



## ***Strategic Plan 2020-2024***

***Our Vision:*** To serve as the voice, convener, and catalyst for support of unpaid family caregivers across the lifespan.

***Our Mission:*** To advance the well-being of caregivers by promoting collaboration that improves access to quality supports and resources including respite for family caregivers across the lifespan.

***Our Values:*** Collaboration, communication, inclusiveness and capacity building for family caregivers across the lifespan.

*The Idaho Caregiver Alliance (ICA) is a statewide coalition of over 400 caregivers, organizations, and agencies working together to raise awareness of the impact of caregiving and to advocate for policies and practices that support caregivers.*

*Each year, 200,000-300,000 Idahoans provide unpaid care and support for their family members and friends. They do this out of love, respect, and necessity to postpone placement in an institution or avoid an unnecessary emergency room visit.*

*This document details the 2020 ICA Action Plan and outlines opportunities, challenges, and strategic objectives. Evidence of the critical role family caregivers fill is provided in the appendix. We welcome your input and engagement as a supporter of the ICA. You can find us online at [www.idahocaregiveralliance.com](http://www.idahocaregiveralliance.com).*

## STRATEGIC GOALS

## STRATEGIC OBJECTIVES

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| <p><b>Goal 1: FAMILY CAREGIVER SUPPORTS:</b> Ensure a streamlined, coordinated system of supports for caregivers across the lifespan, recognizing the unique needs of Idaho’s diverse population.</p> | <ol style="list-style-type: none"><li>1. <i>Develop statewide respite resources</i></li><li>2. <i>Improve access to training for respite providers across the lifespan</i></li><li>3. <i>Ensure accessible and culturally appropriate information and resources are available to caregivers across the lifespan</i></li><li>4. <i>Improve access to training resources for family caregivers on caregiving tasks and strategies for self-care</i></li><li>5. <i>Establish a statewide public/private network of individuals equipped to serve as information and support navigators for family caregivers</i></li></ol> |
| <p><b>Goal 2: PUBLIC AWARENESS:</b> Increase public awareness about unpaid family caregiving across the lifespan and help people within our communities identify as caregivers.</p>                   | <ol style="list-style-type: none"><li>6. <i>Increase awareness of the role and value of family caregivers</i></li><li>7. <i>Increase awareness among policy makers and the general public of the contributions and needs of family caregivers across the lifespan</i></li><li>8. <i>Increase recognition of the family caregiver in the workplace</i></li></ol>   |
| <p><b>Goal 3: SYSTEMS CHANGE:</b> Recognize the importance of family caregiving across the lifespan and embed the voice of family caregivers in policy and system changes.</p>                        | <ol style="list-style-type: none"><li>9. <i>Promote a workforce of trained care providers that is available and accessible to provide supports, respite and backup to family caregivers</i></li><li>10. <i>Embed family caregiver perspective and involvement in Idaho’s efforts to transform its primary care, long-term care, and behavioral health systems</i></li><li>11. <i>Include family caregivers in Idaho’s efforts to enhance employment opportunities and tax policies that support families and the state’s economic vitality</i></li></ol>  |
| <p><b>Goal 4: INFRASTRUCTURE:</b> Ensure a coordinated voice for family caregivers across the lifespan through the development of a sustainable structure for the Idaho Caregiver Alliance.</p>       | <ol style="list-style-type: none"><li>12. <i>Expand the capacity of the Idaho Caregiver Alliance to serve as voice, convener, and catalyst</i></li><li>13. <i>Maximize use of web, social media, and other communication strategies to engage family caregivers and the public</i></li><li>14. <i>Employ assessment and evaluation strategies that provide evidence needed for effective use of resources, decision making, and planning</i></li></ol>  |

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

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.

***STRATEGIC OBJECTIVES:***

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

- A. Expand a directory of web-based resources that include a wide range of available respite services.
- B. Expand sustainable community-based respite programs.
- C. Promote use of respite and caregiver support programs offered through collaborative community organizations.

