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## Luther S. Olsen

State Senator

14th District

**TO:** Senate Committee on Workforce Development, Military Affairs and Senior Issues

**FROM:** Senator Olsen

**DATE:** January 10<sup>th</sup>, 2018

**SUBJECT:** Testimony for Senate Bill 552

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Thank you Chairman Testin and members of the Senate Committee on Workforce Development, Military Affairs and Senior Issues for holding a hearing and allowing me to testify in support of Senate Bill 552.

At some point in our lives we have all needed help making a well-informed decision. Whether it was about college, a career, a house, a new car, or healthcare. When making an important decision, we often ask questions and gather information from people around us that we trust or from people that are experts in their field.

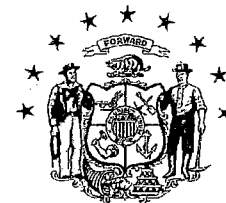
Often times, older adults and people with disabilities reach a point in their lives that they may need assistance in making a well-informed decision. Under currently law, if an adult or person with disabilities cannot make a decision on their own, their options are a Power of Attorney or Guardianship. Under both of these options, they would give someone of their choice some or all decision making authority for themselves. Many older adults and people with disabilities are capable of making decisions, but they need help to gather information to make a well-informed decision.

Senate Bill 552 would allow older adults or people with disabilities to create an agreement to allow another person to assist them in making a well-informed decision. This "supporter" would assist the adult in gathering information that is relevant to a medical, financial, or educational decision. This bill directs The Department of Health Services to provide access to a form that would need to be signed and dated before two adult witnesses or a notary. They will also be required to provide information regarding supported decision making.

This legislation will allow adults to continue to make their own decisions rather than giving up their ability to make the final decision just because they needed some assistance. Thank you members, I ask for your support on Senate Bill 552 and I am happy to answer any questions that you may have.

STATE REPRESENTATIVE  
**DEBRA KOLSTE**

44TH DISTRICT



WISCONSIN STATE ASSEMBLY

**Testimony of State Representative Debra Kolste**  
**Senate Bill 552: Supported Decision-Making Agreements**  
**Senate Committee on Workforce Development, Military Affairs and Senior Issues**  
**January 10, 2018**

Thank you, Chairman Testin, Vice-Chair Feyen, and fellow committee members, for holding a public hearing on SB 552. This bill would authorize the creation and implementation of supported decision-making agreements for people with disabilities and the elderly.

Currently in Wisconsin, individuals that need assistance with decision-making have very clear, but limiting, options. They can enter into a power of attorney arrangement or choose a limited or full guardianship. Each of these three options either restricts or removes entirely their authority to make decisions and places that power with someone else.

Supported decision-making agreements would provide a much needed additional option for older adults and people with disabilities that would allow them to retain independence while still receiving advice or guidance.

An individual would choose a supporter – likely a trusted relative, friend, or persons with expertise in a specific area - to help them gather information, understand options, and communicate decisions to others. With supported decision-making, the supporter may give advice, but the individual makes the final decision.

Supporters can help with decisions regarding housing, health care, or financial affairs, to name a few. The agreements can also be used in conjunction with a power of attorney so that independence is maintained in certain areas while other decisions are handled by a legal surrogate or guardian.

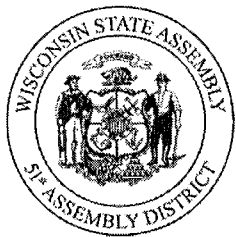
SB 552 outlines the items that the Department of Health Services (DHS) would include as part of a decision-making agreement. DHS would then be required to provide access to this agreement in paper and electronically.

We are pleased to have AARP, Disability Rights Wisconsin, and Magellan Health registered in support of this legislation.

Thank you for your consideration of SB 552 - including supported decision-making as a legally recognized option for older adults and people with disabilities. I, respectfully, ask for your support of this bill.

A handwritten signature in cursive script that reads "Debra Kolste".

Deb Kolste  
44<sup>th</sup> Assembly District



# TODD NOVAK

STATE REPRESENTATIVE • 51<sup>ST</sup> ASSEMBLY DISTRICT

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January 10, 2018

## SB 552

Thank you Chairman Testin and members of the committee for allowing me to testify in favor of Senate Bill 552 which allows individuals with disabilities to enter into a Supported Decision-Making agreement with a friend or family member. These agreements are to be viewed as an additional option and alternative to guardianship for those who require additional help with important decisions related to healthcare, finances, or any other significant decision that is made on a day to day basis.

The decision to co-author this piece of legislation was easy. I currently serve as a court appointed guardian in Iowa County. This position requires me to make difficult decisions for people, often at a point where they have little involvement in the decision making process. Had these individuals been given the opportunity to enter a supported decision making arrangement with a friend or family member, many of the cases I dealt with could have been avoided.

Currently, there are no options available that span such a wide variety of topics and do not take away the individual's right to make the final decision. A guardianship agreement restricts the ability of the individual to make their own decisions and Powers of Attorney do not involve issues beyond distinctive categories such as financial and health care. It is important to note that these alternate arrangements can be used alongside Supported Decision Making Agreements – they are not mutually exclusive. Under supported decision making, the areas affected by the arrangement are flexible and can change based on the individual's decision-making capacity. Each agreement can be tailored to the needs of the person's wishes.

Supported Decision Making agreements require that the individual for whom the agreement is made remain in charge of the final decision. The supporter is there simply for to provide advice and assistance in the capacity requested by the individual. This legislation is necessary so that professionals such as bankers and physicians are able to share information to the individual providing support.

This bill has received support from numerous organizations including AARP, Disability Rights Wisconsin, and the Wisconsin Board for People with Disabilities. States like Texas and Delaware have already enacted legislation similar to this and more states plan to do so in the near future.

Thank you

Todd Novak

Re: SB 552 Supported Decision-Making

Good Morning Senators,

Thank you for the opportunity to provide public comment in support of SB 552. Supported Decision-Making can help a lot of people with disabilities and their families.

People with disabilities want the same things as everyone else; a job they enjoy, a comfortable place to live they can take pride in, relationships with people they like, the right to vote, and the ability to do or buy things that they want. But too often, families are advised—often when a child is just 17—to obtain guardianships over people with disabilities, which takes away some or all the person's civil rights to make decisions.

When I turned 18 and was getting things set up as an adult. My mother was advised by the Social Security Administration to become my payee for my SSI (Supplemental Security Income). We let them do it. By doing this I felt like a person that had to wait for my payee to go to the bank and cash my check. Or have my payee give me an allowance like a child. After a few months we went back to the Social Security Administration to get the checks put in my name and open a checking account in my name. This is one example in my life where we need to have a choice other than guardianship.

No one makes perfect decisions, certainly not at age 18. But that is exactly the age where many youth with disabilities decision-making capacity is evaluated, and once a guardianship is granted it is rarely changed. People with disabilities can acquire new skills and decision-making capacity throughout their lives. Yet, guardianship is used first and almost exclusively when it should be used last and rarely.

As Vice President of People First Wisconsin, our board hears at our state meetings how restrictive guardianships are for our members. We have had a few of our members get their guardianship removed. One of the biggest rights that they get back is the right to vote and are using the Supported Decision Making tool.

Even though under the law people are presumed to be competent to make their own decisions, however often the first questions a person with a disability is asked by service providers and others is "who is your guardian?" They see the disability, not the person, and automatically assume that someone else—a guardian—makes decisions for them.

