

Caregivers in Idaho

A Report from the Idaho Family Caregiver Task Force
and the Idaho Caregiver Alliance

December, 2015

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Idaho Caregiver Alliance (sponsored by the Idaho Commission
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EXECUTIVE SUMMARY

Every day, thousands of Idahoans work 24/7, with love and dedication taking care of a family member who is elderly or has a physical or intellectual disability or mental illness. For some, caregiving lasts a few years. For others, particularly parents of children with physical or emotional disabilities, it lasts a lifetime. These caregivers are the largest workforce in Idaho and, while they find joy in their role as a caregiver, they are exhausted and burning out.

In response to this need and HCR 24, passed in 2015, the Idaho Caregiver Alliance formed a Task Force comprised of a wide array of individuals, many of whom had not worked together before, to examine policies, resources and programs available for caregivers in Idaho and other states. The Task Force also studied innovative ways to support unpaid family caregivers.

What the Task Force discovered was that although there are well-intentioned efforts across the state, they are fragmented, siloed, and often limited to specific conditions or geographic areas. In short, **the supports for unpaid family caregivers are inadequate to meet the present and forecasted needs**. Caregivers in Idaho must manage multi-faceted and complex care on behalf of their loved one, and they must do this without the information, training, and support they need. The result of this is caregiver burnout, costly hospitalization, or institutional care for the care recipient.

Task Force Findings:

- ✓ Family caregiving impacts all aspects of a family's economic, physical, cultural, and social wellbeing.
 - Most caregivers are juggling paid work and caregiving.
 - Caregiver stress has costs.
- ✓ Assistance is fragmented and mostly focused on the care recipient.
- ✓ Demographics are changing; 23 % of Idaho's population will be over age 60 by the year 2030, an increase of 33 % from 2012 (US Census Bureau, 2009 Projections).
- ✓ Non-profit organizations have not been a sustainable source of support for caregivers.
- ✓ Respite care is inadequate.

We can and must do better. The Task Force offers the following recommendations to begin the process of supporting these caregivers. Recommendations have been organized by support category and color.

FAMILY CAREGIVERS SUPPORTS

- **Priority #1** – Equip and expand a network of individuals who assist family caregivers to understand, access, and arrange complex services.
- **Priority #2** – Provide access to training for caregivers on fundamental care responsibilities and self-care strategies.

COMMUNITY AWARENESS AND ENGAGEMENT

- **Priority #1** – Increase public awareness about caregiving including helping people identify as caregivers.

SYSTEMS CHANGE

- **Priority #1** - Influence health care providers to recognize family caregivers as integral members of the health care team.
- **Priority #2** - Build community resources within the medical-health neighborhood to support those in a family caregiver role, through the seven State Health Innovation Plan (SHIP) Regional Health Collaboratives.
- **Priority #3** - Integrate the needs and contributions of unpaid family caregivers in other system transformation efforts.

But this is just the beginning. Addressing the priorities identified by the Task Force will not happen without a coordinated and sustained effort. The Idaho Caregiver Alliance has made progress (**see Attachment A**), but developing the supports caregivers need and deserve will require the involvement of policy makers and private and public funding. We know an investment in family caregivers will save the state of Idaho money, jobs, and lives.

We ask that you:

- ✓ Learn more about the issues facing unpaid family caregivers in Idaho
- ✓ Identify the caregivers in your life
- ✓ Partner with the Idaho Caregiver Alliance to identify resources for family caregivers
- ✓ Endorse the collaboration between the Idaho SHIP and the Caregiver Alliance
- ✓ Support the development of a plan to implement the recommendations identified in this report
- ✓ **Become a caregiver champion!**

INTRODUCTION

There is a huge, invisible workforce in Idaho. Each year, more than 300,000 Idaho family members (more than 1 in 4), assume critical, ongoing care responsibilities for aging parents, siblings, spouses, children or grandchildren with physical or emotional disabilities, or chronic illnesses.¹ These family members provide 201 billion hours of uncompensated care annually at an estimated value of \$2 billion to Idaho's economy.² This is equivalent to Idaho's budget for all publicly-funded long-term care services.³

