual, maximizing the Individual’s ability to make informed, voluntary choices.

The Individual is the decider and the decision maker.

Some Benefits of SDM—

- Individual is always at the center of decisionmaking
- Individual decides who offers support
- Individual retains legal rights
- No expensive attorney fees or court fees
- Teaches individual about decisionmaking and self-determination

Why does Supported Decisionmaking need to be in statute?

After learning about the Supported Decisionmaking model, ND providers and self-advocates met for over a year to study this model. The group reached out to national and state leaders who have implemented the program in their states. The committee gathered local input by sharing information with additional stakeholders in ND and asking for their ideas and feedback.

There was a concern whether the Supported Decisionmaking 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 then made the decision to pursue legislation.

Guardianship in North Dakota

In North Dakota, guardians with unnecessarily broad decisionmaking authority are far too common. There are not enough potential guardians (relatives or professional guardians) to satisfy the demand for guardians.

Statistics regarding guardianship in North Dakota:

- Guardianship numbers are growing.
 - As of February 2016, there were 2,802 adult guardianship cases in ND.
 - By July 2018 the number had risen to approximately 3,120 active cases.
- Currently, there are waiting lists for corporate guardians. One agency reported:
 - they currently provide guardianships to 466 people,
 - they have 122 individuals on the waiting list for a guardian, and
 - the waiting list is growing, with individuals remaining on the list for more than a year.

Use of Supported Decisionmaking agreements would help to address the shortage of qualified guardians in the State. If North Dakota had Supported Decisionmaking, the demand for new guardians would be less.

Supported Decisionmaking empowers people to make their own choices so they can live more independent and self-directed lives. While this model may not work for everyone, it can be an alternative to guardianship. It is flexible. It can change with the needs of the Individual.

For additional information, contact:

Judy DeWitz, Disabilities Advocate
ND Protection & Advocacy Project
400 East Broadway, Suite 409
Bismarck, ND 58501
(701) 328-2950
Email: judewitz@nd.gov

HB 1378
3/6/19
#3 pg.1

Senate Human Services Committee
Sixty-Sixth Legislative Assembly of North Dakota
House Bill No. 1378
March 6, 2019

Good morning, Chairman Lee and Members of the Senate Human Services Committee. I am David Boeck, a State employee and a lawyer for the Protection & Advocacy Project. The Protection & Advocacy Project is an independent state agency that acts to protect people with disabilities from abuse, neglect, and exploitation, and advocates for the disability-related rights of people with disabilities.

I have served as staff for the Steering Committee that wrote HB 1378 through a grant from the North Dakota Council on Developmental Disabilities. As well, I participated in the IVN (Interactive Video Network) input sessions with stakeholders.

Nearly everyone can make and communicate legitimate choices of one kind or another. Only very small categories of individuals cannot. Examples of the latter include an individual in a coma, an individual incapable of rational thought, an individual incapable of communicating. Many choices can be made with very little capacity for independent thinking and very little capacity for communication.

North Dakota's guardianship laws are well written and require an individual to be afforded the right to live with the benefit of "alternative resource plans." Most families, lawyers, and judges are

not aware of supported decisionmaking arrangements, so they do not consider them as alternative resources.

Many North Dakotans think of guardianship and conservatorship as generous ways of assuring a good life for their impaired children, parents, or grandparents. In recent times, professional guardians serve those unable to rely upon relatives as guardians.

Supported decisionmaking has proven in other states and nations to be an effective means of restoring an impaired individual to enjoying some control over the individual's life. Many individuals with disabilities who have a guardian could make well-informed, voluntary choices ... if provided some decisionmaking support.

In North Dakota, guardians with unnecessarily broad decisionmaking authority are far too common. There are not enough potential guardians (relatives or professional guardians) to satisfy the demand for guardians.

Use of supported decisionmaking agreements would help to address the shortage of qualified guardians in the State. If North Dakota had supported decisionmaking, the demand for new guardians would be less.

Individuals using supported decisionmaking would no longer be labeled "wards." Many impaired individuals using supported decisionmaking would not fall victim to the common experience of

becoming depressed due to feeling the loss of legal identity, self-esteem, and value as a person.

Many individuals able to benefit from supported decisionmaking would have greater self-fulfillment, greater satisfaction with life, and greater happiness.

The Legislative Council has put the working group's draft into proper legislative format.

Please let me know if you have any questions. Thank you.