People with disabilities can make their own decisions, but they may want support. Not someone to make decisions for them, but to help them understand their options, get information, or communicate their decisions to others.

Did you know that being able to make your own decisions leads to a higher quality of life? Studies show that people with disabilities who have more control of their lives and are more self-determined are:

- healthier
- more independent
- more likely to be employed at a higher-paying job
- better able to avoid and resist abuse

Supported Decision Making provides support as people make decisions and facilitates greater independence. SB 552 gives families and people with disabilities a new option that lets the person with a disability retain their rights to make their own decisions and choose who they want to help them (a Supporter) and the types of decisions they want help with. This bill will benefit many people and their families.

Thank you

Ginger Beuk

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WISCONSIN BOARD FOR PEOPLE  
WITH DEVELOPMENTAL DISABILITIES

January 10, 2018

Senate Committee on Workforce Development, Military Affairs, and Senior Issues  
Senator Testin, Chair  
State Capitol, Room 131 South  
Madison, WI 53707

Dear Senator Testin and members of the committee:

Thank you for the opportunity to provide public comment in support of SB 552, which formally recognizes supported decision-making (SDM) as a legal option that people with disabilities and older adults can use to retain their rights to make their own decisions, select who they want to help them (a Supporter) and the types of decisions they want help with, and define what assistance a Supporter can give (information gathering, access to records, helping the Person understand options, and communicating the Person's decisions to others). SDM can be used for any decisions the Person feels they need additional support—such as housing, health care, financial affairs, employment, or other areas the Person identifies.

The Wisconsin Board for People with Disabilities (BPDD) strongly supports SB 552, and believes that the addition of SDM as a legal alternative to guardianship will benefit many people with developmental disabilities, their families, and ultimately the state. Our board considers SDM to be so important to furthering people's independence and ability to make choices about their lives that it is one of two public policy issues emphasized in our federally required five-year state plan.

SDM is a fundamental part of Self-determination. People with greater self-determination are: healthier, more independent, more well-adjusted, and better able to recognize and resist abuse (safer)<sup>1</sup>.

Nationally, disability organizations, attorneys, courts, and state legislatures are recognizing the value of SDM as an alternative to guardianship. SDM has been endorsed by the U.S. Department of Health and Human Services' Administration for Community Living, which funds the National Resource Center for Supported Decision-Making, and has gained international recognition, notably in the United Nations Convention on Rights of Persons with Disabilities (CRPD).

The American Bar Association adopted a Resolution August 14, 2017 encouraging the use of Supported Decision Making as an alternative to guardianship, and specifically urged states to revise their statutes to include supported decision-making as a legally recognized option. Texas and Delaware have already enacted supported decision-making legislation, with legislation pending in Tennessee. Indiana, Maine, and North Carolina are also exploring Supported Decision-Making legislation.

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<sup>1</sup>Wehmeyer, Palmer, Rifenburg, & Little 2014; Powers et al., 2012; Khemka, Hickson & Reynolds 2005; Wehmeyer & Palmer, 2003; Shogren, Wehmeyer & Schwartz, 1997 & 1998; Wehmeyer, Kelchner, & Reynolds 1996

Under Wisconsin law, all adults are considered to have the capacity for decision-making. But too often, families of people with Intellectual or Developmental Disabilities (I/DD) are advised—often when a child is just 17—to obtain guardianships, which takes away some or more commonly all of the person’s civil rights to make decisions about their lives. No one makes perfect decisions, certainly not at age 17-18. But that is exactly the age where many youths with disabilities’ decision-making capacity is evaluated, and once a guardianship is granted it is rarely changed.

People with disabilities can acquire new skills and decision-making capacity throughout their lives. Everyone, no matter their limitations, needs opportunity, experience, and support in order to learn how to make well-informed decisions. SDM can provide support as the person practices making decisions, and SDM agreements can be updated easily as the Person’s ability and capacity to make decisions changes over time.

Unfortunately, guardianship is used first and almost exclusively for people with I/DD when it should be used last and rarely. Parents routinely tell us that guardianship is presented as the only option, and is portrayed as administrative process rather than a decision that has permanent legal ramifications for both the individual and families.

BPDD focus groups on SDM found that many parents were unaware of the role and responsibilities of a guardian, did not feel their children were legally incompetent, but also felt that guardianship was expected and were unaware of alternatives. Our focus groups also found that if SDM was an option many families would have tried it first, and that it would have helped them evaluate whether a guardianship was needed.

Formally establishing SDM agreements as a legal expression of an individual’s wishes gives Professionals a document they can rely on and establishes a legal framework for Supporters to document their role in helping the Person to others (bankers, state agencies, other professionals, etc.). Even though under the law people are presumed to be competent to make their own decisions, often the first question a person with a disability is asked by service providers and others is “who is your guardian?” They see the disability, not the person, and automatically assume that someone else—a guardian—makes decisions for them.

Formalizing SDM within Wisconsin’s statutes provides a needed continuum between no support and full guardianship. SB 552 will result in greater independence, self-determination, and community inclusion for people with I/DD, and we urge the committee to advance this bill to the full Senate.

BPDD is charged under the federal Developmental Disabilities Assistance and Bill of Rights Act with advocacy, capacity building, and systems change to improve self-determination, independence, productivity, and integration and inclusion in all facets of community life for people with developmental disabilities.

Our role is to seek continuous improvement across all systems—education, transportation, health care, employment, etc.—that touch the lives of people with disabilities. Our work requires us to have a long-term vision of public policy that not only sees current systems as they are, but how these systems could be made better for current and future generations of people with disabilities.

Thank you for your consideration,

A handwritten signature in cursive script that reads "Beth Swedeen".

Beth Swedeen, Executive Director, Wisconsin Board for People with Developmental Disabilities



The Arc Wisconsin  
P.O. Box 201  
Stoughton, WI 53589

T 608.422.4250  
Lisa Pugh, State Director  
pugh@thearc.org  
arcwi.org

January 10, 2018

To: Senator Testin, Chair  
Members, Senate Committee on Workforce Development, Military Affairs and Senior Issues

From: Lisa Pugh, Executive Director

Re: Senate Bill 552, Supported Decision-making Agreements

Position: Support SB 552

The Arc Wisconsin is a statewide organization that advocates for and with people with intellectual and developmental disabilities (I/DD). We have 15 local Wisconsin chapters and are connected to a network of more than 650 chapters across the country. The Arc is the oldest and largest disability rights advocacy organization in this state and in the nation.

The Arc is one of the original proponents of Supported Decision-Making nationally, and has been actively promoting the adoption of supported decision-making legislation in states like Wisconsin that have high rates of guardianship. In Wisconsin, there were more than 38,000 active guardianships in 2015.

The Wisconsin Guardianship Association indicates that guardians are:

- Court-appointed and bound by statute
- An advocate for the ward
- A surrogate decision-maker
- A coordinator of services
- A financial planner

A Guardian is Not...

- A caregiver
- A companion
- A service provider
- A warden
- A reformer
- A savior
- A substitute family

These categories leave out one important area that we hear many people with disabilities need and want, a supporter to help them make their own decisions.



Due to the seriousness of the loss of individual rights, guardianships are and should be considered only as a “last resort.”

The Arc’s renewed position statement on guardianship indicates that State laws should be reformed to prioritize less restrictive alternatives to full and partial guardianship, including without limitation informal supports, supported decision-making, limited (and revocable) powers of attorney, health care proxies, trusts, and limited guardianships that are specifically tailored to the individual’s capacities and needs. These alternatives should always be considered first.