This report tells you their story. It highlights the current state of caregiver services in Idaho. It offers recommendations to support this workforce, ensuring they have the information and resources needed to prevent caregiver burn out and the inability to continue providing care. The recommendations were developed during an intensive 6-month period of shared learning, deliberation, and consensus building among a diverse group of professionals from private and public sectors, caregivers, and care recipients striving to remain in their home and community. The energy and commitment to this process embodies the urgency and gravity of the state of affairs for family caregivers in Idaho

WHO ARE FAMILY CAREGIVERS?

- An attorney in solo practice in Boise whose otherwise healthy wife had a stroke and was being discharged from a rehabilitation facility.
- A young couple in Bonners Ferry with two small children, the father works in the North Dakota oilfields, and they have a new baby with significant disabilities.
- A 42-year-old mother of four in Eagle who works full time and whose 10-year-old adopted daughter struggles with critical behaviors due to schizoaffective disorder and reactive attachment disorder.
- A 45-year-old long-haul trucker who lives in Payette who learns that his 73-year-old mother in Salmon was found wandering in the street unaware of where she was.

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

¹ 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); Idaho 2014 Needs Assessment, Boise State University, Center for the Study of Aging

² Ibid.

³ FY 2016 Legislative Budget Book, Department of Health and Welfare FY 2015 appropriation, p. 2-8

- A 69-year-old-widow in Filer who just learned that her daughter had been seriously injured in an accident; the widow is the only family member who can care for her three grandchildren, ages 2, 5, and 7.
- A school teacher in Caldwell, trying to help her teenage son with disabilities find a job after high school, while also supporting her 85-year-old grandmother who has Parkinson's, diabetes, and a heart condition.

What do these Idahoans have in common? They are all family caregivers. They are your brothers and sisters, parents and grandparents, children, cousins, friends. They are you. There are thousands of family caregivers across Idaho who work every day, 24/7, with love and dedication to take care of their family member. For some, it lasts a few years. For others it lasts a lifetime. Caregivers recognize and accept their responsibilities but they are isolated, frustrated, and exhausted. They are burning out.

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 and an aging parent.⁴ For parents of children or adults with disabilities, it is a full-time job. If the caregiver is employed outside the home and has no flexibility such as personal leave, caregiver demands may require reducing paid employment or leaving employment altogether. Employment changes cause a ripple effect: loss of health care benefits, diminished financial independence, and physical and emotional stress.

Family caregiving impacts all aspects of a family's economic, physical, cultural, and social wellbeing. The demands create stress not only on the caregiver, but other family members as well. The demands can jeopardize the health of the caregiver. Caregiving can jeopardize a family's ability to maintain their housing or provide community-based care for a loved one, or cause a family member (including the caregiver) to postpone educational opportunities that could improve their future. For families with children with disabilities, siblings also feel the impact as the family focuses their energies and attention on the demands of the child with special needs.

"I was surprised that my doctor's office had no information. Putting brochures and giving them information seems like a good place. Everything I learned I had to research and ask lots of questions because none of the agencies had information about options but their own."

Respondent to NWD Survey, p. 60

Informational resources are fragmented and difficult to access. As family caregivers seek information about services, they are confronted with a confusing array of information filled with acronyms and complex eligibility requirements. Information and programs are often poorly coordinated, siloed, inconsistent, or the family just does not

⁴ Idaho Caregiver Needs and Respite Capacity Report, 2014., Tami Cirerol and Sarah E. Toevs, p. 8

know what they need or where to find it. Families without easy access to the internet are particularly challenged to know where to seek help. And as the baby boomers age and the care becomes more complex, the pressure on caregivers is increasing.

