



PATRICK TESTIN

STATE SENATOR

DATE: January 10, 2018

RE: **Testimony on Senate Bill 528**

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

FROM: Senator Patrick Testin

Thank you Committee members for accepting my testimony on Senate Bill 528, which would create a nonrefundable individual income tax credit for expenses incurred by a family caregiver who is assisting a family member.

Every day in this country, 10,000 baby boomers turn 65. With this increase in the aging population, a growing number will want to age in place at home, but will need help caring for themselves. Due to limited financial resources, and often a desire to respect a family member's wish, family members step in to provide care.

Family caregivers selflessly take on the role of caring for loved ones. In addition to the emotional and physical toll this puts on the caregiver, it can also take a financial toll. According to AARP, those caring for loved ones spend an average of nearly 20 percent of their annual income on caregiving expenses.

In many ways, these caregivers save taxpayers money by keeping loved ones out of costly nursing homes that are funded or subsidized by state tax dollars. This tax credit will help provide more financial stability for the caregiver while enabling them to remain in the workforce.

Senate Bill 528 creates a nonrefundable individual income tax credit for expense incurred by a caregiver caring for a family member. They may claim 50 percent of the cost of qualified expenses, with a maximum credit of \$1,000.

I hope you will join me in supporting this bill that seeks to help our aging population and those that provide care for them. Thank you for your consideration of Senate Bill 528.



Wisconsin Personal Services Association, Inc.

933 Erie Avenue, Suite 9 Sheboygan, WI 53081

January 10, 2018

TO: Senator Testin, Chair, Senate Committee on Workforce Development, Military Affairs and Senior Issues and Committee Members
FROM: The Wisconsin Personal Services Association

RE: Senate Bill 528

Thank you for the opportunity to provide testimony in support of Senate Bill 528, which creates a family caregiver tax credit in Wisconsin.

The Wisconsin Personal Services Association (WPSA) is the longest standing professional organization for personal care and other home care providers in Wisconsin. WPSA has educated, advocated, and united agencies and individuals in all Wisconsin counties for over 25 years to provide quality personal/supportive home care services to over 10,000 consumers and as many, if not more, direct care workers.

WPSA thanks Senator Testin and Representative Skowronski for authoring this important piece of legislation, which recognizes the financial and emotional impact of caring for a family member or loved one.

Wisconsin is currently experiencing a crisis-level shortage of direct care workers that is leaving families without options and people with disabilities and older adults without needed care. Direct care workers help people get out of bed, use the bathroom, get dressed, prepare meals, travel to and from work or school and other activities necessary for daily living. More than 85% of Wisconsinites who rely on direct care workers for some or all of their support needs say they cannot find enough workers.

Now, more than ever, family members are needed to provide care and other necessary supports to sustain the health and independence of their loved ones. This often means: covering the cost of needed supplies and equipment ; missing work or taking unpaid time off to care for family members, to attend doctor's appointments and other unforeseen caregiving duties. AARP estimates that unpaid family caregivers have out-of-pocket caregiving costs of roughly \$7,000 per year. SB 528 can help alleviate some of this financial strain.

It is vitally important to support our family caregivers because without their contributions, many older adults and people with disabilities would not be able to continue living in the community due to the extreme shortage of direct care workers in Wisconsin. Care provided in the community is significantly more cost-effective than care provided in nursing homes or institutions and is shown to increase quality of life. The federal Department of Health and Human Services recently issued a report on the Federal Money Follows the Person program, which found that individuals who transitioned out of

institutions through the program generated \$978 million in Medicaid and Medicare cost savings during the first year after moving into home and community-based care.

By alleviating the financial strain on family caregivers, Wisconsin can help support our family caregivers who help make it possible for older adults and people with disabilities to continue living at home or in the community. This saves state taxpayer dollars.

SB 528 also helps families cover the costs of hiring a direct care worker, which can pose a significant cost for families that do not qualify for Medicaid or long-term care programs like Family Care. Personal care is a cost-effective alternative to more expensive home health services for people with chronic illnesses and severe disabilities.

WPSA asks that you support SB 528.

Please don't hesitate to contact us with additional questions.

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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 528, Caregiver Tax Credit

Position: Support SB 528

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.