### **Supported Decision Making Facts**

- All people use Supported Decision Making (SDM) to make important life decisions for such things as financial decisions, buying a house or car, car repairs, education or choices in medical treatments.
- Supported Decision Making empowers individuals with disabilities who are capable of making decisions to use available supports to make their own choices and live a self-directed, independent life.
- Even if a person with a disability needs extra help to make significant life decisions, their right to make their own choices should not be taken away (such as guardianship) without exploring all options and less-restrictive alternatives.
- Supported Decision Making does not replace more formal substitute decision making legal structures, such as Advanced Health Care Directives, Powers of Attorney, or guardianships.
- Supported Decision Making is one more alternative, another tool in the toolbox, and would be the least restrictive option, enabling people to use their own support systems and family to obtain information and make decisions instead of having someone else make decision for them.
- Supported Decision Making agreements formalize the use of these support structures to obtain and assess information to make decisions.
- Supported Decision Making agreements would be less costly to both the State and the consumer by avoiding expensive court process and unnecessary legal fees.
- Under a Supported Decision-Making agreement the supporter can:
  - Obtain and understand information relevant to his or her decisions.
  - Help the individual understand the options, responsibilities, and consequences of his or her decisions.
  - Communicate decisions to the appropriate people.
  - Assist in, but not make decisions for, the individual that has chosen them for guidance.
- Supported Decision Making legislation has been enacted in Texas and Canada, and is being considered worldwide.

Many guardianships in Wisconsin are instated when a youth with disabilities turns 18, often at the direction of the school to parents as a means to remain involved in the youth’s special education planning. This is unnecessary and problematic because parents are often provided with little information and no alternatives. An 18-year-old youth (with or without disabilities) is rarely a fully mature decision-maker, but should not be stripped of basic rights. A provision of SB 552 that The Arc has strongly advocated for is the final section which would require that schools provide both the youth and parents with information on supported decision-making as an alternative to guardianship.

Thank you for considering this important legislation.

People First Wisconsin



See Our dsAbility

## **Testimony: Cindy Bentley, People First Wisconsin Senate Bill 552 -support**

January 9, 2018

People First wants people with disabilities to have the the same rights as everyone else.

I used to have a guardian. I was very lucky to have a good guardian who helped me until I was independent, and we dissolved her guardianship when I was ready. She let me make mistakes and I learned from them. Everyone should have the chance to mess up and make good decisions on their own. Sometimes guardians are too controlling over people with disabilities and they never get this chance.

I have had a lot of Health issues in the past and I the best team of doctors – the cancer doctors all the way down to my general doctor. They all take the time to listen to me. For example, the reason I cannot be here today is that I must get tubes in my ears to help me with some of the problems I have been having trouble with my hearing. Even at 60 years old I am very healthy, but just like everyone else, I have things that come up. It is good that I have doctors who listen to me now, so we can take care of them right away. My sister also goes with me when I need her to, but the communication is always with me first. This is the way it should be for everyone – many of our People First members have been talked over at the doctor's office or their doctors talk to their guardians instead of them. Everyone should have a good relationship with their doctors and health professionals.

Most people under guardianship, you cannot vote. I want to be able to vote and so do all the members of People First. Supported Decision Making wouldn't take that important right away like guardianship does. People under guardianship have fewer rights than people in prison. Felons who have committed serious crimes and put people in danger can make more decisions than people with disabilities. Does that seem fair?

In closing, everyone needs a little support. People with disabilities are just like everyone else in this way. Please help them be able to have all the rights of citizenship as everyone else and stop pushing schools and families towards guardianship.

Sincerely,

**Cindy Bentley**

Executive Director  
People First Wisconsin

***ATTACHMENT: People First Supported Decision-Making Position Paper***

# People First Wisconsin Wants Supported Decision-Making

People First Wisconsin



See Our dsAbility

## Our Position on Guardianship

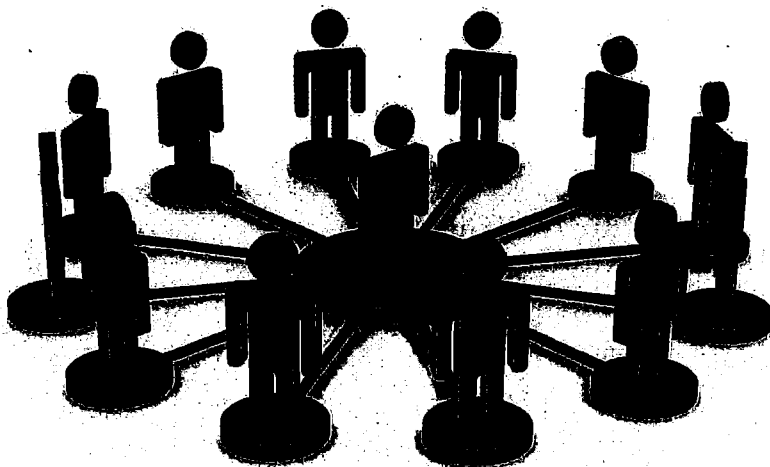
People First Wisconsin believes that people need more choices other than just guardianship in Wisconsin. Sometimes guardians have too much control over people's lives. Guardianship should be the last choice.

## What problems do people with disabilities have with guardianship?

- Guardianship takes away rights that are important to people, including the right to vote.
- Guardianship is hard to change.
- Schools tell parents to get guardianship when a child turns 18. This lasts a lifetime.
- Some places (like banks, doctor's offices) do not respect that a person with a disability can make their own decisions.



## Why do People First members think Wisconsin should have Supported Decision-Making?



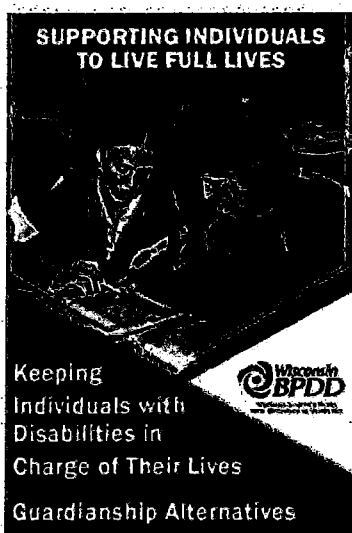
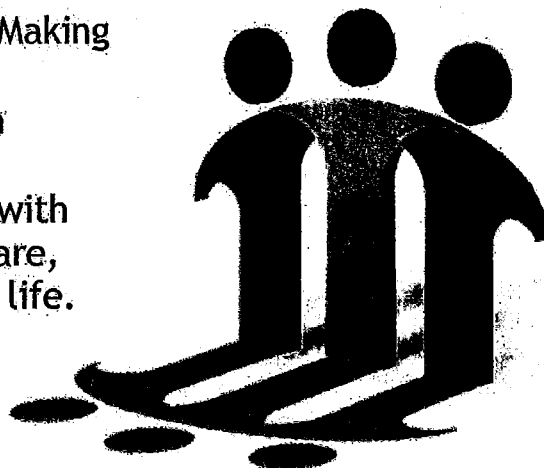
Supported Decision-Making is really practicing Self-Determination.

People with greater self-determination are:

- Healthier
- More independent
- Better able to recognize and resist abuse (safer)

## What is Supported Decision-Making?

- Many states are passing Supported Decision-Making laws.
- With Supported Decision-Making people with disabilities are in charge of their decisions.
- Supported Decision-Making can help people with important decisions about housing, health care, money, employment, or other areas in their life.
- The person with a disability can choose any trusted person to be their Supporter.
- The person with the disability is always the final decision-maker (not the Supporter).



