

# *Idaho's Lifespan Family Caregiver Action Plan*



Idaho  
Caregiver  
Alliance

October, 2016

# Acknowledgements

## Idaho Family Caregiver Alliance

This plan is the product of countless hours of research, outreach, deliberation, and problem solving. It reflects the voice of thousands of often invisible Idaho caregivers and others. The plan is intended to create awareness among policy makers and others and is intended to stimulate dialogue and encourage movement toward an improved environment for Idaho family caregivers. As described in the plan, a perfect storm is brewing, generated by demographic shifts, advances in health care, economic challenges experienced by caregiving families, and the desire to live and age in the community. The system as it is currently configured cannot address the pressure these changes generate. Idaho must look ahead to what can be done proactively to support caregivers and deflect the catastrophe that might well occur if we do not.

We welcome your interest, ideas, and support. Thank you for your leadership, vision, and action toward advancing this plan.

*“Under Medicare, we are only allowed a short time in a nursing home after a hospital stay. In 2013, my husband fell and sustained a broken neck. He was also a cancer patient. He was discharged to home at 100 days after spine surgery. The cancer doctor said go home with “hospice.” However there are NO hospice services on top of the Greer grade, our area. We had to contend with someone who should have still been in the hospital by ourselves. Total care is hard on backs. In the drug store one day a clerk told me to call the Area Agency on Aging. Our first and only real help. This was after 3 months without help, another hospital stay for my husband, and another nursing home stay. I am trying to stay alive as the only help for my husband and our son, a diabetic since age 2 on insulin for 59 years. I really appreciate the help from the Agency on Aging and wish I had known of it sooner. Thank you.”*

*The voice of an Idaho senior,  
No Wrong Door System Assessment, 2015*

AARP Idaho  
Ada County Community Paramedics  
Advocates for Families/Caregivers  
Area Agencies on Aging  
Blue Cross of Idaho  
Caregivers  
Caregiver Support Service Agencies  
Boise State University –  
Center for the Study of Aging  
Community Partnerships of Idaho  
Disability Action Center NW  
Disability Rights Idaho  
Friends in Action/Legacy Corps  
Home Care and Hospice Agencies  
Idaho Alzheimer’s Planning Group  
Idaho Area Health Education Center  
Idaho Association of Counties  
Idaho Commission on Aging  
Idaho Department of Health and Welfare  
Divisions –  
Behavioral Health, Public Health, and  
Medicaid  
Idaho Federation of Families for Children’s  
Mental Health  
Idaho Health Care Association  
Idaho Hospital Association  
Idaho Parents Unlimited  
Jannus  
Living Independence Network Corporation  
MS Society  
Northwest A.D.A. Center of Idaho  
Qualis Health  
Regence Blue Shield  
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(SHIBA)  
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Treasure Valley YMCA  
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**ICA VISION: To serve as the voice, convener,  
and catalyst for support of unpaid family  
caregivers across the lifespan.**



**The mission of the Idaho Caregiver Alliance is to  
advance the well-being of family caregivers by  
promoting collaboration that improves access to  
quality support and resources, including respite for  
caregivers across the lifespan.**

# *Executive Summary*

**F**amily bonds and support are hallmarks of the State of Idaho and cornerstones of independence for older adults and individuals with physical or emotional disabilities, or chronic illnesses. The support provided by families is often fundamental to this independence and the value of unpaid family caregiving is receiving increased attention in Idaho and throughout the United States.

## **Why this attention now?**

- In part, it is due to demographic change – 10 years ago, the ratio of working age adults to older adults was 6 to 1. By 2020, this ratio will be 3 to 1. In addition, more families of children and adults with disabilities are opting for home-based care. There are and will be fewer and fewer caregivers for a rapidly increasing number of people needing care.
- Family caregivers manage increasingly complex medical and/or psychological conditions without the support and training they need. The supports that do exist are fragmented and difficult to access.
- Family caregiving is not free. The costs include lost income to the caregiver and lost productivity to an employer. For example, the income generating potential for a caregiver is projected to be \$600,000 less over a lifetime and employers lose an estimated \$33.6 billion annually related to employee caregiving responsibilities.
- Caregiving takes its toll on caregiver health and wellbeing and impacts the entire family.
- Support from family caregivers can delay the need for costly institutional care. In 2014, Idaho spent \$271,522,099 or 48% of its Medicaid budget on care in nursing facilities, intermediate care facilities for individuals with intellectual disabilities (ICFs/ID) and inpatient psychiatric hospitals.

The absence of a solid support structure for caregivers takes a serious toll on the economic and social wellbeing of families, businesses, and communities across Idaho.

## **What can Idaho do to support caregivers?**

The Idaho Lifespan Family Caregiver Action Plan offers an evidence-based set of recommendations to put Idaho ahead of the caregiver crisis curve and set a course into a future that is economically viable for caregivers, employers, and service systems. The plan proposes:

- ✓ A range of supports that can mean the difference between caregivers being able to manage their caregiving responsibilities and their own health vs. losing their jobs or placing their family members in out-of-home care. These supports can range from respite care to information and training to legal, financial, and tax-based supports.
- ✓ Increased public awareness to ensure that caregivers identify themselves in order to seek support and a general public that recognizes the contributions and needs of caregivers and understands ways by which family caregivers can be supported.

- ✓ A seat at the table as Idaho pursues changes to its primary care, behavioral health, and long-term supports systems. This will ensure that the voice of family caregivers is recognized and their expertise and experience are included in caregiving decisions.
- ✓ A sustained voice for Idaho caregivers through the continuation of the Idaho Caregiver Alliance, an umbrella organization that promotes collaboration to improve access to quality support and resources for caregivers across the lifespan.

### **What are the Next Steps?**

The perspectives and expertise of caregivers and allies from public and private organizations in Idaho provide the foundation for the Idaho Caregiver Action Plan. The Plan, available on the Idaho Commission on Aging and Center for the Study of Aging, Boise State University websites, is designed to identify and enhance local supports for family caregivers.