House Bill 1378

House Human Services

Wednesday, March 6th, 2019

Chairperson Senator Lee and Members of the Senate Human Services Committee.

My name is Vicki Peterson and I am a Family Consultant for Family Voices of ND.

Family Voices of ND is the Family to Family Health Information Center in ND

I am before you in support of House Bill 1378, Supported Decision Making.

Supported Decision Making is an alternative to Guardianship, an important alternative. Supported Decision Making is the process of a person with any type of disability requesting the support to make life decisions from another trusted person (s) in agreement that does not hinder the self-determination in making those choices. Supporters help gather information, compare options and help with the communication on those decisions.

Under law, all adults have the right to make decisions, whether they have a disability or not. Certain circumstances dictate that there is a need for someone else to make life decisions for someone else. This is still true today, but we must recognize, and give opportunity to the individual person the right to have an agreement to support their decisions and the right and responsible choices for their life.

I am a parent of a child with an intellectual disability and autism. Everyday he is supported in making decisions for himself. Decision Making is a learned skill. He learns this in school, at home and in his community. My son is 17 years of age and so I will have to be making decisions on guardianship very soon and looking at all the options for my son. I am also a family consultant that offers trainings for parents and young adults on guardianship and alternatives to that process. In my trainings, we discuss Supported Decision Making and what that process may look like for a young person. These choices are never easy and should not happen quickly. Supported Decision Making has been one area that we discuss plenty on. Many caregivers have responded by saying this option would fit best for their child as they enter the adult world. We discuss that persons gain experience over time that could increase their potential for making responsible decisions. Changes in their functional skills may also change over time.

Persons with self-determination are typically healthier, more well adjusted and better able to recognize abuse and resist abuse(*Wehmeyer, Palmer, Rifenburg, & Little 2014; Powers et al., 2012; Khemka*). Syracuse University did a survey in 2016(*Quality Trust for Persons with Disabilities*) and found that Supported Decision Making has made the client have more confidence, happier, and try more things in their life they would otherwise not.

On August 14, 2017, the American Bar Association adopted Resolution 113, urging states to:

(1) amend their guardianship statutes to require that supported decision making be identified and fully considered as a less restrictive alternative, before guardianship is imposed, and

(2) require that decision-making supports that would meet the individual's needs be identified and fully considered in proceedings for termination of guardianship and restoration of rights.

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Supported Decision Making will be giving the validity it deserves by putting this in statute. Making Supported Decision Making a law will retain the persons rights to make their own decisions. If it is law , it defines what a supporter is and what assistance the supporter can offer. By adding Supported Decision Making to the law establishes the legal framework for helping and supporting the Person to other agencies and professionals.

I want to thank you for your time and consideration for House Bill 1378.

Vicki L Peterson

vickiasdc@bis.midco.net

701-258-2237

701-527-2889

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3/6/19

#5 pg.1

Senate Human Services Committee:

In Support of HB 1378

I support Supported Decisionmaking as it will benefit a lot of people with and without disabilities.

Arlene Havig
Self Advocate
123 New Jersey Street
Bismarck, ND 58504
701-204-2121

3/6 NB 1378 #5 pg. 2

Senate Human Services Committee:

In Support of HB 1378

I am in support of Supported Decisionmaking. I use something similar right now with my other half. He has a Traumatic Brain Injury and is doing better and has a better outlook on life and is becoming more outspoken with support. This would help him be able to advocate for himself and I can assist him.

Linda Faith
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Lindafaith07@gmail.com

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Senate Human Services Committee:

In Support of HB 1378

Please support Supported Decisionmaking (SDM) as a law. I've thought about using this if it was a law, and I would like to use it in the future. Right now, it's hard for me sometimes to make choices, but I have friends and family that support and help me to make decisions, so they could use SDM with me.

Darcy Andahl
Self-Advocate
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701-934-2358

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Senate Human Services Committee:

In Support of HB 1378

Hi my Name is Sheryl Beard. I live in Williston N.D. I work 5 day a week. I am a self-advocate and involved with several different organizations. My passion is making a difference in the world. Doing the right thing for people with disabilities. I do have dreams. These are my dreams. To be included in a community. Seeing people with disabilities be more accepted by people. I am my own guardian I need advice like anyone else.