### Ways to Learn More about Supported Decision-Making

- Video: [https://youtu.be/rBNL\\_R4sJPo](https://youtu.be/rBNL_R4sJPo)
- Supported Decision-Making Toolkit: <http://wi-bpdd.org/index.php/SupportedDecision-Making/>

### Our Asks: Wisconsin Should Promote Supported Decision-Making

- Pass the Supported Decision-Making bill, Assembly bill 655 and Senate bill 552. This bill has many Republican and Democrat sponsors.
- Make sure that the Department of Health Services, Family Care and IRIS put policies in place to talk to people about Supported Decision-Making.
- Require training on Supported Decision-Making for case managers in the long-term care system and people at the ADRC.
- Make sure the Department of Public Instruction and schools do not tell parents to get guardianship for their kids at age 18. Talk to them about Supported Decision-Making.



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Lisa Pugh, State Director  
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January 10, 2018

To: Senator Testin, Chair  
Members, Senate Committee on Workforce Development, Military Affairs and  
Senior Issues

From: Lisa Pugh, Executive Director

Re: Senate Bill 552, Supported Decision-making Agreements

Position: Support SB 552

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- Supported Decision Making agreements formalize the use of these support structures to obtain and assess information to make decisions.
- Supported Decision Making agreements would be less costly to both the State and the consumer by avoiding expensive court process and unnecessary legal fees.
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  - Obtain and understand information relevant to his or her decisions.
  - Help the individual understand the options, responsibilities, and consequences of his or her decisions.
  - Communicate decisions to the appropriate people.
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Thank you for considering this important legislation.

# disabilityrights | WISCONSIN

Protection and advocacy for people with disabilities.

To: Senator Patrick Testin, Chair, Senate Committee on Workforce Development, Military Affairs, and Senior Issues

Senate Committee on Workforce Development, Military Affairs, and Senior Issues

From: Disability Rights Wisconsin, Mitchell Hagopian, Supervising Attorney

Date: January 10, 2018

Re: Testimony in Support of SB 552, supported decision-making agreements

As the Protection & Advocacy system for people with disabilities in Wisconsin, DRW strongly supports SB 552. This bill provides the means by which people with disabilities can formally engage the people they trust to help them make decisions about important issues in their lives.

Unfortunately, it is a sad reality that people with disabilities, particularly intellectual disabilities, are presumed by many in society to be incompetent and presumed to need a guardian. All too often, a young person with a mild cognitive disability gets a date with the probate court for her 18<sup>th</sup> birthday present. Rather than celebrating the independence that comes with reaching the age of majority, she instead has all of her rights stripped by a court that is not equipped to understand her.

I recently talked to a 17-year-old woman with an autism spectrum disorder and her mother. They had been told by their school district that it was imperative that mom petition for guardianship before her daughter turned 18 or risk so that she would not lose her right to make decisions for her daughter. There was nothing visibly disabled about this young woman. She was articulate and calm. I asked them if she had ever made any questionable decisions. The only thing either could think of was the purchase of somewhat pricey habitat maze for her pet ferret. Had she made the purchase with someone else's money or credit card? No. Did she have enough of her own money to pay for it? Yes. Where did she get the money? She had gotten a job and earned the money she used to pay for it. Was it a somewhat extravagant purchase? Possibly—in retrospect she thought maybe she should have saved the money for college. If this young woman needs a guardian—we all do.

Yet somehow, because she was in special education, her school counselors assumed that she had to have one.

This bill goes a small, but very important, way, toward preventing the unnecessary imposition of guardianships on people with disabilities. It allows people to formally designate the people they want supporting them. It gives the supporter a seat at the table when decisions are being made and allows the individual to consult with their supporter when they need it. It creates the expectation that the supporter will be allowed to participate, explain, and, when asked by the individual, offer advice about what to consider when making the decision.

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**RICE LAKE**

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Rice Lake, WI 54868

715 736-1232  
715 736-1252 FAX

disabilityrightswi.org

800 928-8778 consumers & family

From a legal perspective it is important to understand what this bill does NOT do.

- Most important, it does NOT transfer any decision-making authority to the supporter. The decision-making authority is always retained by the individual.
- It does NOT abrogate HIPPA or other statutes relating to confidential information. An entity in possession of confidential information can still require the individual to sign a release before the entity has to release information to the supporter.
- It does NOT open a door to financial or other abuse. As the P&A we have thought long and hard about this. Because the bill does not transfer any decision-making authority to the supporter, it cannot be used to access funds in bank accounts, apply for credit, engage in contracts or admit someone to a facility. We have consulted with our colleagues at Disability Rights Texas to see if there had been any increase in abuse of people with disabilities there since Texas introduced a sanctioned supported decision-making process. There has not. SB 552 is modeled on the Texas law.

What it DOES do is give the entity that is being approached by the person with a disability and their supporter (bank, school district, landlord, etc.) confidence that this person has taken self-protective measures—by engaging a supporter—and is going to make a decision that will not be questioned later.

DRW believes that guardianship plays a necessary protective role in the lives of vulnerable people with disabilities who lack the competency to make decisions. But guardianship should be the last resort—not the first. Supported decision-making fills a void in the continuum of capacity that starts with complete capacity and ends with guardianship. The bill creates a less restrictive alternative to guardianship that courts may consider before considering guardianship.

Thank you for the opportunity to provide input on this very important legislation, which will allow people with cognitive impairments maintain their liberty and retain their right to make decisions for themselves. It will give them the confidence that the person they choose to help them make decisions will be accepted and respected by the agencies with whom they are negotiating. SB 552 will fill an important gap in our current system while respecting the rights of older adults and people with disabilities the ability to make decisions about their lives.

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# disabilityrights | WISCONSIN

Protection and advocacy for people with disabilities.

To: Senator Patrick Testin, Chair, Senate Committee on Workforce Development, Military Affairs, and Senior Issues

Senate Committee on Workforce Development, Military Affairs, and Senior Issues

From: Disability Rights Wisconsin, Mitchell Hagopian, Supervising Attorney

Date: January 10, 2018

Re: Testimony in Support of SB 552, supported decision-making agreements

As the Protection & Advocacy system for people with disabilities in Wisconsin, DRW strongly supports SB 552. This bill provides the means by which people with disabilities can formally engage the people they trust to help them make decisions about important issues in their lives.

Unfortunately, it is a sad reality that people with disabilities, particularly intellectual disabilities, are presumed by many in society to be incompetent and presumed to need a guardian. All too often, a young person with a mild cognitive disability gets a date with the probate court for her 18<sup>th</sup> birthday present. Rather than celebrating the independence that comes with reaching the age of majority, she instead has all of her rights stripped by a court that is not equipped to understand her.

I recently talked to a 17-year-old woman with an autism spectrum disorder and her mother. They had been told by their school district that it was imperative that mom petition for guardianship before her daughter turned 18 or risk so that she would not lose her right to make decisions for her daughter. There was nothing visibly disabled about this young woman. She was articulate and calm. I asked them if she had ever made any questionable decisions. The only thing either could think of was the purchase of somewhat pricey habitat maze for her pet ferret. Had she made the purchase with someone else's money or credit card? No. Did she have enough of her own money to pay for it? Yes. Where did she get the money? She had gotten a job and earned the money she used to pay for it. Was it a somewhat extravagant purchase? Possibly—in retrospect she thought maybe she should have saved the money for college. If this young woman needs a guardian—we all do.