The aim of the **ACTION PLAN** is to be proactive; to prevent or delay the need for costly institutional care, maximize independence, and keep families together in their communities. Implementation of the **ACTION PLAN** will require an investment of resources, but as demonstrated by caregiver initiatives in other states, the effort will yield significant dividends.

An electronic copy of the Idaho Lifespan Family Caregiver Action Plan and Executive Summary is available through [Center for the Study of Aging](https://hs.boisestate.edu/csa/idaho-lifespan-family-caregiver-action-plan/) at Boise State University, <https://hs.boisestate.edu/csa/idaho-lifespan-family-caregiver-action-plan/>

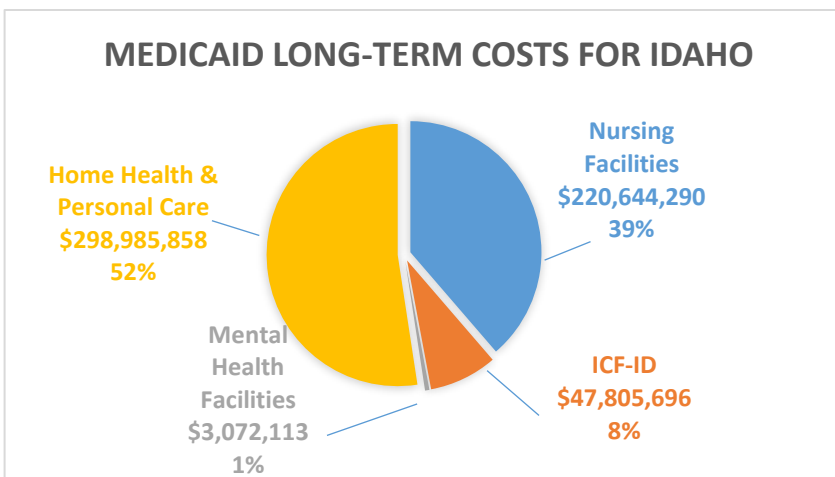
# Introduction

The work force of unpaid family caregivers is receiving increased attention in Idaho and throughout the United States. This is due, in part, to recognition of the critical role families play in the health care delivery system. The **Idaho Caregiver Alliance (ICA)**, a collaborative initiative of the Idaho Commission on Aging, the Center for the Study on Aging at Boise State University, Jannus Corporation, Idaho Parents Unlimited, Idaho Department of Health and Welfare (Public Health, Medicaid, Children’s Behavioral Health, and Service Integration), AARP Idaho, family caregivers and others, is leading this effort in Idaho. The mission of the ICA is to advance the well-being of caregivers by promoting collaboration that improves access to quality support and resources for family caregivers across the lifespan. This document outlines the rationale and goals for a Lifespan Family Caregiver Action Plan for Idaho.

There is a vast, invisible workforce of caregivers in Idaho. Each year, more than 300,000 - **1 out of every 4 adults in Idaho** - assume critical, ongoing care responsibilities for aging parents, siblings, spouses, children, or grandchildren with physical or emotional disabilities, or chronic illnesses<sup>1,2</sup>. These family members provide over **201 million hours of uncompensated care annually** at an estimated value of **\$2 billion to Idaho’s economy**.<sup>3</sup> This is equivalent to Idaho’s current budget for all publicly-funded long-term care services.<sup>4</sup>

**300,000**   
Idaho family caregivers

**201,000,000**   
Hours of caregiving annually



Access to support for family caregivers is important in delaying the need for costly institutional care. As in many states, a significant proportion of Idaho Medicaid expenditures for individuals eligible for both Medicare and Medicaid are for services in nursing facilities, intermediate care facilities for individuals with intellectual disabilities (ICFs/ID) and inpatient

Figure 1 – Idaho Medicaid Long-Term Care Costs

<sup>1</sup> *Across the States: Profiles of Long-Term Care and Independent Living Idaho 2012: Valuing the Invaluable Update: Understanding the Impact of Family Caregiving on Work* (AARP Public Policy Institute)

<sup>2</sup> *Idaho Caregiver Needs and Respite Capacity Report, 2014.* (Cirerol, T & Toevs, S.E. )

<sup>3</sup> *Across the States: Profiles of Long-Term Care and Independent Living Idaho 2012: Valuing the Invaluable Update: Understanding the Impact of Family Caregiving on Work* (AARP Public Policy Institute)

<sup>4</sup> *FY 2016 Legislative Budget Book* (Department of Health and Welfare FY 2015 appropriation, p. 2-8)

psychiatric hospitals. In 2014, Idaho’s Medicaid spending for long-term care was **\$570,507,957**, just under 1/3 of its total budget. Of this amount, **48% or \$271,522,099 was spent on care in these settings.**<sup>5</sup> An investment in family caregivers reflects Idaho’s values of fiscal responsibility and the Governor’s commitment, “to using common sense in ways that make better use of our tax dollars now and in the future.”<sup>6</sup>

## Who is a Caregiver?

As expressed by Rosalynn Carter, “There are four kinds of people in the world: those who have been caregivers; those who currently are caregivers; those who will be caregivers; and those who will need caregivers.” Caregiving encompasses many responsibilities and has many different faces. A family caregiver may be a parent caring for a child with serious medical issues, or a young adult taking care of a grandparent with a heart condition. Caregiving may be a sister caring for a brother with schizophrenia, or a husband supporting and caring for a wife with dementia. Often, a caregiver fulfills a combination of these roles. The care provided may range from a trip to the grocery store or a medical appointment, to 24/7 care involving medication administration, wound care, or other complex medical services. A caregiving role may last a few months or a lifetime, and although these responsibilities are taken on willingly and with love, they come at a cost to individuals, families and society.

The ICA acknowledges that the term “caregiver” can carry a negative connotation. *Care partner* or *carer* or an individual’s relationship to the care recipient (spouse, parent, sibling, etc.) is often preferred terminology. It is important to acknowledge that words matter and can influence our thinking and actions. However, the ICA has opted to use the term “caregiver” based on its use by local and national organizations, funding agencies, and its broad recognition by the general public and stakeholders. There is no intention to demean or diminish the work being done or the reciprocal relationship between the recipient of services and the person providing the support.