Changing demographics. From 2015 through 2020, the number of Idahoans age 65 and older will increase by more than 20%, while those 25 to 64 (those providing care for the older population) will grow by 5% or less.⁵

CAREGIVER RESOURCE GAPS IN IDAHO

Assistance is limited, fragmented and based mostly on the care recipient. Across Idaho, there are pockets of assistance for family caregivers. These supports are often specific to a defined health condition, such as autism or Alzheimer’s disease or only available in a limited number of communities. Services and resources are not connected across disciplines, communities or agencies, and **in almost every situation, available support is based on the needs of the care recipient, not the caregiver.** Privacy regulations specific to health information also make it difficult for caregivers to get the information and support they need to be effective in their caregiving responsibilities.

Inadequate training and information for caregivers. Caregivers are increasingly expected to manage complex medical and/or psychological conditions with little to no information, instruction, or support. They may need technical medical information to manage changes in behavioral health, provide wound care, operate medical equipment in the home, or administer medications correctly. Caregivers must anticipate needs and changes in health status, but they are often not included in the conversation or they are overwhelmed by the information. The results of this can be costly – crises, medical complications, hospitalization, even death.

Caregiver support is lacking. In addition to technical information, caregivers benefit from time off from caregiving (respite), transportation assistance, spiritual and emotional support (such as provided through a church or support group), sharing of caregiving responsibilities so a job is not in jeopardy, flexible work hours, and other tangible supports are needed. These forms of assistance can mean the difference between the care recipient remaining at home, or being placed in a nursing home or other facility.

“Caregiving isn’t a disease. Although many similar issues are involved, caregiver stress inexorably arises from caregiving duties.”

Pamela T.

Caregiver of adult son with disabilities

⁵ 2015 Fiscal Facts. Idaho Legislative Services Office, p. 7

Caregiver stress has costs. When a family caregiver is not empowered with knowledge and resources, they feel overwhelmed with the endless tasks in caregiving which can lead them to taking their loved one to the emergency room. When the community does not

“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*

prioritize the health of the caregiver, the amount of people needing medical care is exponentially increased. Not only will the patient need services, so will the caregiver. “These caregivers fill an important role for their families and provide an estimated \$375 billion in cost savings nationwide”⁶, costs that the health care system will incur if caregivers are not supported.

Non-profits have not been a sustainable resource. Utilizing a private non-profit model to meet the needs of caregivers in Idaho has proven to be unsustainable. An example is the Boise-based Friends in Action (FIA), founded in Boise in 2004 with seed money from the Robert Wood Johnson Foundation. FIA trained volunteers to deliver a wide array of services to caregivers across the Treasure Valley, including respite, caregiver coaching, and education. In 2015, after many years of seeking grant support, private donations, and collaboration with other organizations, FIA was forced to drastically reduce services due to lack of funding. The two remaining staff are struggling to provide services to the more than 100 families currently on a waiting list.⁷

“I wait on my (blind) husband 24/7. Sometimes I need to get away. Sometimes I need to shop for necessities. Family members are not reliable. They have families of their own to care for. When I want to scream, I am not so nice to my husband and he is a wonderful person.”

Respondent to NWD Survey, p. 62

Legacy Corps, an AmeriCorps program focused on providing support to caregivers of veterans and military family members, will allow respite services to continue through 2017, although all other education and support services offered through FIA will cease in March of 2016. This will leave a large gap in services among some of Idaho’s most vulnerable caregiving populations.

Legacy Corps is funded partially by federal tax dollars through the Corporation for National and Community Service, with match funding provided primarily by the Idaho Division of

⁶ Institute of Medicine. Retooling for an Aging American: Building the Health Care Workforce. Washington, DC: The National Academies Press; 2008; http://books.nap.edu/openbook.php?record_id=12-89. Accessed March 24, 2011

⁷ Email communication from Kelle Sweeney, Friends in Action, 12/18/2015

Veteran Services. Without funding from this federal and state partnership, these services too would cease.