Yet somehow, because she was in special education, her school counselors assumed that she had to have one.

This bill goes a small, but very important, way, toward preventing the unnecessary imposition of guardianships on people with disabilities. It allows people to formally designate the people they want supporting them. It gives the supporter a seat at the table when decisions are being made and allows the individual to consult with their supporter when they need it. It creates the expectation that the supporter will be allowed to participate, explain, and, when asked by the individual, offer advice about what to consider when making the decision.

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## Why make Supported Decision-Making a law?

Adding Supported Decision-Making as a legally recognized agreement benefits older adults and people with disabilities, their support networks, and the professionals with whom they interact.

For older adults and people with disabilities, including Supported Decision-Making in the statutes means they have a new option that retains their right to make their own decisions, allows them to choose who they want to help them and the types of decisions they want help with, and defines what assistance a Supporter can give (information gathering, access to records, helping the Person understand options, and communicating the Person's decisions to others).

For friends, neighbors, extended family members or others who the Person selects as trusted Supporters, codifying Supported Decision-Making in the statutes establishes a legal framework for Supporters to document their role in helping the Person and that professionals can rely on as a legal expression of the Person's wishes.

Likewise, statutory language is needed so that doctors, bankers, and other professionals know that the Person has given the Supporter consent to hear, receive, and discuss information, and that the Supported Decision-Making agreement satisfies statutory privacy or other requirements to release records to the Supporter (if applicable).

## How is Supported Decision-Making different than Guardianship?

With Supported Decision-Making, older adults and people with disabilities remain fully in charge of their decisions. Limited and full guardianships restrict or remove entirely the Person's right to make decisions in some or all areas of decision-making.

Supported Decision-Making agreements can provide the Person with the support they need or want without losing their right to make their own decisions. For many people, Supported Decision-Making agreements may be the only tool they need.

Supported Decision-Making is flexible and can be updated easily as the Person's ability and capacity to make decisions changes over time, through gaining of experience and skills or acquiring additional functional impairments. Supported Decision-Making agreements can include more or fewer Supporters and types of decisions with which the Person wants assistance.

In contrast, guardianships are extremely difficult to change. For example, if guardianship is chosen for an 18-year-old with a disability, it may never be revisited or revoked, even if the young adult matures and becomes more capable.

Supported Decision-Making can be used in combination with other legal arrangements (including Power of Attorney or limited guardianship). These options are not mutually exclusive, and can be used to complement each other. For example, a Supported Decision-Making agreement can ensure the Person's

independence in certain areas of life while designating other decisions to a Power of Attorney or Guardian.

## Are other states using Supported Decision-Making?

Texas and Delaware have already enacted supported decision-making legislation, with Tennessee poised to pass legislation this session.

Additional states exploring Supported Decision-Making legislation include Indiana, Maine, and North Carolina. Virginia recommended Supported Decision-Making legislation in response to a study required by the state legislature. Vermont has established a Task Force on Supported Decision-Making.

The American Bar Association adopted a Resolution August 14, 2017, encouraging the use of Supported Decision Making as an alternative to guardianship, and specifically urged states to revise their statutes to include supported decision-making as a legally recognized option.

## Does Supported Decision-Making save money?

There is no cost to Supported Decision-Making legislation, and there may be some cost savings if the option to use Supported Decision-Making is chosen instead of more restrictive measures, like guardianships, that require a court process and frequently formal legal advice.

Families often incur legal costs (ranging from \$700 - \$1500) when pursuing a guardianship and each petition for guardianship goes through the court system. In addition to scheduling county court's time for a hearing, once a guardianship is granted there are ongoing reporting requirements and the court continues to have oversight over the Guardian/Ward.

Guardianships can also result in over reliance on paid public supports. Guardians may choose more restrictive and expensive settings due to ease of administration. Assistance provided by Supporters makes it possible for older adults to remain living at home longer, avoiding the need to move prematurely into institutional (and more costly) settings and preserving private resources.

In Wisconsin, there is currently no option for older adults or people with disabilities who want to retain all or some of their own decision-making authority over their life decisions, but need support to do that.

## Does information remain confidential under Supported Decision-Making agreements?

The bill limits access to personal information to only information that is relevant to the decision with which a Supporter has been asked to assist, and establishes clear parameters on how records protected by confidentiality can be accessed by a Supporter with the permission of the Person.

The bill requires Supporters to ensure all personal information they access in the course of fulfilling a Supported Decision-Making agreement is kept privileged and confidential and is not subject to unauthorized access, use, or disclosure.

## **Are people who use Supported Decision-Making at risk for financial or other exploitation?**

With Supported Decision-Making the Person is always in control of their own decisions and their Supported Decision-Making agreement; they can choose to revoke a Supported Decision-Making agreement at any time. Supported Decision-Making agreements are automatically revoked if the Supporter has a substantiated allegation of neglect or abuse of the person, the Supporter has been found criminally liable for abuse or neglect, or there is a restraining order against the Supporter.

Anyone who suspects that a Supporter is abusing, neglecting, or financially exploiting an older adult or person with a disability can report their concerns to the elder or adult at risk agency, or appropriate law enforcement agency.

## Testimony

### Senate Committee on Workforce Development, Military Affairs and Senior Issues

**Susan Fadness**

**January 10, 2018**

Hello. My name is Susan Fadness. Thank you for allowing me to testify today. I request the committee's support for two of the bills before you: Senate Bill 528, the Caregiver Tax Credit and Senate Bill 552, Supported Decision Making. I am a retired medical social worker who worked for the last 18 years of my career at UW Hospital and Clinics, assisting patients and families with discharges from the hospital. For over 10 years I also provided care and support for my mother, a retired school teacher, until she passed away at age 92.

In working with many older patients and families to facilitate safe and successful hospital discharges, often I would see the look of dismay when I explained that contrary to their beliefs, durable medical equipment, home modifications, medical supplies, assistance in the home would not be covered by Medicare, but was an out of pocket expense. For many low to moderate income people, this information was extremely stressful due to their fixed and low incomes that already were stretched to meet basic needs. When people returned for follow up clinic appointments or when hospitalized, we sometimes found that they had not gotten medication or supplies due to choosing to pay for utilities and other necessities verses care supplies and so on.

Family often stepped forward to help, but they too were trying to utilize their own limited income for their family needs as well as that of their parents and their own younger children. The Caregiver Tax Credit would assist those family members who do provide financial assistance. I know that even with my mother and the very small income she had, I often paid for the items she needed.

In Wisconsin there are 578, 000 unpaid family caregivers. Older adults, living in their own homes, need assistance to stay out of institutional care. We need to recognize caregivers by allowing a method of tax credit for caregiver expenses and promoting greater financial security in their own retirements.

Regarding Senate Bill 552, as a hospital social worker I often saw patients who due to illness had variable levels of ability to understand and carry out tasks. Having the option to designate a trusted "Supporter" who can gather information directly from providers and help sort through the information would have enabled patients to feel heard, understood and in control. Guardianship was often not needed, but patients routinely needed some assistance depending on the exacerbation and remission of the illness process. The need for and type of assistance also waxed and waned with the illness. The Supported Decision-Making Agreements bill fills the need for those patients in a simple and effective manner by allowing the flexibility needed to respond to changing conditions while respecting the patients' wishes.

Thank you for your time and attention.



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## Testimony

### Senate Committee on Workforce Development, Military Affairs and Senior Issues Helen Marks Dicks January 10, 2018

Good Afternoon. My name is Helen Marks Dicks and I am the State Issues Advocacy Director for AARP Wisconsin.