**Changing demographics.** While the number of older adults is increasing across the country, Idaho has the ninth fastest growing population of people over the age of 65. Based on current projections, 20% of the population in Idaho will be 65 or older by 2020, whereas the population of working age adults will

- What do Family Caregivers Provide?**
- ✓ Complex medication management
  - ✓ Care coordination
  - ✓ Wound care
  - ✓ Mental health planning & supervision
  - ✓ Personal care
  - ✓ Financial management
  - ✓ Health insurance advocacy
  - ✓ Transportation
  - ✓ Emotional and spiritual support
  - ✓ Medical equipment operation
  - ✓ Interpreting medical directions

<sup>5</sup> *Distribution of Spending on Long-Term Care* (Kaiser Family Foundation, 2014)

<sup>6</sup> *Idaho indicators aging and work. State Perspectives at Boston College* (Wong, M., McNamara, T., Shulkin, S., Lettieri, & C., Careiro, V., 2008)



only increase by 0.2% a year over the next decade.<sup>7</sup> Ten years ago, there were approximately 6 working age adults for every person age 65 and older. By 2020, this ratio is projected to decrease to 3:1 – a 50% reduction.<sup>8</sup> This demographic shift foreshadows a caregiver crisis; Idaho will have significantly fewer family caregivers to care for a growing aging population.

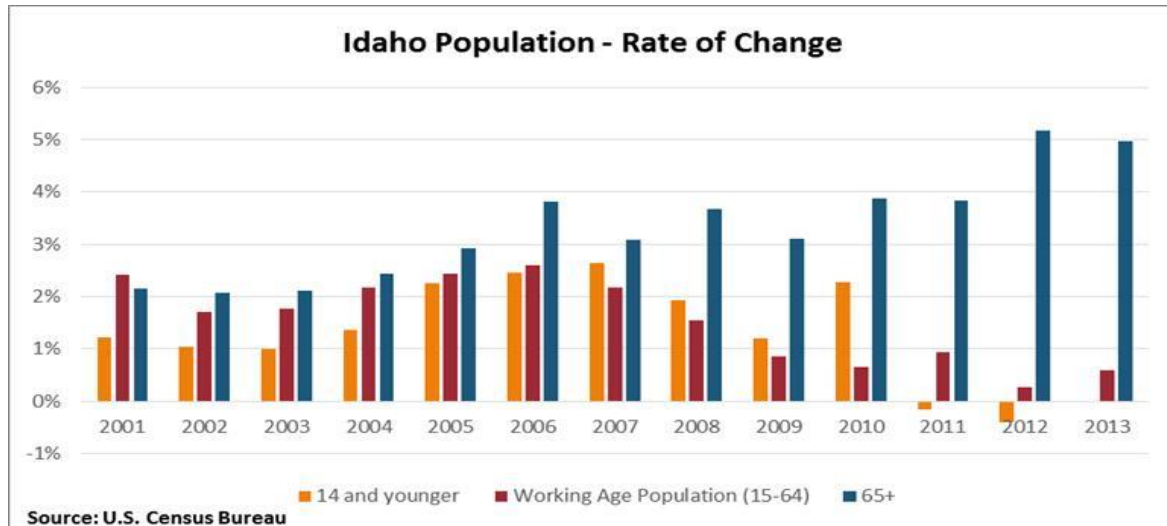


Figure 2 – Change in age distribution of Idaho population: 2001 -2013  
Idaho Department of Labor

Caregiving is not just about older adults. It also impacts families caring for children with disabilities. In 2012, 8% of U.S. adults reported providing unpaid care to a child living with health challenges or disabilities, up from 5% in 2010.<sup>9</sup> As the U.S. population ages and as medical advances save and extend more lives and more people across the lifespan opt for home-based care, this upward trend in the need for family caregivers will continue.

## The Costs of Caregiving

### Impact of Caregiving on the Caregiver and Family

**Family caregiving impacts all aspects of a family’s economic and physical wellbeing.** Caregiving can jeopardize a family’s ability to maintain their housing or provide care for a loved one, or cause a family member (including the caregiver) to postpone educational opportunities that could improve their future. The demands of caregiving create stress not only on the caregiver, but other family members as well. For families with children with disabilities, siblings also feel the impact as the family focuses energy and attention on the demands of the child with special needs. The demands are further heightened for individuals providing care for a child and an older family member simultaneously.

<sup>7</sup> *Idaho’s Population Growth Slowed During Recession* (Idaho Department of Labor, 2015)

<sup>8</sup> *Ibid*

<sup>9</sup> *Family Caregivers are Wired for Health*. Pew Internet and American Life Project (Fox, S., Duggan, K., Purcell, K., 2013)

**Uncompensated caregiving is not “free.”** There are many hidden financial, physical, and emotional costs to uncompensated caregiving. Twenty-two percent of caregivers of younger adults with disabilities indicate they are experiencing financial strain from out of pocket support.<sup>10</sup> These contributions reflect a diminished capacity on the part of many working families to take care of themselves and their (other) family members. According to a 2015 retirement confidence survey, 29% or 3 in 10 people say they are currently providing direct financial support to a relative or friend. According to a Pew Research Center study, 28% of adults with a parent age 65 or older helped their parents financially within the past year.<sup>11</sup> The financial impact of caregiving increases with the intensity of the care provided, the geographic distance between care recipient and care provider’s places of residence, and access to supportive resources.