***#2: Improve access to training for respite providers across the lifespan.***

- A. Identify and promote training opportunities for respite providers, service agencies, and caregivers.
- B. Support implementation of coordinated statewide training for respite providers
- C. Support development of minimum training requirements and standards for respite providers.

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

- A. Identify and share information designed to meet the needs of under-represented populations, including those in rural areas in Idaho.
- B. Advocate for the development of information that is accessible to all users by promoting ICA communication in compliance with Section 508 of the 1973 Rehabilitation Act.

***#4: Improve access to training resources for family caregivers on caregiving tasks and strategies for self-care.***

- A. Advocate for the use of a common caregiver assessment tool.
- B. Promote the use of caregiver training resources, including self-care supports such as the Powerful tools for Caregivers (PTC) program.
- C. Promote the use of a variety of training resources and delivery modalities.

*#5: Establish a public/private statewide network of individuals equipped to serve as information and support navigators for family caregivers.*

- A. Partner with existing agencies and organizations to enhance or expand navigator services within their structures.
- B. Develop a business plan for implementation of a statewide navigator program.
- C. Promote the use of navigation services to family caregivers.

**Goal 2: PUBLIC AWARENESS:** Increase public awareness about unpaid family caregiving across the lifespan and help people within our communities identify as caregivers.

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.

***STRATEGIC OBJECTIVES:***

*#6: Increase awareness of the role and value of family caregivers.*

- A. Ensure family caregivers and others are equipped to advocate for the supports needed so that they can continue to provide care.
- B. Increase knowledge of family caregiving through publications and presentations tailored for the community, elected officials, faith-based organizations, veterans and veterans organizations, employees, employers and others.
- C. Promote the use of a caregiver self-assessment tool to help caregivers recognize their caregiving role and its impact.

*#7: Increase awareness among policy makers and the general public of the contributions and needs of family caregivers across the lifespan.*

- A. Expand community engagement through continued coordination of regional caregiver summits and statewide Idaho Caregiver Alliance (ICA) meetings.
- B. Provide information on family caregiving through workshops and presentations.
- C. Increase awareness and support of family caregiving issues among local, state, and national elected officials.

*#8: Increase recognition of family caregivers in the workforce.*

- A. Promote the development of benefit packages tailored to meet the needs of caregivers.
- B. Partner with the Idaho Department of Labor and other entities to gather Idaho specific information on the impact of family caregiving on employers and employees.
- C. Provide information on family caregiving to employers and employees through workshops and presentations.

**Goal 3: SYSTEMS CHANGE:** Recognize the importance of family caregiving across the lifespan and embed the voice of family caregivers in policy and systems changes.

Family caregivers are often invisible in the design and implementation of service delivery systems. The patient or member is usually the focus of the system's structure, but the impact on the family is often overlooked. The role of the family is critical because they bear much of the responsibility for ensuring that the person they are caring for is safe, healthy, and as independent as possible. Systems of care and the laws and policies that support them must recognize the important role of family caregivers and include them in their decisions, structure, and operations. An integrated system provides family caregivers with information about resources and supports, and when appropriate, includes them in planning with/for their family member and, when appropriate, also provides the training needed for specialized care.

**STRATEGIC OBJECTIVES:**

*#9: Promote a workforce of trained care providers that is available and accessible to provide supports and respite to family caregivers.*

- A. Advocate for secondary and post-secondary education programs to include curricula and service-learning opportunities for students to prepare them to identify and support family caregivers.
- B. Promote an accessible and quality direct care workforce including the utilization of community health workers to identify and address caregiver support needs.

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

- A. Ensure the ICA (or a caregiver representative) has representation on councils, commissions, and workgroups that advise state policies regarding primary care, long-term services and supports and behavioral health issues.
- B. Advocate for training that includes modules on how to identify and support family caregivers.
- C. Advocate for the development of funding proposals that support family caregivers.
- D. Collaborate with national initiatives that support family caregivers.

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

- A. Collaborate with policymakers to promote leave policies and benefits that are supportive of caregivers.
- B. Work with employers and organizations representing employers to support the growing population of working caregivers through 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: INFRASTRUCTURE:** Ensure a coordinated voice for family caregivers across the lifespan through the development of a sustainable structure for the Idaho Caregiver Alliance.