Respite care resource information is inadequate and respite resources underfunded.

An analysis of respite care, the ability to have some “time away” from the responsibility of providing care, in Idaho, conducted by Boise State University, demonstrates the inadequacy and fragmentation of respite assistance. This research reveals that there is:

- no common definition of “respite care”
- no standards for respite care providers (except for basic standards in Children’s Mental Health)
- no statewide registry of providers
- widely varying costs and reimbursement rates for a range of services that might fit under the definition of respite.

These gaps and inconsistencies create challenges for the consumer/caregiver including:

- lack of understanding about what respite is
- difficulty finding respite care, and
- difficulty having the resources to pay for it.

These challenges lead to underutilization of available services and caregiver burnout.

Currently there are no options for pediatric respite care in Idaho. According to case manager Freda Reed, RN at St. Luke’s Children’s Hospital in Boise, respite admissions at St. Luke’s Children’s Hospital account for up to 3% of annual admissions. Parents of children with life-limiting, multi-faceted and complex diagnoses have nowhere to turn but to inpatient hospitalization when they have reached the point of caregiver burnout. When possible, case management and social workers at St. Luke’s try to secure nursing hours for patients through private home health agencies, but this is not always possible depending upon the caregiver’s income, geography and insurance. There is currently an effort by a private individual to open a small respite facility in Eagle for children with such conditions. Lucas House, named after a son born with significant disabilities, is in fundraising mode and completion of the facility is still uncertain.

TASK FORCE PROCESS:

The Task Force (See **Attachment B** for members) began its work in July, 2015, and over the course of 6 months invested significant time and energy in learning from each other, discussing challenges and ideas, reviewing data (see **Attachment D**) and brainstorming innovative concepts that can improve the status quo. Task Force members were informed about:

- respite needs and use statewide

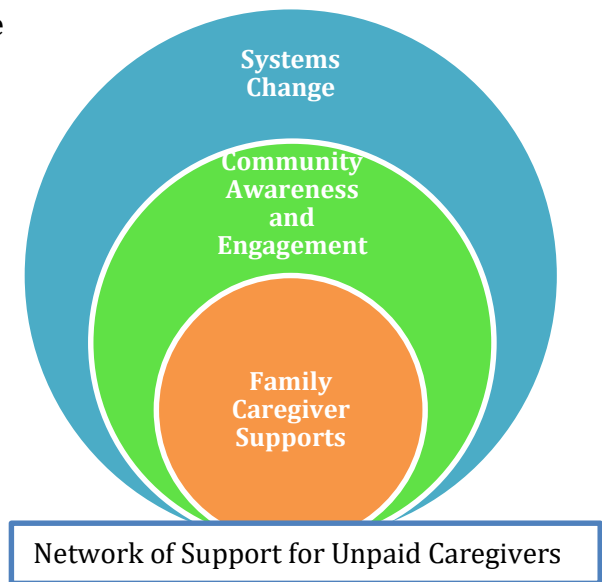
- the State Healthcare Innovation Plan (SHIP) and how caregivers can be integrated in the development of medical/health neighborhoods
- the Idaho Commission on Aging’s No Wrong Door (NWD) Initiative’s intent to streamline access to long-term care and the important role caregivers assume in accessibility to long term care
- caregiver challenges expressed at two regional summits attended by more than 200 caregivers
- care coordination within insurance plans
- policy issues impacting caregiving at the national level as well as in other states.

By examining current policy initiatives and available information and research, members grouped their concerns into categories for more in-depth work, listed in **Attachment C**. That work resulted in the following recommendations. These recommendations reflect initial steps in the development of a network of support and assistance for caregivers in Idaho.

RECOMMENDATIONS:

A. FAMILY CAREGIVERS SUPPORTS:

Supports for Family Caregivers – Family caregivers 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. Receiving this support and training translates into better caregiving and cost savings to our health and social service systems.



● Priority #1 – Equip and expand a network of individuals who assist family caregivers to understand, access, and arrange complex services.