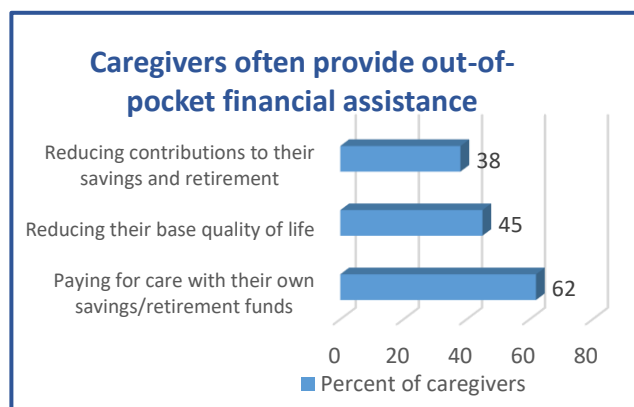


Figure 3 – Out-of-pocket financial assistance  
*Beyond Dollars: The Expanding Circle of Care, Executive Summary, Genworth Financial, 2016*

**Families are unable to manage the cost of long-term care.** Insurance policies for long-term care can be purchased as a means of paying for all or part of the cost of care in a facility or at home, but this option is becoming increasingly unaffordable.<sup>12</sup> People with low incomes and few financial resources have no option but to rely on Medicaid. At the other end of the wealth spectrum, people can pay for extended care out of their savings. The dilemma is hardest for the large number of people in the middle. With significantly increased premiums and fewer benefits, retirees on fixed incomes are increasingly canceling their long-term care policies.<sup>13</sup> A major factor in the decision to purchase – or keep – long term care insurance is whether the person will have family or friends to provide at least some unpaid help. Many people are counting on such free help, but there is a shrinking number of family caregivers, due to smaller families and other demographic shifts.<sup>14</sup>

**Most caregivers are juggling work and caregiving.** While each situation is unique, nearly 70% of Idaho caregivers are employed full or part-time and caring for their own children or an aging parent.<sup>15</sup> A national study indicates that 6 out of 10 caregivers have had to make workplace accommodations to meet their caregiving responsibilities (see Figure 4). These changes can range from cutting back work

<sup>10</sup> Caregivers of Younger Adults: A Focused Look at Those Caring for Someone Age 18 to 49, (AARP Public Policy Institute), June, 2016, p.8

<sup>11</sup> *Family Support in Graying Societies: How Americans, Germans and Italians are Coping with an Aging Population* (Pew Research Center, 2015)

<sup>12</sup> *Long-Term Care Insurance Less Bang More Buck* (Kaiser Family Foundation, March 17, 2016)

<sup>13</sup> *Why Do People Lapse Their Long-term Care Insurance?* (Hou, W., Sun, W., & Webb, A. Center for Retirement Research at Boston College, October 2015, 15-17)

<sup>14</sup> *Long-Term Care Insurance: Is It Worth It?* (Scism, L, Wall Street Journal, May 1, 2015)

<sup>15</sup> *Idaho Caregiver Needs and Respite Capacity Report, 2014.* (Cirerol, T & Toevs, S.E. )

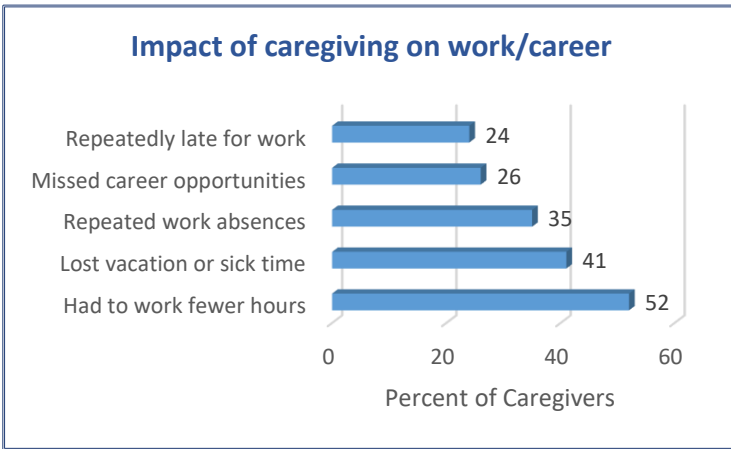


Figure 4 - Impact of caregiving on work/career  
*Beyond Dollars: The Expanding Circle of Care, Executive Summary, Genworth Financial, 2016*

caregivers lose about \$660,000 in wage wealth over their lifetime because of work sacrifices.<sup>17</sup>

Employment difficulties such as these cause a ripple effect: loss of health care benefits, diminished financial independence, and severe physical and emotional stress for the caregiver.

hours to taking a leave of absence, to receiving a warning for poor performance or attendance.<sup>16</sup> The demands of caregiving may also require reducing paid employment or leaving employment altogether. In fact, employment outside the home may be impossible for some parents of children or adults with disabilities, because caregiving is their uncompensated full-time job. A recent study estimates that working

**Caregiving can negatively affect the health of the caregiver.** According to the 2012 *Stress in America* report, individuals who care for family members who are chronically ill have higher levels of stress and poorer health than the population at large.

What’s more, while older adults often report lower stress levels, those who shoulder caregiving responsibilities are more stressed and have poorer physical health than their peers.<sup>18</sup> This stress can lead to depression, anxiety, sleep problems, and health issues such as obesity and high blood pressure. Caregivers are also more likely to get sick than the general population, 17% versus 6%, respectively.<sup>19</sup> There is also evidence that spouses caring for a partner with dementia are at an increased risk of dementia themselves.<sup>20</sup> With these negative health impacts, caregivers are ultimately at risk of needing care – and a caregiver – themselves.

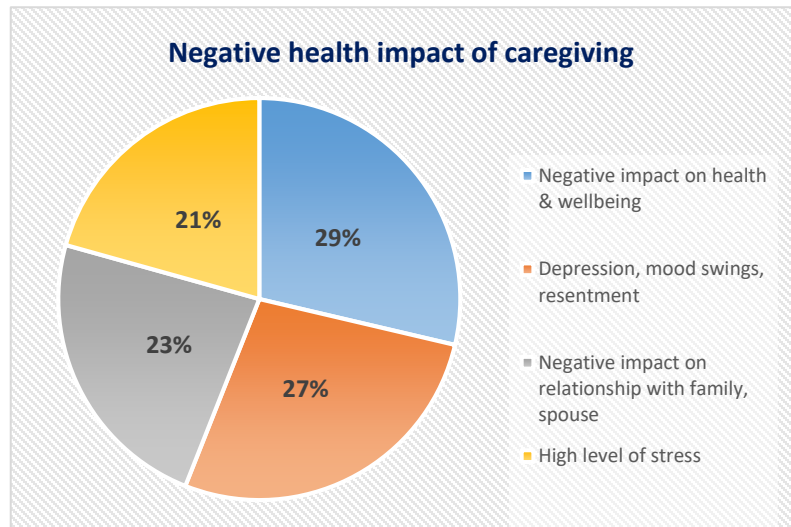


Figure 5 – Negative health impact of caregiving  
*Beyond Dollars: The Expanding Circle of Care, Executive Summary, Genworth Financial, 2016*