The 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 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.

*#12: Expand capacity of the Idaho Caregiver Alliance to serve as voice, convener, and catalyst.*

- A. Establish sustained funding for the Idaho Caregiver Alliance through public and private partnerships and grants.
- B. Serve as a voice and advocate for family caregivers across the lifespan to ensure the perspective of the caregivers is considered in all agendas.
- C. Invite and include caregivers and their perspectives and concerns in ICA activities.

*#13: Maximize use of web, social media, and other communication strategies to engage family caregivers and the public*

- A. Develop and implement a statewide marketing plan for outreach and education.
- B. Provide regular policy updates regarding issues impacting family caregivers.
- C. Collaborate with existing database networks to exchange information and expand contacts

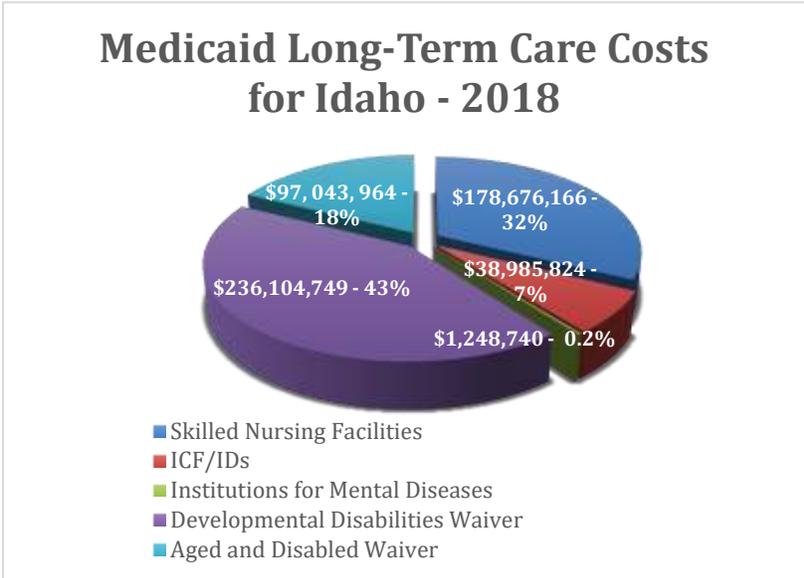
*#14: Employ assessment and evaluation strategies that provide evidence needed for effective use of resources, decision making, and planning.*

- A. Implement ongoing data collection efforts regarding the needs of family caregivers in Idaho, including the impact on caregiver stress, employment, finances, and health.
- B. Implement data collection strategies to evaluate impact of programs and systems change on family caregivers.
- C. Ensure ICA policy and service system recommendations are evidence-based.

# Appendix

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 **171 million hours of uncompensated care annually** at an estimated value of **\$2.3**



**billion to Idaho’s economy.**<sup>3</sup> This is equivalent to Idaho’s current budget for all publicly funded long-term care services (see Figure 1).<sup>4</sup>

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 psychiatric

<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 2018: Valuing the Invaluable Update: Understanding the Impact of Family Caregiving on Work* (AARP Public Policy Institute)  
<sup>4</sup> *Medicaid claims data, 2018; waiver costs do not include Medicaid services outside of HCBS waiver services*

hospitals. In 2018, Idaho’s Medicaid spending for long-term care was \$552,059,444, just under 1/4 of its total budget of \$2,343,605,500.<sup>5</sup> Of this amount, **40% or \$218,910,730 was spent on care in these settings.**<sup>6</sup> An investment in family caregivers reflects Idaho’s values of fiscal responsibility.

## 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.

### 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

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.