AARP Wisconsin has over 840,000 members over the age of 50 in Wisconsin. AARP looks at the impact of legislation on the 50+ population. We are supporting five of the bills on today's agenda mainly those concerned with caregivers and others that support people aging at home in Wisconsin. We do so because AARP Wisconsin has a strong interest in supporting Wisconsin's 578,000 unpaid family caregivers. They are Wisconsin's unsung heroes that make it possible for so many people to remain in their homes until the end of life. Some of these caregivers also serve both as official decision makers such as guardians and sometimes they assist their family members in making the decisions of daily life that can become overwhelming as we age.

On today's agenda there are five bills AARP has registered in favor of: SB 552, for supported decision making; SB 527, grants for Alzheimer's and dementia awareness; SB 548, establishing a palliative care council; SB 518 dealing with adult guardianship jurisdiction; and SB 528, the caregiver tax credit. I am going to restrict my comments to the three bills that are the most important to us, The Caregiver Tax Credit, The Supported Decision Making Bill and the Adult Guardianship Jurisdiction Bill.

All these are good bills but the best bill, and the one we give our most enthusiastic support to, is the Caregiver Tax Credit, SB 528. I have attached to my testimony an infographic about the costs to families in caring for a loved one. The out of pocket costs average around \$7,000 a year if you are reasonably nearby. If you are doing long distance caregiving it is close to \$12,000. Few people realize that except for Family Care/IRIS, which helps low income people and long-term care (LTC) Insurance which is not affordable for all, there are no programs that help people stay in their homes as they age and who require assistance to maintain their independence. Traditionally, government programs fund institutional care, which is expensive and often more care than a person needs. By supporting caregivers who are helping their family members stay in their homes, the care recipient, the caregiver, and the state all win. The caregiver is supported because the expense is a little less burdensome and the recognition of their difficult task is important. The care recipient benefits because they get to age in their homes as they wish, and the state benefits because it keeps people off taxpayer-supported programs.

Caregiving is truly a nonpartisan, nonpolitical issue. We are all going to be caregivers or care recipients at some time in our lives. A modest tax credit will recognize and support these unsung heroes while softening the financial impact of their efforts.

The need for this bill is best told by the stories of the caregivers themselves and professional who work with caregivers. Susan Fadness, one of our AARP Advocates from Madison, who was herself a caregiver and worked as a hospital social worker doing discharge planning, will be sharing her story and perceptive.

The second bill I would like to address is the SB 552 creating supported decision agreements. You will hear testimony today from representatives in the advocacy community for people with disabilities and from people with disabilities themselves. I agree that these supported decision making agreements can be used to assist people in learning to make decisions themselves. But for the aging populations they serve a very different purpose. One of the challenges of aging is admitting that you need assistance in areas that you used to handle yourself without support or even sometimes input from others. With the growing complexity of the world at a time when our capacities may be dimming, this bill not only gives us older people a way to request support but also gives us a vehicle to acknowledge the need for help and start the discussion with family and friends. It normalizes the request to our family and friends to go with us and help us when decisions become complex or a painful reminder of our limitations.

And finally, the Uniform Adult Guardianship Jurisdiction Act brings us in line with other states in dealing across state lines on issues of guardianship without compromising our unique protective system. AARP Wisconsin would like to thank the Elder Law Section of the State Bar of Wisconsin for working on this. I also served on the Elder Law's Committee and will leave it to them to take the lead on testifying in this area because of their expertise.

We hope these five bills, with particular emphasis on the Tax Credit, Supported Decision Making and Guardianship Jurisdiction move forward and become law this session. They are good for caregivers, their families and their supporters. And I would like to have them all in place so that someday all of us may benefit from them, if necessary.

If you have questions about this or any other legislative position taken by AARP Wisconsin, please feel free to contact me at 608-286-6337 or by email at [hmdicks@aarp.org](mailto:hmdicks@aarp.org)

# REPORT SPOTLIGHTS FINANCIAL TOLL OF FAMILY CAREGIVING

Credit for Caring Act Could Help

# \$6,954

Average Out-of-Pocket Expenses for Family Caregivers in 2016

## Family Caregivers in the U.S. Provide \$470 Billion in Unpaid Care

Source: Valuing the Invaluable 2016 Update: Undeniable Progress, but Bigs Gap Remain, AARP Public Policy Institute

# \$11,923

Average Out-of-Pocket Expenses for Long-Distance Caregivers in 2016

More than three in four family caregivers (78%) are incurring out-of-pocket costs as a result of caregiving.

# 78%

# 20%

Family caregivers are spending, on average, nearly 20% of their income on caregiving activities

### AFRICAN AMERICAN

# \$6,616

Average Out-of-Pocket Expenses in 2016

# 34%

of Income Spent on Caregiving Activities, on Average

### HISPANIC/LATINO

# \$9,022

Average Out-of-Pocket Expenses in 2016

# 44%

of Income Spent on Caregiving Activities, on Average

### ASIAN AMERICANS & PACIFIC ISLANDERS

# \$2,935

Average Out-of-Pocket Expenses in 2016

# 9%

of Income Spent on Caregiving Activities, on Average

**AARP** Real Possibilities

Source: Family Caregiving and Out-of-Pocket Costs: 2016 Report [aarp.org/caregivercosts](http://aarp.org/caregivercosts)

To learn more about the Credit for Caring Act (H.R. 2505/ S. 1151) visit [aarp.org/supportcaregivers](http://aarp.org/supportcaregivers)



# Valuing the Invaluable: Putting a Dollar Value to Family Caregiving

In 2013, about **40 million** family caregivers in the United States provided an estimated **37 billion hours** of care. The estimated value of their unpaid service was approximately **\$470 billion**.

HOW DOES FAMILY CAREGIVING COMPARE?  
2013-2014 in billions

Walmart Annual Sales \$477

Family Caregiving estimated value \$470

Combined Annual Sales \$469

Apple, IBM, Hewlett Packard and Microsoft

Total Medicaid Expenditures \$449



## TIME COMMITMENT



Caregivers spend an average of  
**18 hours per week**  
providing care to a family member.

**60%** Family caregivers caring for an adult while employed full or part time.

Provide **21+ hours** of family care per week while working a job.

**22%**

## FINANCIAL COMMITMENT



**68%**

Family caregivers who say they have to use their own money to help provide care to their relative.

**39%**

felt financially strained.

## EMOTIONAL COMMITMENT

**55%**

Caregivers who felt overwhelmed by the amount of care needed for a family member.



## WORK COMMITMENT

**1 in 4 workers age 25+** are family caregivers.



**72%**

workers 40+ that say allowing work flexibility for caregiving would help improve work/life balance.



Greater Wisconsin  
Agency on Aging Resources, Inc.



January 10, 2018

To: Senator Testin, Chair  
Members, Senate Committee on Workforce Development, Military Affairs and Seniors Issues

From: Janet Zander, Advocacy & Public Policy Coordinator  
Greater Wisconsin Agency on Aging Resources, Inc. & the Wisconsin Aging Advocacy Network

Re: Support for Supported Decision-Making Agreements Bill – SB 552 & Support for Alzheimer's and Caregiver Bills – SB 518, SB 527, SB 528, & SB 548

Good day, Chairman Testin, Vice Chair Feyen and members of the Committee. I am Janet Zander, Advocacy & Public Policy Coordinator for the Greater Wisconsin Agency on Aging Resources (GWAAR), one of three Area Agencies on Aging in Wisconsin. I am also here representing the Wisconsin Aging Advocacy Network (WAAN), a collaborative group of individuals and associations – including Wisconsin's three Area Agencies on Aging and other professional associations representing Wisconsin's senior centers, nutrition directors, aging units and Aging & Disability Resource Centers (ADRCs), Benefit Specialists, Adult Day Services, the Alzheimer's Association and the Wisconsin Institute for Healthy Aging (WIHA). This network of older adults and professionals work with and for Wisconsin's older adults to shape public policy that improves the quality of life of older people throughout the state.