<sup>16</sup> *Caregiving in the U.S., Executive Summary* (AARP Public Policy Institute, June, 2015, p.22)

<sup>17</sup> *About Caregiving, Guide to Long Term Care Planning* (Day, T. National Care Planning Council, 2016)

<sup>18</sup> *Stress in America: Our Health at Risk* (American Psychological Association, January, 2012, p. 5)

<sup>19</sup> *Stress in America: Our Health at Risk* (American Psychological Association, January, 2012, p. 8)

<sup>20</sup> *Does caring for a spouse with dementia promote cognitive decline? A hypothesis and proposed mechanisms* (Vitaliano, R.P., Murphy, Young, H.M., Echeverria, D., & Borson, S., *Journal of the American Geriatric Society*, 59, 900-908)

## Economic Consequences of Caregiving on Employers

It is estimated that U.S. businesses lose \$25-28 billion annually in lost productivity due to the absenteeism of caregivers.<sup>21</sup> That figure increases to \$33.6 billion when including the costs of replacing employees, workday distractions, supervisory time and reduction in hours from full to part time.<sup>22,23</sup> In fact, the average annual cost to employers per full-time working caregiver is \$2,110.20.<sup>24</sup>

**\$2,100**



*Average cost to employer for caregiving employee*

## How Can Idaho Support the Caregiver?

### We Need Caregiver Supports

Caregivers need support to sustain and expand their caregiving capacity and avoid costly health challenges. These supports include such things as transportation assistance, spiritual and emotional support, and workplace flexibility. These forms of assistance are important, often decisive factors between the care recipient remaining at home or being placed in a nursing home or other facility; between a caregiver remaining employed, or being pushed out of the workforce; between a family being able to remain in their home town, or having to relocate to access needed services. Critical supports include:

✓ **Respite Care:** Having some “time away” from caregiving prevents or delays burnout, relieves caregiver stress, and allows caregivers time to take care of themselves. A clear understanding of what respite services are and their importance, how to find and access respite care, methods of funding such services, standards for respite providers, and a statewide respite registry are needed to provide this vital form of assistance to caregivers. Respite care is an investment in both family and community wellbeing by keeping caregivers employed and socially engaged.

✓ **Information and Training:** Caregivers are increasingly expected to manage complex medical and/or

psychological conditions with little to no information, instruction, or support. At present, assistance and information for caregivers is limited, fragmented, and based mostly on the needs of the care recipient, and not resources for the caregiver. Comprehensive information and training are needed for caregivers

*“Caregiving has all the features of a chronic stress experience: It creates physical and psychological strain over extended periods of time, is accompanied by high levels of unpredictability and uncontrollability, has the capacity to create secondary stress in multiple life domains such as work and family relationships, and frequently requires high levels of vigilance.”*

*Schulz and Sherwood*

*In Physical and Mental Health Effects of Family Caregiving, 2009*

<sup>21</sup> *The Cost of caregiving to the U.S. economy, and what business leaders can do about it Business Journal*, (Witte, D., December 1, 2011. Data are from the Gallup-Healthways Well-Being Index, 2011)

<sup>22</sup> *MetLife Study of Working Caregivers and Employer Health Care Costs* (MetLife Mature Institute, National Alliance for Caregiving, & University of Pittsburgh, February 2010)

<sup>23</sup> *Caregiving in the US. 2015 – Focused Look at Caregivers Age 50+* (National Alliance for Caregiving & AARP Public Policy Institute, 2015)

<sup>24</sup> *MetLife Caregiving Study: Productivity Losses to U.S. Business* (MetLife Mature Market Institute & National Alliance for Caregiving (NAC), 2006. The lost productivity estimates are based on the 2004 survey of U.S. caregivers conducted by NAC and AARP, Caregiving in the U.S. 2004)

to be effective, safe, and supported in their caregiving responsibilities. In addition, caregivers need to be recognized by health care providers as an important part of their family member’s medical care team.

✓ **Financial and Legal Supports:** Many caregivers face confusing and complicated legal issues connected with their caregiving responsibilities. For example, families caring for children with disabilities require information about guardianship and trusts to provide financial support to their child upon reaching the age of majority. For families caring for seniors, guardianship issues, financial, and end-of-life planning can also be complex. Although Idaho has enacted the Uniform Adult Guardianship and Protective Proceedings Jurisdiction Act, access to this expertise remains challenging and expensive. Therefore, financial and legal resources are needed to help family caregivers navigate the complexities of this nuanced, crucial area of providing support and care for a loved one.

✓ **Tax-based Supports:** Caregivers need enhanced tax-based supports to ameliorate the often staggering costs incurred by caregiving. Under Idaho tax code, Title 63, Chapter 30, caregivers are allowed up to three annual \$1,000 deductions for qualifying care recipients who receive at least half of their support from the taxpayer. Although a good starting place, this tax credit is inadequate. The growing number of national and state proposed caregiver tax credits and deductions recognize that such tax-based incentives help caregivers maximize their often limited fiscal resources and help reduce the need for publicly funded services. Updating the existing Idaho tax code to provide more comprehensive caregiver deductions as well as tax credits is a step in the right direction to ensure family caregivers remain financially stable and independent.

## **We Need Public Awareness to Identify Caregivers**

Caregivers must be able to identify themselves as such in order to seek support. The very role of caregiving is often misunderstood, and not well defined. Public awareness campaigns and other initiatives are needed to establish a cogent, recognizable definition of caregiving that will help bridge this gap in understanding for both caregivers and the general public.