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<sup>5</sup> 2018 Legislative Fiscal Report, Medicaid Total Appropriation for 2018

<sup>6</sup> Medicaid claims data, 2018; waiver costs do not include Medicaid services outside of HCBS waiver services

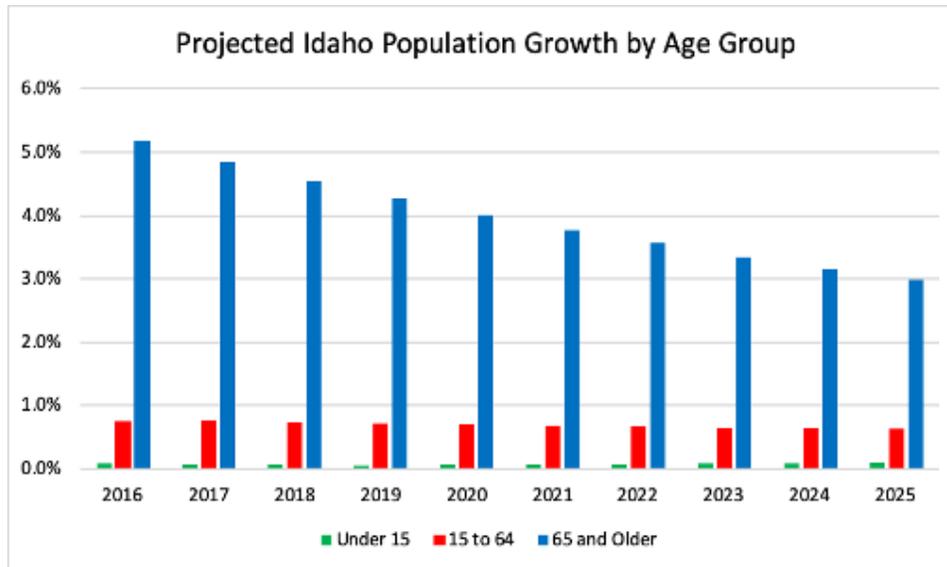


Figure 2 – Change in age distribution of Idaho population: 2016 – 2025  
Idaho Department of Labor

**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 (see Figure 2), the population aged 65 and older in Idaho will grow by 4.0% annually over the next decade, while the working age population will grow by a mere 0.7%.<sup>7</sup> Between 2001 and 2025, the projected

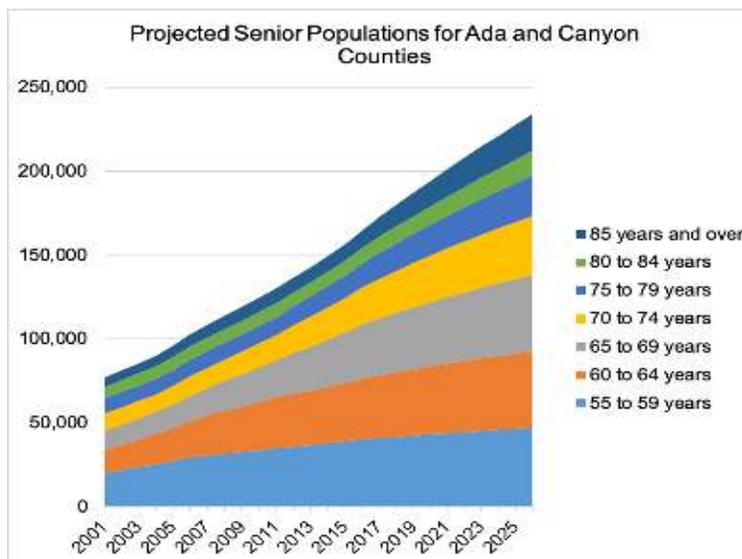


Figure 3 – Change in age distribution of Ada and Canyon county population: 2001 - 2025  
Idaho Department of Labor

population growth in Ada and Canyon counties of persons 55 years of age and older increases from nearly 77,000 to over 230,000 people (see Figure 3).

Ten years ago, there were approximately 6 working age adults for every person age 65 and older. By 2025, this ratio is projected to decrease to 3:1 – a 50% reduction.<sup>8</sup>

Consider the family caregiver pool is also shrinking. In 2015, there were 7 people ages 45 to 64 (peak caregiver ages) to each person age 80 or older (peak care recipient age group). It is estimated that by 2030, this ratio

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

<sup>8</sup> Ibid

decreases to 4:1. By 2050, the ratio further drops to 3:1.<sup>9</sup> These demographic shifts foreshadow a caregiver crisis; Idaho will have significantly fewer family caregivers to care for a growing aging population.