I am speaking today in support of SB 552 regarding supported decision-making agreements, as well as in support of all four of the Alzheimer's and Caregiver Bills on the agenda for today's hearing – SB 518 regarding uniform adult guardianship jurisdiction, SB 527 regarding grants for Alzheimer's disease and dementia awareness, SB 528 regarding creation of a state caregiver tax credit, and SB 548 regarding establishing a palliative care council.

Our ability and capacity to make decisions changes over time. For some those changes are due to maturity, for others the changes may be due to functional impairments resulting from illness, injury, or conditions in which change may occur through the rehabilitation processes or progressive conditions. The Supported Decision-Making Agreements bill (SB 552) provides a legally recognized option for older adults and people with disabilities to remain fully in charge of making some or all of their own life-decisions by creating agreements that can easily be put into place by an older adult or person with a disability in response to their changing needs. These agreements with a trusted "Supporter" (of their choosing) allow individuals to receive any needed assistance with the decision-making process such as gathering information, understanding available options, and/or communicating their decisions. These agreements are flexible and as needs and circumstances change, so can the type and amount of agreements an individual chooses to have. Supported decision-making agreements do not replace Wisconsin's existing guardianship system; instead they can be used in combination with other legal arrangements such as limited guardianship or Power-of-Attorney.

With over half a million family caregivers in Wisconsin, and over 40 million nationwide, it is very likely many of us know someone who was/is providing care for a family member or we are involved in caregiving ourselves. I have worked in the aging network for over thirty years and have also been a caregiver for multiple family members. Family caregivers contribute great value to our society. The Alzheimer's and Caregiver bills recognize and support the vital role of family caregivers and work to improve the lives of those with Alzheimer's and related dementias and those with life-threatening illnesses.

The Uniform Adult Guardianship Jurisdiction bill (SB 518) would adopt the Uniform Guardianship Jurisdiction Act (passed in some version by 50 states and territories) into Wisconsin law and improve communication with people and courts in other states. This bill will clarify guardianship jurisdiction across state lines and offer vulnerable people additional protections from abuse and exploitation.

Currently over 115,000 people are living with Alzheimer's disease and related dementias in Wisconsin. This number is expected to increase to over 190,000 people in the next 20 years. The Alzheimer's Disease and Dementia Awareness Grants (SB 527) will help increase awareness of Alzheimer's disease and dementia in rural and underserved urban areas. This increase in outreach and awareness can help lead to a higher level of dementia screening, diagnosis, and treatment. Connecting individuals with Alzheimer's disease and their family members to information and resources early on, gives them the much-needed opportunity to plan and prepare.

More than three-quarters of all family caregivers experience out-of-pocket expenses related to their caregiving. On average, they spend about \$7,000 per year on caregiving expenses. For those who have needed to cut back on their work hours due to caregiving responsibilities, this can be especially financially challenging. For those who must leave the labor force early because of caregiving duties, the costs are much greater when caregiver expenses are combined with lost wages, lower Social Security benefits, and reduced pensions. The Caregiver Tax Credit (SB 528) creates a state income tax credit for family caregivers who have spent their own funds to meet the care needs of a family member. This bill sends a message that Wisconsin recognizes the valuable service provided by these caregivers and will offer some help to ease the financial burden of family caregiving.

Palliative care is a rapidly growing specialty. Unfortunately, this type of care focused on providing people with serious health conditions relief from the symptoms and stress of their illness, is not available in all parts of the state. The Palliative Care Council bill (SB 548) establishes a palliative care council that can evaluate the palliative care system in Wisconsin and make policy recommendations to the legislature on how to improve it, so that improved quality of life through palliative care can be available to patients with serious illness and their families no matter where they live in the state.

Thank you for this opportunity to offer testimony in support of the Supported Decision-Making Agreements bill (SB 552) as well as the Alzheimer's and Caregiver Bills (SB 518, SB 527, SB 528, and SB 548). I am happy to respond to any questions that you may have.



**Testimony Provided to Wisconsin Senate Committee on Workforce Development  
Military Affairs and Senior Issues  
Madison, Wisconsin  
January 10, 2018**

**Tim Harrington,  
Development Coordinator- Workplace Relations and Advocacy Focus  
Alzheimer's Association of Southeastern Wisconsin**

**Chairman Testin, Vice-Chair Feyen and members of the Committee,**

Thank you for allowing me to speak today around this important package of legislation aimed at making Wisconsin a more dementia capable State. I am Tim Harrington, Advocacy lead for the Alzheimer's Association in Wisconsin. I am speaking today on behalf of the three Alzheimer's Association Chapters in Wisconsin. We support care and support for Wisconsinites impacted by Alzheimer's and dementia, raise concern awareness of the disease, advocate the rights in the best interest of those impacted and offer support of research in every county of the State of Wisconsin.

It is not an exaggeration to say the State of Wisconsin, like every in the U.S., is facing a public health crisis when it comes to Alzheimer's disease and related dementias. There are currently over 115,000 people living with the disease in Wisconsin, out of over 5 million nationally, and the Department of Health Services predicts this number will grow by 68% in less than 20 years to over 190,000. These demographic numbers play out in different ways in different parts of our State. For example, currently only two counties, Door and Vilas have more than 27% of the population over the age of 65, mainly due to a higher concentration of retired people. By 2035 however, 25% of the population will be over 65 in the entire northern tier of counties, and no Wisconsin county will have less than 20% of the population over 65. This poses issues across the State, but especially in rural Wisconsin. As the children in a family go off to school and find jobs elsewhere, older adults can become increasingly isolated. Recent surveys indicate that as many as 30 percent of Wisconsinites with Alzheimer's live alone in their communities.

This growth is due to several factors including increased longevity, the aging Baby Boomer population and the increasing racial and ethnic diversity of our State.

**Medical, Health Care, Research and Public Health Issues**

The medical treatments available for Alzheimer's today only work on the symptom of memory loss and do not slow the underlying disease process. As indicated earlier, diagnostic rates for Alzheimer's disease are not consistent with the number of people with cognitive decline, partly due to stigma and partly due to the difficulty of making an accurate diagnosis and the lack of effective treatments. The unfortunate consequence is that many people do not seek help, and many doctors may not make a thorough assessment even when they suspect a problem. This can lead to reversible forms of dementia that go untreated, and can also make it more difficult for the person and the family to begin financial and legal planning to prepare for the future.



Scientists now know that for the person who develops the symptoms of Alzheimer's by age 70, brain changes were occurring for at least 20 years. In the future, we hope to have effective treatments that slow or reverse the course of the disease, and a reliable biomarker that helps identify the people who are developing the disease, even when they are still largely asymptomatic. Coupling those two advances would lead to the ability to prevent or substantially delay the most difficult stages of the disease.