## **We Need Involvement in Making System Changes**

Caregivers need a seat at the decision-making table as Idaho embarks on making significant revisions to primary care, the behavioral health care system, and long-term care services and supports. These efforts include:

✓ Recognition of family caregivers as an important component of the “medical neighborhood,” both as a resource and a potential recipient of services as the **Statewide Healthcare Innovation Plan** (SHIP) transforms primary care clinics into patient or person-centered medical homes (PCMHs).

✓ Inclusion of the voice of family caregivers in efforts to redesign the **Behavioral Health** care system (which encompasses mental health and substance use disorders) in Idaho. Important strides have been made in recognizing the need for preventative and crisis services at the local level; it is imperative that the voice and experience of family caregivers be included in these efforts.

✓ Inclusion of the perspectives of both the care recipient and their caregiver in efforts to coordinate and streamline transitions between care settings (hospitals, assisted living, home) across systems (Medicaid, Medicare, Veterans Health Administration) through the **No Wrong Door Initiative** (an effort by the Idaho Commission on Aging and others to work together to make it easier for people of all ages, abilities and income levels to learn about and access the services they need).

✓ Inclusion of family caregivers in Idaho's efforts to enhance workplace supports and tax policies that support families and the state's economic vitality.

## **We Need a Sustained Voice for Caregivers Across the Lifespan**

**The Idaho Caregiver Alliance (ICA)**, established through a 3-year Lifespan Respite Grant to the Idaho Commission on Aging from the Administration on Community Living (ACL), has made significant strides in recognizing the importance of family caregivers in Idaho. It is imperative ~~that~~ this work be ~~is~~ sustained. The continued presence of ICA as an umbrella organization is critical to the success of efforts underway to support and sustain the unpaid family caregiver workforce, but with grant funds ending, the future of ICA is uncertain. ***An organizational home and funds to sustain the work of the Alliance are needed to ensure the momentum generated through the Lifespan Respite grant is not lost.***

## **What are the Next Steps?**

The perspectives and expertise of caregivers and allies from public and private organizations in Idaho provide the foundation for the following Action Plan. The plan incorporates evidence-based practices to enhance and build local supports for family caregivers. The aim of this **ACTION PLAN** is to be proactive: to prevent or delay the need for costly institutional care, maximize independence, and keep families together in their communities. Implementation of this **ACTION PLAN** will require an investment of resources, but as demonstrated by caregiver initiatives in other states, the effort will yield significant dividends.

**Goal #1:** Ensure a streamlined, coordinated system of supports for caregivers across the lifespan, recognizing the unique needs of Idaho’s diverse population.

## *Family Caregiver Supports*

Family caregivers often require assistance to navigate the complex systems and information essential to providing quality care. They also need training on fundamental caregiving responsibilities, such as dispensing medications and managing complex medical and psychological conditions, providing personal care, financial management, and coordinating transportation. Further, caregivers need tools and information regarding prioritization of their own physical and emotional wellbeing or “self-care.” Receiving this support translates into more effective caregiving and cost savings to families and healthcare and social services systems.

### **Objective:**

***#1: Develop statewide respite resources***

### **Steps to accomplish:**

- A. Convene a respite task force comprised of family caregivers, public and private agencies and organizations, and healthcare and social service providers to:
  - Compile, maintain, and promote use of a resource directory of available respite and respite-like resources such as homemaker, companion services, personal care services, etc.
  - Explore development of a standards-based, statewide respite registry for caregivers across the lifespan
  - Inform caregivers and local information and referral networks about respite and other caregiver support programs offered through the Area Agencies on Aging (AAAs), Centers on Independent Living (CILs), and other entities
  
- B. Improve training for respite providers across the lifespan.
  - Identify online training resources
  - Maintain a library of resources on Idaho 2-1-1 Careline website
  - Market training opportunities to caregivers, service agencies, and individual respite workers through statewide networks

## **Objective:**

***#2: Ensure culturally appropriate information and resources are available to caregivers across the lifespan.***

## **Steps to accomplish:**

- A. Embed information about evidence-based caregiver resources into existing statewide information systems, such as the Idaho 2-1-1 Careline and websites for Live Better Idaho, Behavioral Health, Center for Disabilities and Human Development/Family Support, and others.
- B. Compile community resources to support those in a family caregiving role.
  - Partner with AARP Idaho in the development and distribution of a Question and Answer Resource Guide for family caregivers across the lifespan
  - Make these guides available through various audiences including the medical-health neighborhoods built through the seven State Healthcare Innovation Plan (SHIP) Regional Collaboratives and the Regional Behavioral Health Boards (RBHBs)
  - Coordinate with Information and Assistance/Referral specialists at the regional agencies such as Area Agencies on Aging (AAAs) and the Centers on Independent Living (CILs) to promote information and resources for caregivers
- C. Promote the availability of information resources for caregivers to employers, health care and social service providers, faith-based organizations, and others.

## **Objective:**

***#3: Establish training resources for family caregivers on caregiving responsibilities, techniques, and strategies for self-care.***

## **Steps to accomplish:**

- A. Oversee implementation of the *Powerful Tools for Caregivers (PTC)* training<sup>25</sup>, ensuring that it is offered across Idaho.
  - Identify funding strategies for delivering both the traditional curriculum that focuses on caring for adults, and the newly developed version for caregivers of children
  - Promote the expanded delivery of PTC

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<sup>25</sup>Powerful Tools for Caregivers, 2016



- Assess the impact of the training including process (attendance, reach) and outcome (satisfaction and impact of class on participants) measures and share these findings with stakeholders.
- B. Collaborate with other organizations on training opportunities for various populations such as:
- Support an annual Family Caregiver Conference
  - Co-sponsor trainings that have a lifespan focus
  - Coordinate with Idaho Department of Health and Welfare (IDHW), Idaho Parents Unlimited (IPUL) and the Federation of Families for Children’s Mental Health (FFCMH) on training for families caring for children/youth with disabilities
  - Provide updates via the Regional Care Coordination Coalitions through Qualis, SHIP Regional Collaboratives, and others

**Objective:**

***#4: Establish a statewide network of experts equipped to serve as information and support navigators or guides for family caregivers across the lifespan.***

**Steps to accomplish:**

- A. Partner with existing local information and referral networks to embed assistance for caregivers across Idaho’s increasingly diverse populations.
- Identify individuals with system knowledge and care management experience within these networks in each geographical area of the state
  - Develop training tools to prepare individuals within organizations to serve as guides to needed services and supports for family members
  - Acknowledge and formally recognize people and organizations who guide caregivers to services and supports
- B. Identify sustainable funding to hire and train personnel to assist caregivers across the lifespan to access services and supports.
- C. Implement marketing campaigns to communicate the availability of assistance for family caregivers and professionals who interact with caregivers.