Support Decision Making in place will help people have control of their life and their choices. Please take time look at- Jenny Hatch Supported Decision Making. There are 12 States that now have as a legal statement in law. To learn more about Support Decision Making, this is everyone's right to make their own choice. Person with a disability have right live the way they choose and those that may need that bit of help to find answers or information on anything that may affect their lives. I know you have question on why on Decision Making HB 1378 need be in Law for the simple reason as an alternative to guardianship. If it is a statute, then it is less likely to be overlooked and forgotten. This is a less restrictive alternative, if it were to be you would you want to able make decisions for yourself or not have that option.

Links to Jenny Hatch videos

<https://www.youtube.com/watch?v=ict5ahgrO5M&feature=youtu.be&list=PLKdIRbjdmxgeDSVBZhEFyrzIli9zjO3Mc>

Sheryl Beard
Self-Advocate
505 12th St. W
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701 770-3405

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Senate Human Services Committee:

In Support of HB 1378

Guardianship is a legal proceeding that strips an individual of multiple or ALL rights. People under guardianship cannot make their own choices about: where they live; where they work; what kind of medical care they get – or whether they will get any medical care; what they eat; who they spend time with; and whether they will get married.

With such a major deprivation of fundamental liberties, it is important to have a rigorous process to evaluate whether a guardianship is needed, and how to limit its reach. Even though guardianship has serious, life-long consequences, it is often imposed as a matter of course. Parents are frequently told that they *have* to get guardianship over a child with a disability turning 18, if they want to continue to help with education plans and medical treatment. This condemns an adult with a disability to a perpetual childhood – first parents make all decisions, and then, when the parents are no longer able to serve, a stranger may be appointed to make every choice for the individual.

Guardianship is not the only option.

Supported Decision-Making is an alternative model, where people with disabilities keep their rights and their decision-making capacity. Instead of having a guardian make choices *for* them, people with disabilities have supporters who *help* them make *their own* choices. A person using supported decision-making appoints trusted advisors, such as friends, family, or professionals, to serve as supporters. The supporters help the person with a disability understand, make, and communicate his/her own choices.

This model empowers people to have control over their own life; to pursue their own destiny and celebrate their independence.

Julianne Horntvedt

Executive Director, The North Dakota State Council on Developmental Disabilities

1500 E. Capitol Ave.

Bismarck, ND 58501

701-328-4847

Senate Human Services Committee:

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In Support of HB 1378

Hi! My name is Steven Beard and I live in Williston. I am a person with a disability and an advocate. I am not sure if you have heard of a group called ALL (advocates Leading their Lives) non-profit group of which I am the President. I was and am a member of the steering committee that drafted this legislation that is before you as this time. I and others of the steering committee feel that it is time for this as an alternative to guardianship as it may help lower those that are in a guardianship now that have the ability to make their own decisions with some help in gathering the info they may not know how to find get or understand once they do find it. With the help of a person they trust, they can get help and understanding to make the decision on the own. Those of us in the so-called normal world use this concept more than we realize. If you go to someone and ask them a question about money options that is the same as SDM you are gathering info so that you can make a better-informed decision. This is what this bill is about, letting people with disabilities make their own mind up about how they want to live, die, spend their money or health care. Let's keep those guardianships for those that really need it.

Steven Beard
Self-Advocate
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Williston, ND 58801
701 770-3405

Senate Human Services Committee:

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In Support of HB 1378

I support this bill because I think it would be helpful for younger people to use this as they turn 18. I had a guardianship when I was young, once I turned 18. I did not make decisions for myself. I had to go to court to get rid of my guardian. I am now my own guardian and I am 27. I use friends for help all the time. I would like to use them as my official "supporters" if this bill passes. I think this system works well for those who don't need guardians.

Trevor Vannett
Self-Advocate
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Senate Human Services Committee:

In Support of HB 1378

I am in support for this bill because it allows people to get help, but not full help, like a guardianship. Sometimes guardians take away choices, we are strong people and should have choices. With supporters we can do anything like anyone can.

Cynthia Kyle
Self-Advocate
418 Oakland Ave S.
Fargo, ND 58103
701-202-2019

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Senate Human Services Committee:

In Support of HB 1378

With Supported Decisionmaking, we get the chance to make our own decisions. I took Partners in Policymaking in the past and learned how to make my own choices. I had a guardian for a few years, then was able to become my own guardian. If I have people in my life to help me make decisions, I don't need a guardian. If this bill becomes a law, these people can become official in my life. I don't make decisions in haste, I take time to make decisions and talk to people in my life about them.