Until that day arrives the Alzheimer's Association is encouraging states to see Alzheimer's disease as a public health issue, and to take public health steps to raise awareness in local communities that can lead to a higher level of dementia screening, diagnosis and treatment. We are very encouraged that Wisconsin is a leader in participating in the Public Health Road map for Alzheimer's disease, and with the Alzheimer's Association and AARP Wisconsin, has produced the Dementia Friendly Communities Toolkit and the Dementia Friendly Employers Toolkit.

Wisconsin has been ahead of many states in these efforts starting with the convening of a task force put together by Former Secretary of Health Services, Kitty Rhodes, who brought together key stake holders to set the platform for and implement our Wisconsin State Alzheimer's plan, followed by the Speakers Task force in the Assembly on Alzheimer's and Dementia that introduced a comprehensive package of bills that addressed many areas of need, then furthered even more by the legislature's insistence on continuing and expanding the funding for the Dementia Care Specialist position in the ADRC's around the state.

The bills before you today are another example of Wisconsin's dedication to staying ahead of what is being termed the Silver Tsunami, the rise in numbers of the baby boomer generation who are living longer and as such are more likely to develop Alzheimer's or a related dementia.

In regard to remaining gaps and concerns, the Alzheimer's Association would like to ask for your support of the following bills that are certain to keep us moving to become a truly dementia capable state:

- (SB 527) A State wide awareness campaign that aims to catch Alzheimer's and dementia sooner in those living with and also raise awareness for caregivers, co-workers, friends and family about the resources available to them while caring for a loved one targeting areas and demographics in the state that are currently underserved
- (SB 528) The creation for a caregiver tax credit for families who are caring for a loved one and accruing large out of pocket costs while doing so, an estimate from a Met Life study showed this could be as high as \$15,000 on average for an individual caregiver.
- (SB 518) Review and adjust our robust Guardianship Laws to allow Wisconsin courts to effectively communicate with other courts when a jurisdictional issue arises and transfer guardianship across state lines.
- (SB 548) Create a palliative care advisory council made up to help guide The Department of Health Services to evaluate the impact Palliative Care has on families, experiences of families

that have used Palliative Care services, practices and protocol of doctors within the Palliative care field and in areas where Palliative Care can be improved.

- (SB 552) Allows adults with functional impairment to create a SDM agreement to allow another person, referred to as a "supporter", to assist the adult with certain decision-making by providing assistance with understanding options, accessing and obtaining needed information, understanding information once it is obtained, and/or communicating the adult's Decision(s) to the appropriate people

Thank you again for the opportunity to address you today and I would be happy to entertain any questions.



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January 9, 2018

Senator Patrick Testin

Senate Committee on Workforce Development, Military Affairs and Senior Issues.

Re: Written Testimony for Committee Hearing on January 10, 2018

Dear Senator Testin and Committee:

I am writing to express my support for bills that are before the Committee on January 10, 2018. These bills advance the dire need to provide care and support to individual with Alzheimer's and other dementias. Some go even farther to provide support to individuals with disabling or terminal conditions of any kind.

My connection with the devastating condition that is Alzheimer's is on a variety of levels. I - along with my brothers - was the caregiver for my mother, Velma who had the disease for 15 years until her death in January 2015. Also, as an elder law attorney, I work on a daily basis with families who are facing the challenges of Alzheimer's and other conditions. Finally, as an advocate, I hope to see an end to this disease in my lifetime.

1. Caregiver Credit SB 528: As I work with families who are providing care, I see the financial toll it takes on them as individuals. (It takes a toll on the health of the caregiver as well.) That is why SB 528 is a critical step in the right direction to provide some financial relief. According to the Alzheimer's Association, in Wisconsin alone, there are an estimated 193,000 people providing unpaid care for someone with Alzheimer's or dementia. These unpaid caregivers put in 219,000,000 (that's two hundred and nineteen MILLION) hours of unpaid care. If this care were valued it would be worth \$2,775,000,000. (That's two TRILLION 775 million dollars.) Caregivers make financial sacrifices - 48 percent cut back on spending for themselves and 43 percent cut back on saving because of the out-of-pocket cost of caring for someone with dementia. The bill would allow a tax credit for qualifying expenses:

- Spending \$800 to have a grab bar installed in the shower of your home would get a tax credit of \$400.
- Paying \$1500 in a year for an aide who comes in when you need to be away from your loved one would net a credit of \$750.
- Spending \$2000 on legal fees related to your loved one would allow a credit of \$1000.
- Spending \$500 on incontinence supplies such as Depends in a year would provide a \$250 tax credit.

The credit would put some money back in the pockets of caregivers, which quite frankly they would most likely use for more costs related to their loved ones. This bill, if enacted, would not only benefit families of people with Alzheimer's, but also parents caring for adult children with disabling conditions, and similarly situated families.

2. Uniform Guardianship: The bill related to uniform guardianship jurisdiction (AB 629/SB 518) would provide much-needed solutions to a problem that I see as an Elder Law Attorney. Where guardianship has been entered in one state and needs to be transferred to Wisconsin because the ward is moving, the process is so difficult under current law that usually it is necessary to start a whole new proceeding, adding time and costs. I personally have had to start entirely new guardianships where a person moved from out of state and we were not able to get the out of state court to provide the documentation required under Wisconsin's existing law. Families are frustrated by this since they already had to go through the stress and turmoil of a proceeding once, they should not be subjected to the entire process a second time. It should be a streamlined process that eliminates unnecessary repetition. This bill achieves that by facilitating the transfer process in the proposed Chapter 53. It also provides a process where a guardianship entered in Wisconsin can be recognized in another state. This is critical as well. I work with parents who are the guardians of adult children with disabling conditions. As the parents age, they look to siblings as the logical successor guardians. In many cases, siblings live in another state. The new Chapter 53 will make the transfer a much smoother process at a time where the family is already going through upheaval and transition. Most other states have already adopted this legislation.

As a member of the Elder Law Section of the State Bar of Wisconsin, I and a group of other attorneys worked directly with the drafter to make sure that this uniform bill had language that would allow it to dovetail correctly with Wisconsin's existing guardianship and protective placement law. One of the lawyers who had participated in the committee raised what I believe to be largely unsubstantiated issues about this proposed legislation in testimony before the Assembly Mental Health Committee. The majority of



the committee members involved in the drafting recommendations, myself included, feel that this bill is essential to the smooth functioning of our judicial system when it comes to the issue of interstate guardianships.

3. Palliative Care Council (SB 548 / AB 633): Not enough people use palliative care appropriately. Palliative care provides comfort and pain management, and while it is often used in Hospice situations, it does not need to be confined to a person in Hospice. People with chronic conditions can benefit greatly from the use of palliate care. Providing ongoing pain management and comfort can help stabilize an ongoing condition and avoid acute / emergency situations. Creating a council to study and positively impact the policies regarding palliative care will help maximize the ways in which people are able to make use of this benefit. It is a timely step in the right direction toward increased awareness and effective use of this treatment.
4. Awareness Grants (SB 527): According to the Alzheimer's Association 2017 Facts and Figures report, there will be an increase of 20,000 in the number of people living with Alzheimer's between now and 2025. The grant to provide education regarding community services and Alzheimer's issues will help those 20,000 newly-diagnosed people to find the services they need, or to become sufficiently educated so as to be able to obtain a needed diagnosis in order to plan for the future. Increasing awareness will also help the 110,000 people already living with the disease in our state to connect with available support and services and to understand the disease better.

I support these bills and encourage your committee to do so as well. Please do not hesitate to contact me if anything further is needed.

Very Truly yours,



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