Over the last several years and predictably into the future, Wisconsin will continue to rely on the caregiving supports of families for their loved ones with disabilities who need care. Family caregivers play a critical role in providing supports to individuals with intellectual and developmental disabilities (IDD). Wisconsin has the opportunity through SB 528 to provide some relief and support to families doing this essential work.

According to AARP, Wisconsin has 578,000 family caregivers of persons with disabilities or older adults who provide \$7.0 billion dollars in unpaid care annually, with more than three in four family caregivers incurring out of pocket costs. According to the National Alliance for Caregiving (2015), 18.2% of the US population provides supports to a family member with a disability, a chronic illness, or who is aging. These caregivers provide an average of 24.4 hours of care per week.

According to the 2009/10 National Survey of Children with Special Health Care Needs more than a quarter of Wisconsin families were paying more than \$1000 per year in out-of-pocket expenses related to their child's care. Nearly one-fifth of Wisconsin families of children with special health care needs indicate that providing this care is causing financial difficulties while about a quarter report cutting back on hours or stopping working altogether.

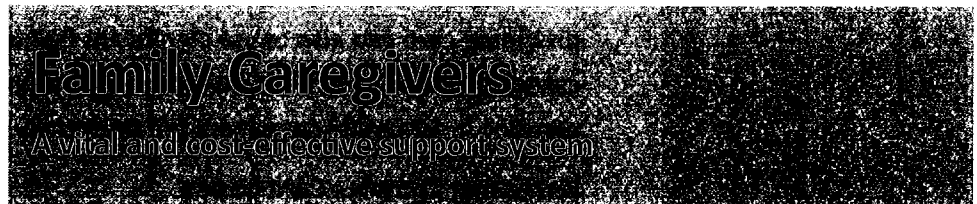
In 2010, The Arc of the United States conducted a national internet survey that aimed to capture the perspectives of family caregivers of people with intellectual or developmental disabilities (IDD), including families in Wisconsin. Nearly 5,300 family respondents participated in the "Family and Individual Needs for Disability Supports" (FINDS) survey. FINDS asked caregivers questions about services received, quality of those services, supports needed, caregiver provided supports and about caregiver outcomes. Nearly sixty percent (59.8%) of family caregivers reported providing more than 40 hours of care per week for their family member.

Data tell us that families are the backbone of the community-based support system. The amount of caregiving hours and tasks provided, coupled with other obligations such as employment or providing care to other family members (e.g., aging parent, spouse, or other children), may lead to the high stress rates often reported by caregivers (Williamson & Perkins, 2014).¹

Our state's reliance on family caregivers to support loved ones means we must address the fact that within less than a decade the aging of baby boomers will critically shift the supply and demand ratio for caregivers. Supporting family caregivers is an investment that means families will be able to provide care for longer, reducing the likelihood their loved one or they themselves will see their health decline and require more expensive care.

The tax credit for family caregivers as proposed in SB 528 would provide eligible family caregivers caring for loved ones of all ages with some financial relief and help them pay for services such as home care, adult day care, respite care, and other supports. This relief can reduce the need for publicly-funded supports.

¹ The Arc of the United States; FISP (Supporting Individuals and Families Information Systems); Research Brief: Issue No. 2 2017.



Core Member Organizations

- Aging and Disability Professionals Association of Wisconsin (ADPAW)
- Alzheimer's Association SE Wisconsin Chapter
- Wisconsin Adult Day Services Association (WADSA)
- Wisconsin Association of Area Agencies on Aging (W4A)
- Wisconsin Association of Benefit Specialists (WABS)
- Wisconsin Association of Nutrition Directors (WAND)
- Wisconsin Association of Senior Centers (WASC)
- Wisconsin Institute for Healthy Aging (WIHA)

The Wisconsin Aging Advocacy Network is a collaborative group of individuals and associations working with and for Wisconsin's older adults to shape public policy to improve their quality of life.

WAAN State Issue Brief
 July 2016

WAAN's Position: Strengthen support for caregivers by passing the CARE Act, creating a tax credit for those shouldering the financial burden of caring for a loved one and expanding dementia care specialist services statewide.