Darrel Wahl
Self-Advocate
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701-838-3737

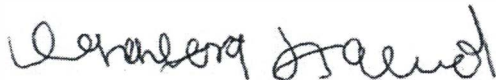
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SUPPORTED DECISION MAKING BILL HB 1378

Dear all Senators,

My names is Samantha Aalund and I live in Minot, ND. I'm writing to you about HB 1376- the supported decision-making bill as an alternative to guardianship for people with disabilities. This bill will be good for people who don't already have guardians and would make it easier for families that aren't comfortable taking a guardianship role.

Thank you for the work that you do,

A handwritten signature in black ink, appearing to read 'Samantha Aalund', written in a cursive style.

Samantha Aalund

1101 11th Ave SE

Minot, ND

Samatha.aalund@gmail.com

Senate Health and Human Services

HB 1378

March 6, 2019

Madam Chair Lee and members of the committee, my name is Kirsten Dvorak. I am the executive director of The Arc of North Dakota, which includes all six Arc chapters in the state: Bismarck, Bowman, Dickinson, Fargo, Grand Forks, and Valley City. Our mission is to improve the quality of life of people with intellectual and developmental disabilities (I/DD) and actively support their full inclusion and participation in the community.

The Arc of North Dakota supports HB 1378 and believes that this is a valuable tool in helping individuals with disabilities to have full participation in their own personal lives.

As a parent of an adult with Autism, this tool would help him in making decisions about his life. This would allow him to decide whom he would like to help him make decisions about his life, such as a parent, cousin or a friend that he trusts. As one of his supporters, this would allow me to help him gather information and to explain that information in a way that he could understand and make the decision for himself.

The personal autonomy, liberty, freedom, and dignity of each individual with I/DD must be respected and supported. Legally, each individual adult or emancipated minor is presumed competent to make decisions for himself or herself, and each individual with I/DD should receive the preparation, opportunities, and decision-making supports to develop as a decision-maker over the course of his or her lifetime.

Kirsten Dvorak, Executive Director

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#7 pg. 1

HB 1378
Senate Human Services
Wednesday, March 6, 2019

Madam Chair Lee and Members of the Senate Human Services Committee:

My name is Roxane Romanick and I'm representing Designer Genes of ND, Inc., as their Executive Director. Designer Genes' membership represents 220 individuals with Down syndrome that either live in our state or are represented by family members in North Dakota. Designer Genes' mission is to strengthen opportunities for individuals with Down syndrome and those who support them to earn, learn, and belong.

I am here today to ask for a "do pass" on HB 1378. Adults living with Down syndrome will benefit from a broader continuum of supports for help with decision-making and we are grateful for the work of the bill sponsors and task force that has moved this bill forward. While the concept of "dignity of risk" sounds good in theory, many of us, as parents and siblings, worry about the vulnerabilities that come with living with an individual with intellectual disability. Typically, family members and/or loved ones of individuals with Down syndrome turn to guardianship as the only alternative. For many of us, this step feels counterintuitive to the work of independence, growth, and inclusion during childhood and adolescence.

Creating intentionality around making decisions and providing education to individuals with Down syndrome and other intellectual disabilities is important, but so often can be neglected. Individuals with Down syndrome are often victims to lowered expectations and do not have the opportunity to "learn" because people believe they can't. Given the opportunity and needed accommodations, making choices about options and desires is possible. Jenny Hatch, a young woman with Down syndrome, who challenged her guardianship and was granted the opportunity to live with people she chose versus a group home her parents chose, was one such individual. She was one of the sparks needed to move the supported decision-making option forward.

Here is a text that I received from my daughter who lives with Down syndrome about a month ago: "Mom, I will be working on my scholarship by myself with my friend, Hannah. Do you think I should use my Minot

State address or our home address? Don't worry about this, I have it taken care of. Can you send the login to my bank account, so I can see how much money I have?" I shudder to turn over the possibility of up to a \$5000 scholarship application over to her, but I am also exceedingly proud of the display of independence that she's exhibiting. Elizabeth deserves the supported decision-making option in ND, and no one should assume that she needs a guardianship just because she was born with a diagnosis of Down syndrome.

Formally recognizing supported decision-making in ND will help us to think with more intention around supporting individuals with Down syndrome and other intellectual disability to make decisions, even those individuals who do have guardianship. I foresee additional training and education for both decision-makers and supporters. Thank you for your time. I'd be willing to answer any questions.