**Goal #2:** Increase public awareness about unpaid family caregiving and help people within our communities identify as caregivers.

## *Public Awareness*

A “family caregiver” or “care partner” is a family member or friend who provides physical and/or emotional support or assistance to a loved one of any age who is ill, frail, or has disabilities. Caregivers are relatives or friends who provide support without compensation. Family caregivers are more likely to seek information, respite, and training assistance when they recognize they are in a caregiving role. Such self-identification removes a major hurdle for those who would benefit from assistance. A public campaign is needed to increase awareness about the value of caregivers and to help family caregivers identify and connect with support, information, and training.

### **Objective:**

***#5: Family members recognize themselves as caregivers and the general public is aware of the needs and contributions of family caregivers across the lifespan.***

### **Steps to Accomplish:**

- A. Expand community engagement through continued coordination of regional caregiver summits and statewide Idaho Caregiver Alliance (ICA) meetings.
  - Coordinate with regional entities such as the AAAs, the CILS, and the RBHBs regarding ICA activities and recommendations
- B. Employ a variety of media and public awareness strategies to promote the value of family caregivers.
- C. Increase awareness and support of family caregiving issues among local, state, and national elected officials.
  - Maintain regular communication with Idaho’s local, state, and federal officials regarding ICA activities and recommendations
  - Support November as National Family Caregiver Month through a Governor’s Proclamation and other means.

- Advocate for all members of Idaho’s Congressional Delegation to join the bipartisan, bicameral Assisting Caregivers Today (ACT) Caucus.
- D. Recognize Idaho employers who demonstrate exemplary accommodation of the needs of family caregivers.
- Inform Idaho employers of the needs of family caregivers and the benefits to both employer and employee of supporting those needs.
    - Develop and distribute awareness information through civic groups, business organizations, and Chambers of Commerce
    - Identify employers who express interest in increased workplace flexibility
  - Promote the use of the WorkFlex Tool Kit<sup>26</sup> to targeted employers
  - Nominate exemplary employers for the *When Work Works* Award<sup>27</sup>

**Goal #3:** Recognize the importance of family caregiving and embed the voice of family caregivers in policy and system changes.

## *Systems Change*

Caregivers are critical, but often unrecognized, members of the healthcare team. Integrating family caregivers into a team-based, person-centered paradigm with other health care providers will assist them in delivering more effective care. Such integration is critical to achieve the triple aim of improved care (quality and satisfaction), better health, and reduced health care costs. An integrated system provides family caregivers with information about resources and supports, and when appropriate, includes them in treatment planning with their family member and provides the training needed for specialized care.

### **Objective:**

***#6: Recognize family caregivers as part of their family members’ health care and social support team.***

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<sup>26</sup> Families and Work Institute, Society for Human Resource Management, & Life Meets Work. (2012). Workflex employee toolkit. Retrieved from [http://www.whenworkworks.org/downloads/workflex\\_employee\\_toolkit.pdf](http://www.whenworkworks.org/downloads/workflex_employee_toolkit.pdf)

<sup>27</sup> The award is part of [When Work Works \(WWW\)](#), a research-based initiative which highlights how [effective and flexible workplaces](#) can yield positive business results and help employees succeed at work and at home. It is awarded annually.

### **Steps to Accomplish:**

- A. Advocate for training programs for community health emergency medical services (CHEMS) and community health workers (CHWs) to include modules on family caregiving.
  - Ensure the curriculum for training CHEMS personnel and CHWs include learning outcomes specific to caregiver identification, assessment, and support
- B. Advocate for post-secondary education programs to include curricula that equips health care and social service professionals with the skills to identify and support family caregivers.
- C. Develop a process for use of an assessment tool to determine caregiver training and self-care needs
  - Identify and promote the use of an assessment tool
  - Provide caregiver assessment tool kits to health and behavioral healthcare providers and local and regional agencies who interact with caregivers

### **Objective:**

***#7: Embed family caregiver perspective and involvement in Idaho's efforts to transform its primary care, long-term care, and behavioral health systems.***

### **Steps to Accomplish:**

- A. Ensure the Idaho Healthcare Coalition is apprised of family caregiver issues and concerns.
  - ICA's representative to the Idaho Healthcare Coalition (IHC) will share ICA information, reports, and plans at IHC meetings.
  - Advocate for caregiver representation on each of the SHIP's seven Regional Health Collaboratives
- B. Increase the awareness and knowledge of family caregiving concerns and resources for members of the BHPC and the RBHBs.
  - Share information between the BHPC and the ICA through reports to both bodies at their respective meetings
  - Ensure that caregivers on the BHPC and the RBHBs are equipped with caregiving information to serve as advocates

- C. Promote the involvement of family caregivers in the efforts to coordinate and streamline Idaho’s long-term care system via the *No Wrong Door Initiative*.
- Ensure that the Person-Centered Planning/Counseling training curriculum includes modules on how to identify and support family caregivers

**Objective:**

***#8: Include family caregivers in Idaho’s efforts to enhance employment opportunities and tax policies that support families and the state’s economic vitality.***

**Steps to Accomplish:**

- A. Collaborate with policymakers to minimize barriers that prevent family caregivers from maintaining paid employment.
- Enact leave policies and benefits that are supportive of caregivers
  - Reduce restrictions on the availability of leave benefits
  - Expand the definition of care recipients and applicable conditions under which leave can be taken
- B. Work with employers and organizations representing employers to support the growing population of working caregivers.
- Enhance caregiver information and support available through benefit plan
  - Implement fair and flexible personnel policies
- C. Collaborate with policymakers and others to update the state tax code to provide more comprehensive caregiver deductions and tax credits.