Caregivers Save Money for the Health Care and Long-Term Care Systems

In Wisconsin approximately 578,000 people are providing family caregiving to a loved one at home. The value of this care is estimated at \$7 billion and demographic shifts are driving even more need as roughly 10,000 baby boomers turn 65 every day.* The work of these caregivers enables older Wisconsinites to stay where they want to be and where costs are the lowest: In their homes. Family caregivers perform a variety of caregiving duties—including help with bathing and dressing, feeding, medication management, wound care, and transportation. By providing this care, family caregivers save taxpayer dollars by helping to prevent or delay their loved ones' needs for more costly residential care and unnecessary hospital readmissions.



Cost to the Caregiver

In 2013 family caregivers in Wisconsin provided 538 million hours of care. Many studies report a significant correlation between caregiving and psychological and physical health. Those who serve as family caregivers to older relatives report higher levels of stress and poorer health than the population at large. A recent AARP study reports over half of the caregivers surveyed reported being overwhelmed by the amount of care their family member needs. On top of stress, poor health, and loss of personal time,

*<http://states.aarp.org/wi-caregivers-provide-7-billion-in-unpaid-care-sc-wi-wp-advocacy/#sthash.jRv56kAA.dpuf>

providing care can also cause significant financial strain. Nearly 70% of family caregivers have used their own money to help care for their loved one and nearly 4 in 10 family caregivers felt financially strained by these costs.

Increasing Complex Care Needs

Wisconsin's population is aging—increasing the need for family caregiving. Caregivers are increasingly responsible for administering medical or nursing care to family members, but are often not trained in how to provide this complex care or are left out of treatment decisions. Family caregivers' needs should be assessed as part of the care planning process and caregivers should be included in the planning process as appropriate. Dementia care specialists (DCSs) available across the state can help ensure individuals with Alzheimer's disease or other dementias are connected to appropriate diagnostic and treatment centers, while also helping to ensure that care is safe and cost-effective and making sure family members who are providing care (which can be especially overwhelming and stressful when caring for someone with dementia) receive the resources they need to care for their loved ones. However, Wisconsin currently has only 19 DCSs serving 26 counties and 3 tribes.

Supporting Family Caregivers

Family caregivers face increasing challenges—lack of time, loss of income, health problems, and stress. An increasing number of people will find themselves facing these challenges as the population ages and more adults find themselves in the role of family caregiver. We must address these challenges immediately. Specific measures include:

- **Pass the CARE Act.** The Caregiver Advise, Record, Enable (CARE) Act includes provisions to keep family caregivers informed about the patient's treatment and ensure caregivers receive explanation and live instruction of the medical tasks the family caregiver will perform at home.
- **Create a Wisconsin state tax credit to ease the financial burden of caregiving.** A Wisconsin income tax credit for qualified caregiving expenses—like assistive technology and adult daycare—will reduce financial strain on family caregivers.
- **Expand the number of dementia care specialists** to cover every ADRC in Wisconsin. DCSs provide vital services to assist individuals with dementia to remain active and in their homes, support ADRC staff and county and tribal programs to be better prepared to support individuals with dementia and their families, and to act as a catalyst for the creation of dementia-friendly communities.



Contact WAAN

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**Find this and other WAAN
issue briefs at:**

<http://gwaar.org/waan>

CAREGIVING IN THE U.S.

Statistics on Unpaid Family Caregivers in the United States



43.5 million

family caregivers provide unpaid care to an adult or child

That amounts to nearly

15%

of the U.S. population

The average caregiver is

49

years old caring for someone aged

69

years old



22% of caregivers support someone with Alzheimer's disease, dementia, or memory issues

Approximately **2.8 million** people care for someone who is managing cancer

At least **8.4 million** Americans care for an adult with an emotional or mental health issue

Family caregivers spend an average of

24.4

hours per week providing care

Nearly

70%

of family caregivers say they received no paid help from other direct care workers

Caregivers Need:

- Inclusion in the health care team
- Workplace flexibility
- Support and training for medical tasks
- Emotional/financial support

For more information visit
www.caregiving.org



National Alliance for Caregiving

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.

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

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 2015 Update: Undeniable Progress, but Bigs Gap Remain, AARP Public Policy Institute

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

78%

\$11,923

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

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

To learn more about the Credit for Caring Act (H.R. 2505/ S. 1151) visit 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 that 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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WESSELS
LAW OFFICE LLC
ELDER & SPECIAL NEEDS LAW

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,



Carol J. Wessels

Attorney at Law
Cedarburg, Wisconsin