Action Steps:

- Create a system of individuals with expertise in caregiver needs and assistance to serve caregivers across the lifespan. This should be linked to the new initiatives of the SHIP and NWD.*
- Identify an assessment tool and process that can be used to determine caregiver needs and competencies to assume and maintain caregiving responsibilities.*

- c. *Develop the scope for a collaboratively funded, standards-based statewide Respite Registry, providing caregivers with information to make decisions about care providers.*
- d. *Equip the Idaho 2-1-1 Careline and the No Wrong Door systems with a caregiver portal designed to provide access to person-centered information and resources.*
- e. *Develop an individualized package of information, local caregiving resources, and strategies that can be provided to caregivers and others at critical points.*


 **Priority #2 – Provide access to training for caregivers on fundamental care responsibilities and self-care strategies.**

Action Steps:

- a. *Expand the Powerful Tools for Caregivers training program throughout the state.*
- b. *Identify other best-practice training, such as REST (Respite Education and Support Tools training) that could be accessed or made available to Idaho family caregivers.*
- c. *Include a track for training caregivers at the annual Human Partnerships conference and other events/venues as appropriate.*

B. COMMUNITY AWARENESS AND ENGAGEMENT:

Information, Education and Public Awareness – Family caregivers are more likely to seek help such as respite, information, and training when they recognize they are in a caregiving role. This self “identification” removes a major hurdle to seeking assistance with stress, isolation, and other caregiving challenges. A public campaign is needed to increase the number of individuals who recognize they are caregivers, to increase awareness about the value of caregivers, and to connect family caregivers with support, information and training so they can continue providing care.

 **Priority #1 – Increase public awareness about caregiving including helping people identify as caregivers.**

Action Steps:

- a. *Utilize social media and other strategies to build awareness of caregiving and help caregivers self-identify.*
- b. *Inform and build support for family caregivers using a variety of venues (workshops, presentations, conferences, networking, the written word, public service announcements, etc.).*
- c. *Continue to expand community engagement through the coordination of regional and statewide alliance meetings.*

- d. *Promote November as National Family Caregiver Month with a Governor’s Proclamation and other means.*
- e. *Develop liaison with other like-minded organizations and coalitions to advance similar agendas (e.g. Justice Alliance for Vulnerable Adults, JAVA).*

C. SYSTEMS CHANGE:

Integration of Family Caregivers into Health Systems Transformations –

Caregivers are a critical but often unrecognized member of the health care team. Integrating family caregivers into a team-based approach helps caregivers be effective in providing the specialized care their family member needs, and is critical to reducing unnecessary medical care use (e.g. emergency room visits or hospitalizations). Integration means family caregivers are included appropriately in decisions about their family member’s health and medical care, including access to the person’s medical records, training regarding specialized procedures or medication administration, or being provided information about caregiving resources and support. The current transformation and streamlining of the primary care and long-term service systems to becoming more patient- and family-focused provide opportunities for caregivers to be integrated as a team member.

“How much easier our caregiving journey would have been if more of the medical providers around us had understood what we needed to win our battle. Often we have felt like victims of a paternalistic system dispensed by people who either didn’t realize what we were going through, or who didn’t care.”

*Pamela T.
Caregiver of adult son with disabilities*

● Priority #1 - Influence health care providers to recognize family caregivers as integral members of the health care team.

Action Steps:

- a. *Work with partners and the SHIP initiative to include a caregiver module in training programs for community health emergency medical services (CHEMS) and community health workers (CHWs).*
- b. *Through the seven SHIP Regional Health Collaboratives, work to bring an understanding of caregiver roles and needs to medical practices transforming to patient-centered medical homes.*

● Priority #2 - Build community resources with the medical-health neighborhood to support those in a family caregiver role through the seven State Health Innovation Plan (SHIP) Regional Health Collaboratives.