***Goal #4:*** Ensure a coordinated voice for family caregivers in Idaho through the development of a sustainable structure for the Idaho Caregiver Alliance.

## ***Infrastructure***

**T**he Idaho Caregiver Alliance (ICA) is a broad coalition of public and private organizations and individuals. The goal of the Alliance is to advance the well-being of caregivers by promoting collaboration that improves access to quality support and resources for family caregivers across the

lifespan. All members realize the value of family caregivers and recognize the limitations of existing systems to provide support to caregivers across the lifespan. The ICA has utilized this shared commitment to

- assess the needs and capacity of caregivers and support systems in Idaho
- engage caregivers throughout Idaho by hosting regional summits in Lewiston and Idaho Falls
- build statewide capacity to support caregivers through the evidence-based Powerful Tools for Caregivers (PTC) program by providing training and technical resources
- conduct a pilot program to deliver emergency respite to caregivers
- convene and report findings to members of the Idaho Legislature, IHC and the BHPC
- represent unpaid family caregivers on the IHC.

The continued presence of ICA as a public-private organization is vital to the success of ongoing efforts to support and sustain the unpaid family caregiver workforce. **An organizational home and funds to sustain the work of the Alliance are needed.**

### **Objective:**

***#9: Build on the established foundation of the Idaho Caregiver Alliance and ensure that the Idaho caregivers across the lifespan have a coordinated voice.***

### **Steps to accomplish:**

- A. Establish sustained funding for the Idaho Caregiver Alliance.
  - Meet with public and private partners to secure commitments for ongoing funding
  - Seek grant and other funding sources to support general operations and specific projects as identified in this action plan
  
- B. Serve as a voice and advocate for family caregivers across the lifespan to ensure the perspective of the caregiver is considered in all agendas.
  - Collaborate with a broad array of stakeholders including, but not limited to:
    - public agencies, such as the Idaho Departments of Health and Welfare, Labor, Education, and Commerce; Idaho Commission on Aging; AAAs; District Health Departments: Veterans Administration Medical Center (VAMC) and Veterans Hospital Administration (VHA)
    - planning and advocacy groups, such as IHC, BHPC, Developmental Disabilities Council (DDC), Consortium of Idahoans with Disabilities (CID), FFCMH, IPUL, Idaho Alzheimer's Planning Group (IAPG), Justice Alliance for Vulnerable Adults (JAVA), State Independent Living Council (SILC), Senior Health Insurance Benefits Advisors (SHIBA), etc.

- professional associations, such as Idaho Guardians and Fiduciary Association (IGFA), AARP Idaho, Idaho Association of Community Providers, Idaho Hospital Association (IHA), Idaho Health Care Association (IHCA), Idaho Public Health Association (IPHA), Idaho Primary Care Association (IPCA)
- business groups and individual employers (Chamber of Commerce, etc.)
- healthcare delivery and payer systems, such as hospitals, insurance providers, patient-centered medical homes (PCMHs), behavioral health treatment facilities
- churches and other faith-based organizations
- education systems (community colleges and universities, Family Practice Medical Residency of Idaho, etc.)

**Objective:**

***#10: Assure data are available to inform decision-making related to family caregiver supports and services.***

**Steps to Accomplish:**

- A. Implement ongoing data collection regarding the needs of family caregivers in Idaho.
  - Continue to gather and use information from family caregivers to inform program planning and implementation
  - Continue to collect and improve existing data about caregivers at state and community levels through the use of Behavioral Risk Factor Surveillance System (BRFSS) and other existing tools
  - Partner with economic development and data analysis organizations to track and synthesize data pertaining to economic impact and implications of family caregiving
  
- B. Implement data collection strategies to evaluate impact of programs and systems change on family caregivers.
  - Use findings to guide quality improvement and program planning
  - Report findings to stakeholders, funders, and policy makers to ensure accountability and responsible use of resources

# *Acronyms and Abbreviations*

ACL	Administration on Community Living (federal agency)
AARP	Formerly the American Association for Retired Persons – now just AARP
AAA	Area Agency on Aging, six of these located across Idaho
BH	Behavioral Health, a division within Department of Health and Welfare
BHPC	State Behavioral Health Planning Council
BRFSS	Behavioral Risk Factor Surveillance System
CHEMS	Community Health Emergency Medical Services
CHW	Community Health Workers – personnel that are part of the Statewide Health Innovation Plan
CIL	Center on Independent Living (same as Independent Living Center; three of these across Idaho)
CSA	Center for the Study of Aging at Boise State University
DDC	Developmental Disabilities Council
FPMR	Family Practice Medical Residency
IAPG	Idaho Alzheimer’s Planning Group
ICA	Idaho Caregiver Alliance
ICOA	Idaho Commission on Aging
IDHW	Idaho Department of Health and Welfare
IFFCMH	Idaho Federation of Families or Children’s Mental Health, a non-profit organization
IGFA	Idaho Guardians and Fiduciary Association
IHA	Idaho Hospital Association
IHC	Idaho Healthcare Coalition
IHCA	Idaho Health Care Association (nursing homes and assisted living facilities)
ILC	Independent Living Center (same as Center on Independent Living)
IPCA	Idaho Primary Care Association
IPHA	Idaho Public Health Association



JAVA	Justice Alliance for Vulnerable Adults
NWD	No Wrong Door – an initiative of the Idaho Commission on Aging
PCC/PCP	Person-Centered Counseling/Person-Centered Planning
PCMH	Person-Centered/Patient-Centered Medical Home
PTC	Powerful Tools for Caregivers, an evidence-based program teaching caregivers about self-care
RBHB	Regional Behavioral Health Board
SHIBA	State Health Insurance Benefit Advisors
SHIP	State Healthcare Innovation Plan
SILC	State Independent Living Council
VAMC	Veterans Administration Medical Center
VHA	Veterans Hospital Administration

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