While the typical age of a family caregiver is between 45 to 64 years of age, the “millennial” population (people born between 1980 and 1996) is also engaged in caregiving. It’s estimated that one in every four family caregivers is a millennial. This population of family caregivers balance a typical work week of 36 hours with more than 20 hours per week providing care. In addition, one in three millennial caregivers care for a person with an emotional or mental health problem.<sup>10</sup>

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>11</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.

**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>12</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

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<sup>9</sup> *Across the States, profiles of Long-term Services and Supports.* (AARP, 2018)

<sup>10</sup> *Millennials: The emerging generation of family caregivers.* (AARP Public Policy Institute, 2018).

<sup>11</sup> *Family Caregivers are Wired for Health.* Pew Internet and American Life Project (Fox, S., Duggan, K., Purcell, K., 2013)

<sup>12</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

parents financially within the past year (see Figure 4).<sup>13</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.

**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>14</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>15</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>16</sup>

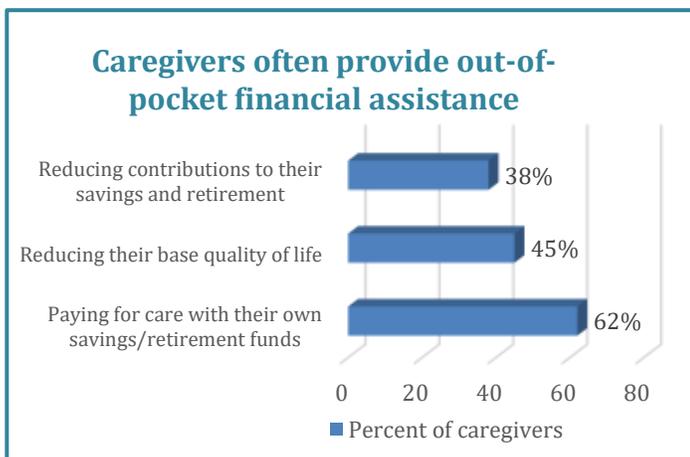


Figure 4 – Out-of-pocket financial assistance  
*Beyond Dollars: The Expanding Circle of Care, Executive Summary, Genworth Financial, 2016*

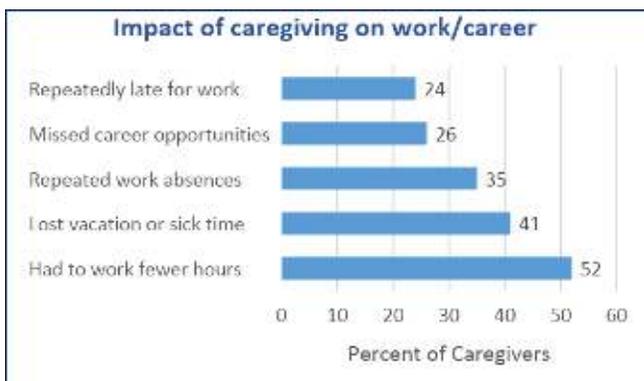


Figure 5 - Impact of caregiving on work/career  
*Beyond Dollars: The Expanding Circle of Care, Executive Summary, Genworth Financial, 2016*

**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>17</sup> A national study indicates that 6 out of 10 caregivers have had to make workplace accommodations to meet their caregiving responsibilities (see Figure 5). These changes can range from cutting back

<sup>13</sup> *Family Support in Graying Societies: How Americans, Germans and Italians are Coping with an Aging Population* (Pew Research Center, 2015)  
<sup>14</sup> *Long-Term Care Insurance Less Bang More Buck* (Kaiser Family Foundation, March 17, 2016)  
<sup>15</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>16</sup> *Long-Term Care Insurance: Is It Worth It?* (Scism, L, Wall Street Journal, May 1, 2015)  
<sup>17</sup> *Idaho Caregiver Needs and Respite Capacity Report, 2014.* (Cirerol, T & Toevs, S.E. )

work hours to taking a leave of absence, to receiving a warning for poor performance or attendance.<sup>18</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 caregivers lose about \$660,000 in wage wealth over their lifetime because of work sacrifices.<sup>19</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.