Action Steps:

- a. *Identify local family caregivers to serve as liaisons to the each of the seven Regional Health Collaboratives.*
- b. *Ensure that family caregiver needs and roles are included in health system transformation through the Idaho Caregiver Alliance serving as a foundational advisory group to the SHIP, the Idaho Healthcare Coalition, and the seven Regional Health Collaboratives.*

 ***Priority #3 – Integrate the needs and contributions of unpaid family caregivers in other system transformation efforts.***

Action Steps:

- a. *Collaborate with the No Wrong Door (NWD) Initiative to include and strengthen the role of and information for caregivers in the development of Person-Centered Planning training.*
- b. *Connect family caregivers serving at the state and regional level in the Behavioral Health Care system to the Idaho Caregiver Alliance.*

GOING FORWARD

Unfinished business. Members of the Idaho Caregiver Alliance and the Task Force wish to underscore the urgency to enact these recommendations. Not only are there significant and growing unmet needs within Idaho’s caregiver population, but as we look to the future, the importance of the caregiver in delaying or reducing the need for institutional care will grow exponentially. In Idaho, Medicaid, the primary public payer for these services, spent approximately \$2.4 billion in 2012 on costs for institutional care.⁸ Imagine if families did not provide home-based care. The costs would be unsustainable. Investing in supports for family caregivers makes sense in both a fiscal and human terms.

We ask that you:

- ✓ Learn more about the issues facing unpaid family caregivers in Idaho
- ✓ Identify the caregivers in your life
- ✓ Partner with the Idaho Caregiver Alliance to identify resources for family caregivers
- ✓ Endorse the collaboration between the Idaho SHIP and the Caregiver Alliance
- ✓ Support the development of a plan to implement the recommendations identified in this report
- ✓ **Become a caregiver champion!**

⁸ Medicaid Expenditures for Long-Term Services and Supports in FFY 2012, CMS, April 28, 2014. <http://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-servoces-and-supports/downloads/ltss-expenditures-2012.pdf>

ATTACHMENT A

IDAHO CAREGIVER ALLIANCE AND FAMILY CAREGIVER TASK FORCE

The Idaho Caregiver Alliance began as the Idaho Lifespan Respite Coalition, a consortium of organizations and agencies that advise and support the Lifespan Respite grant received by the Idaho Commission on Aging and funded by the Administration on Community Living. The mission of this three-year grant, funded in 2013, is to “advance the well-being of caregivers by promoting collaboration that improves access to quality, responsive lifespan respite care across the state.” The Alliance has helped raise awareness of family caregiving, its benefits and costs, and the importance of supporting family caregivers to maximize at-home care.

With the grant funds, the partners within the Idaho Caregiver Alliance have achieved the following:

- ✓ Completion of a statewide respite capacity and needs assessment
- ✓ Implementation of Caregiver Summits in northern and eastern Idaho to engage local communities and caregivers
- ✓ Implementation of a study to examine impact of behavioral health crises on family caregivers, first responders, and health care systems
- ✓ Development of partnerships with 2-1-1 Careline, Idaho’s No Wrong Door Initiative, and the Statewide Healthcare Innovation Plan (SHIP) to assure that the voice of family caregivers is included in statewide transformation activities
- ✓ Implementation of a pilot program of Emergency Respite in collaboration with the Idaho Federation of Families for Children’s Mental Health
- ✓ Passage of HCR 24 during the 2015 Legislative Session which endorsed the Idaho Caregiver Alliance and called for the creation of a Caregiver Task Force to “explore innovative means to support uncompensated family caregivers in Idaho.”

The Idaho Family Caregiver Task Force formed in June, 2015 under the leadership and funding of AARP, the Center for the Study of Aging at Boise State University, the Idaho Commission on Aging and Jannus (formerly Mountain States Group). The Task Force was open to any family caregiver or agency or organizational representative with expertise and an interest in family caregiving. More than 40 caregivers, community leaders, organizational representatives, and others have participated in this effort since June of this year. Members come from across the state and represent diverse perspectives, backgrounds, and expertise, from hospitals to emergency medical personnel to parents of children with disabilities or emotional disturbance. The focus was statewide and across the lifespan.