Roxane Romanick, Executive Director
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HB 1378 Testimony
Senate Human Services Committee
Senator Judy Lee, Chairman
March 6, 2019

Chairman Lee and members of the committee, my name is Matthew McCleary. I am the Youth Coordinator for North Dakota Federation of Families for Children's Mental Health (NDFFCMH), which is a parent-run organization focused on the needs of children and youth with emotional, behavioral, and mental health needs and their families. I am also the peer support Project Coordinator for Mental Health America of North Dakota (MHAND), which is a consumer-run organization whose mission is to promote mental health through education, advocacy, understanding, and access to quality care for all individuals.

On behalf of both NDFFCMH and MHAND, I am testifying in support of HB 1378. Supported decision making is an alternative to guardianship, but is not meant to be a replacement for guardianship. Supported decision making formalizes what many people do every day: consult with trusted sources in order to make a decision. In supported decision making, the supporter does not make decisions on behalf of an individual, they just help make sense of it all. As an aside, my brother, who also has a disability, did need a guardianship. The decision was not taken lightly and although it was the correct decision for him, it was no less devastating to him and his sense of independence and dignity. However, many people in North Dakota are unnecessarily in a guardianship and could use supported decision making instead.

There are many groups who can benefit from supported decision making: the elderly, people with complex medical issues, people with disabilities, and so on. Today I will highlight one that is close to my heart: people with disabilities who are college-bound. The journey to college is exciting and fraught with complex decisions and many small

tasks to complete just to continue being a college student. How do I apply to college? How do I get financial aid? How do I get housing or a meal plan? How do I sign up for classes? How many classes should I sign up for? What do I do if I am failing a course? What are these forms and why do I have so many of them?

When I made my transition to adulthood as a student with a disability, I was blessed to have a strong support network to help with understanding the world of higher education. But I was still away from home and there were many times I had a lot of questions about what to do, how to do it, and what the ramifications of each choice would be. Despite these challenges, I thrived in college. While I often made contacts with my parents and my Vocational Rehabilitation case manager, I was mostly able to adapt to my environment without much additional assistance. But my experience is not going to be like other people's experiences.

There are a number of youth I know, some of whom I have been fortunate enough to serve as a peer support, who need additional supports to make their own decisions. If they are young, these individuals may have parents who have never attended college or who have their own disabilities or other health challenges that make it difficult for them to provide assistance. Likewise, many youth may be attending a campus far enough away from home that can make it difficult for parents to provide support. If there are older individuals with disabilities entering higher education, some of the "natural supports" that exist for younger people may not exist for them.

People with disabilities often need additional supports to make it more likely that they succeed in life, but we also want to have supports that function as naturally as possible. Many of the youth I work with could use additional supports as they enter college, but they do not require guardianships. When they are going off to college, what they may need is someone to make things more understandable. The culture of higher education can assume that being "an adult" means that an individual student must be expected to navigate the entire system by themselves and that involving another person in that process is an indication you are not "growing up" or are somehow not a good fit for being

a college student. I happen to think that instilling that level of independence for a young person is a good thing, but sometimes it is not as helpful as we may think it is. Perhaps we forget the important details, maybe if the steps to solving a problem are complicated, we do not know how to do them. That is why it is useful for some people with disabilities to be able to have a supported decision making agreement and have a supporter help them out. Just as sometimes it is helpful to have someone else with you during a medical appointment, it can be helpful to have someone with you in an appointment at the college level.

Bringing supported decision making to North Dakota may also improve self-determination among youth with disabilities. Although special education has improved the fortunes of millions of people with disabilities, we have never given self-advocacy and self-determination its due. A national study of post-school outcomes for students with disabilities in the mid-2000s found that only 12% of special education students were leaders in creating their own post-school plans. Several years ago a study from Minot State University found that only 19% of North Dakota special education teachers have utilized student-led planning at least once—which means those teachers could be using it with all of their students, or just one. If supported decision making is spread throughout North Dakota and people become aware that more people with disabilities can make their own decisions, perhaps it is possible that services such as special education can encourage and better prepare youth with disabilities to exercise their own decision making skills.

People with disabilities have always had to use a form of moral suasion to convince people that we are capable of making decisions for ourselves. Sometimes that is respected, but other times it has not been. And people with disabilities find this exhausting to deal with on a daily basis. Formalizing supported decision making in state statute ensures that our institutions recognize when vulnerable populations use a process many of us use every day and provides North Dakotans more alternatives to guardianship. I urge this committee to support HB 1378 and bring supported decision making to North Dakota.

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Thank you for your time and I will answer any questions you have.

Matthew McCleary
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