**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>20</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>21</sup> There is also evidence that spouses caring for a partner with dementia are at an increased risk of dementia themselves.<sup>22</sup> With these negative health impacts, caregivers are ultimately at risk of needing care – and a caregiver – themselves.

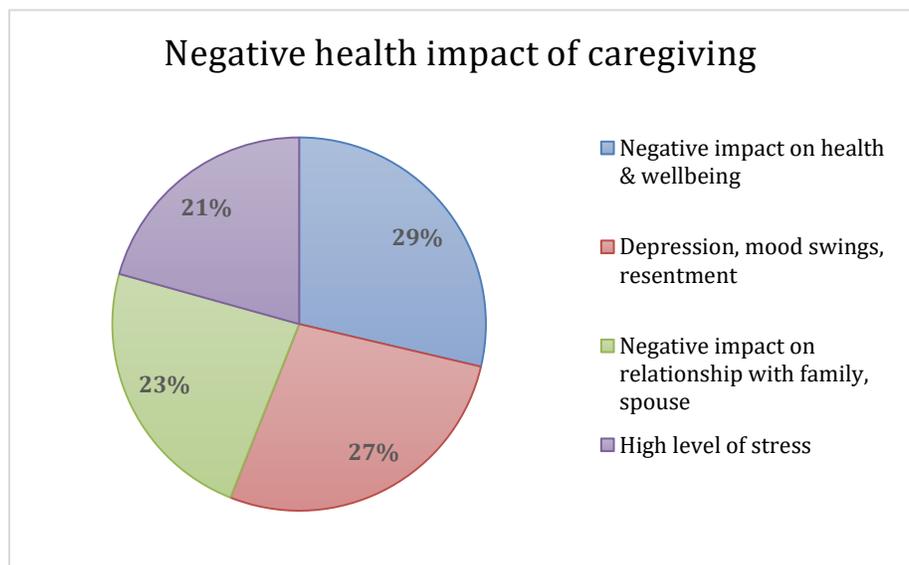


Figure 6 – Negative health impact of caregiving  
*Beyond Dollars: The Expanding Circle of Care, Executive Summary, Genworth Financial, 2016*

<sup>18</sup> *Caregiving in the U.S., Executive Summary* (AARP Public Policy Institute, June, 2015, p.22)

<sup>19</sup> *About Caregiving, Guide to Long Term Care Planning* (Day, T. National Care Planning Council, 2016)

<sup>20</sup> *Stress in America: Our Health at Risk* (American Psychological Association, January, 2012, p. 5)

<sup>21</sup> *Stress in America: Our Health at Risk* (American Psychological Association, January, 2012, p. 8)

<sup>22</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>23</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>24,25</sup> In fact, the average annual cost to employers per full-time working caregiver is \$2,110.20.<sup>26</sup>

## 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 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.

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<sup>23</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>24</sup> *MetLife Study of Working Caregivers and Employer Health Care Costs* (MetLife Mature Institute, National Alliance for Caregiving, & University of Pittsburgh, February 2010)

<sup>25</sup> *Caregiving in the US. 2015 – Focused Look at Caregivers Age 50+* (National Alliance for Caregiving & AARP Public Policy Institute, 2015)

<sup>26</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)

**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 this work be 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.

## *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   |
| HTCI   | Healthcare Transformation Council of Idaho  |
| 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  |
| IHCA   | Idaho Health Care Association (nursing homes and assisted living facilities)                  |
| IHCCA  | Idaho Health Continuum of Care Alliance   |
| 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 and resilience |
| RBHB    | Regional Behavioral Health Board  |
| SHIBA   | State Health Insurance Benefit Advisors   |
| SILC    | State Independent Living Council  |
| VAMC    | Veterans Administration Medical Center  |
| VHA     | Veterans Hospital Administration  |

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