ATTACHMENT B

Idaho Family Caregiver Task Force

Participants

Tammy Avella The Care Managers	Monique Johns Blue Cross of Idaho MMCP
Cindy Bahora Veterans Administration	Zoe Johnson Living Independence Network (LINC)
Jim Baugh Disability Rights Idaho	Courtney Keith 2-1-1 Careline
Stephanie Bender-Kitz Jannus	Karen Kouba Home Watch Caregivers
Mike Berlin Idaho Alzheimer's Planning Group	Toni Lawson Idaho Hospital Association
Mary Biddle-Newberry Treasure Valley YMCA	Angela Lindig Idaho Parents Unlimited
Dan Blocksom Idaho Association of Counties	Amy Mart Community Partnerships of Idaho Care Plus
Pam Catt-Oliason Idaho Commission on Aging	Amber Mausling Formerly with LINC
Karen Clark SHIBA	Cathy McDougall AARP of Idaho
Brenda Collins Living Independence Network	Jenny Moorman Caregiver/Technology Consultant
Dieuwke Dizney-Spencer Division of Public Health, Health & Welfare	Peggy Munson AARP Volunteer Leader
Martha Doyle Regence Blue Shield	Kimberly Ouwehand Treasure Valley Hospice
Kris Ellis Idaho Health Care Association	Pam Page MS Society
Raul Enriquez Idaho Commission on Aging/NWD	Melissa Radloff Friends in Action
Lee Flinn Formerly with AARP of Idaho	Dawn Rae Ada County Community Paramedics
Dana Gover Northwest ADA Center of Idaho	Tammy Ray Idaho Home Choice Program Medicaid/DHW
Honey Goodman Treasure Valley Hospice	Donna Rogers Bright Star Home Care and Medical Staffing
Jennifer Griffis Caregiver/Children's Mental Health Advocate	Jackie Smith Trinity Home Care and Resource
Katherine Hansen Community Partnerships of Idaho	Sarah Swanson St. Luke's, Mountain States Tumor Institute
Jackie Hansen Community Partnerships of Idaho	Kelle Sweeney Friends in Action
Anthony Hickman ElderCare of Idaho	Marilyn Sword The Frontier Group (Task Force facilitator)

Katrina Hoff Idaho Area Health Education Center	Victoria Thompson St. Luke's, Mountain States Tumor Institute
Stephanie Hoffman Behavioral Health, DHW	Pamela Thorson Caregiver/LPN
Roger Howard Living Independence Network	Sarah Toevs Center for the Study of Aging at BSU
Martha Jaworski Qualis	Katie Vant Living Independence Network
Shawna Wasko CSI Area Agency on Aging	

ATTACHMENT C

Caregiver Concerns

Caregiver Supports

- Respite providers are not adequately trained
- Too much responsibility for caregivers; they won't ask for help, especially in rural areas
- Education for caregivers; normalizing and validating their feelings
- Aging caregivers who may need care/help themselves; they may be caring for an adult child
- Need for "mobile" support group; goes to caregiver's home
- Education, insurance plans that are affordable and accessible
- Social isolation can lead to depression
- Develop mentoring relationships between caregivers
- No centralized help/no advocate role
- Timely, easy, effective caregiver assessments
- People go to a facility for respite and never leave
- Emergency respite – who? where?
- Concerns for others in the family; supports for them
- Support groups operating as co-ops
- Crisis situations – inadequate support/resources
- Caregiver advocate role
- Put boundaries on caregiving at the beginning
- Impact on caregiver of physical demands (falls, etc.)/elders taking care of elders
- People do not want others outside the family to help
- Early identification for caregivers; connect them
- Resources for non-indigent; someone to check on family member
- Exhaustion, guilt (parent caring for child)
- Lifespan focus – all ages
- Caregivers should get resources as soon as the person they are caring for leaves a facility (hospital, nursing home, rehab facility)
- Access to self-care (massages, etc.) for caregivers; way to bring in the business community
- Need a crisis (this is different from emergency) respite program for children and families that provides another option than hospitalization. Managing a severe mental health crisis within a family takes specialized resources.
- Funding for respite for children on Medicaid
- Mental exhaustion

Information

- People (all ages) don't know where to go for information or what questions to ask
- Who is prepared to help?
- Need free resource guide with information by region of the state (younger people need this too)
- Accurate, timely information
- Local issue – who is coming into my home?
- Education for caregivers; normalizing and validating their feelings
- Training (in-home, short modules that fit caregiver schedules, accessible)
- Information lacking; would like to see public service announcements (PSAs), etc.

- Timely, easy, effective caregiver assessments
- Information on stress management
- Caregiver Tool Box – What do I need to plan for? Where do I look? What do I ask? (have this through the Employee Assistance Program as well)
- Feel like victims of system, terminology confusing; need a road map and a helper to decode
- EMS services called in (because people wait too long or don't know who else to call)
- Lifespan focus – all ages

Work/Employer Interface

- Lack of employer benefits (folks have to use vacation, sick leave to take leave without pay)
- Education, insurance plans that are affordable and accessible
- Education for employers re: promoting employee assistance programs and encouraging their use (coaching)
- Caregiver Tool Box – What do I need to plan for? Where do I look? What do I ask? (have this through the Employee Assistance Program as well)
- Working full time and trying to meet the needs of my mother
- Exhaustion of sick leave hours at work due to multiple medical events for mother.

Legal/Financial Issues

- Legislature doesn't know what the caregiver gaps are
- Financial assistance
- Power of Attorney problems; hospitals may not recognize; need standardized form
- Information about guardianship
- Advance care planning
- Family member abuse (financial, physical, emotional) of caregiver person

Public Awareness

- Too much responsibility for caregivers; they won't ask for help, especially in rural areas
- Overcoming stigma of being a caregiver
- Legislature doesn't know what the caregiver gaps are
- Promote culture of "it's OK to ask for help"
- Advance care planning
- Information lacking; would like to see public service announcements (PSAs), etc.

Lack of Services

- Lack of services in rural areas
- Financial assistance
- Impact of lack of transportation on isolation
- Increased access to home and community based services (HCBS) and long term care (LTC)
- Insufficient monitoring of chronic conditions and lack of access to primary care that results in overuse of emergency room
- Crisis situations – inadequate support/resources
- EMS services called in (because people wait too long or don't know who else to call)
- Lack of care coordination
- Transportation
- Resources for non-indigent; someone to check on family member

- Caregivers should get resources as soon as the person they are caring for leaves a facility (hospital, nursing home, rehab facility)
- Access in community for people with disabilities
- Need a crisis respite (this is different from emergency) program for children and families that provides another option than hospitalization. Managing a severe mental health crisis within a family takes specialized resources.
- Funding for respite for children on Medicaid

Other

- Non-native English speakers
- Include faith-based community
- System is not very helpful
- Embed ways of measuring impact; how will we know if we are making a difference; need this to effectively tell our story

ATTACHMENT D

DATA SOURCES

2016 Legislative Budget Book, Idaho Legislative Services Office, 2015

Appendix 1: Federal Programs that may be Potentially Accessed by States, Local Agencies, or Individuals for Respite Services, Support, or Funding. ARCH National Respite Network and Resource Center

Caregiver Support Blueprint for Delaware: A Report to the Delaware General Assembly, Family Caregiving Task Force, May 31, 2015.

Caregiver Support Blueprint for Mississippi, prepared by the Mississippi Caregivers Task Force, 2014.

Caregiving in the U.S. Executive Summary, AARP Public Policy Institute and National Alliance for Caregiving, June, 2015

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