

Idaho Family Caregiver Task Force

September, 2015 Update

During the 2015 Idaho Legislative Session, HCR 24 was passed, outlining the contributions of and the challenges facing unpaid family members who care for elders, children and adults living with long-term illness and disabilities. These caregivers are a valuable asset to their families, their communities, and the State of Idaho but they often face significant issues as they fulfill their caregiving role – burnout, loss of employment, health problems, stress, and lack of support. HCR24 called for the formation of a Task Force to study the problems facing family caregivers of individuals across the lifespan, identify the supports available in Idaho, research best practice in other states, and to make recommendations for action in Idaho to support this growing, unpaid, caregiver workforce.

Under the leadership 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 Idaho Family Caregiver Task Force was formed and is currently working to fulfill its charge. Over forty caregivers, community leaders, organizational representatives, and others are involved with the Task Force. The list of Task Force members is attached.

Two meetings have been held and additional monthly meetings are scheduled for the remainder of 2015. The Task Force has received state and national information on family caregiving, including a presentation by AARP national policy advisor Enzo Pastore who shared what is happening in the field at the federal level and in other states. Delaware, Mississippi and New Mexico have Caregiver Task Forces and Rhode Island, Connecticut and Minnesota (among others) are working on specific changes in policy and practice that improve caregiver support.

Information from the July 2015 Idaho Summit held in Lewiston has been shared with the Task Force. This Summit convened more than 80 caregivers, advocates, and providers who generated recommendations for collaborative action and program changes to improve respite services and other supports. Earlier this summer, Task Force members reported their primary concerns about family caregiving. These concerns are being prioritized and used to guide the work going forward. The list of those concerns, grouped into categories, is attached.

At the September 18 meeting, Task Force members will hear presentations on the No Wrong Door Initiative of the Idaho Commission on Aging (aimed at streamlining and coordinating long term services and supports in Idaho) and the Statewide Health Innovation Plan or SHIP (transforming primary care in Idaho). Both of these substantial system restructuring efforts will impact caregivers. Following those presentations, the Task Force Members will divide into Work Teams to begin more detailed work on the topic areas of Supports, Information/Education and Public Awareness, and Health Professional Practices. Throughout the fall, these Work Teams will be gathering information on existing resources, gaps in resources, and identifying groups who may be currently addressing these gaps. The information gathered through this process will be compiled in a report, with recommendations, for policymakers in early 2016.

Your input into the Task Force work is invited. If you know of issues that are not included in the list of attached concerns or if you are aware of groups working on caregiver issues in Idaho, please let us know. The next Task Force meeting will be held from 1:00-5:00 pm on Friday, September 18 at the offices of Idaho AARP, 3020 E. Gentry Way, Suite 100, Meridian, Idaho. The meeting is also available via conference call at 1-866-215-3402, code 1554007#. For more information, contact Marilyn Sword at 208-344-8585 or frontiergroupidaho@gmail.com.

Idaho Family Caregiver Task Force

Members

Tammy Avella, The Care Managers	Toni Lawson Idaho Hospital Association
Stephanie Bender-Kitz Jannus	Angela Lindig Idaho Parents Unlimited
Mike Berlin Alzheimer's Association	Amy Mart Community Partnerships of Idaho Care Plus
Mary Biddle-Newberry Treasure Valley YMCA	Cathy McDougal AARP of Idaho
Dan Blocksom Idaho Association of Counties	Jenny Moorman Caregiver/Technology Consultant
Pam Catt-Oliason Idaho Commission on Aging	Peggy Munson AARP Volunteer Leader
Randi Chapman Alzheimer's Association	Kimberly Ouwehand Treasure Valley Hospice
Dieuwke Dizney-Spencer Public Health/SHIP, DHW	Pam Page MS Society
Martha Doyle Regence Blue Shield	Melissa Radloff Friends in Action
Kris Ellis Idaho Health Care Association	Dawn Rae Ada County Community Paramedics
Raul Enriquez Idaho Commission on Aging	Tammy Ray Idaho Home Choice Program/Medicaid/DHW
Dana Gover Northwest ADA Center of Idaho	Donna Rogers Bright Star Home Care and Medical Staffing
Honey Goodman Treasure Valley Hospice	Jackie Smith Trinity Home Care and Resource
Jennifer Griffis Caregiver/Children's Mental Health Advocate	Stacie Smith Graduate Student/AARP Intern
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
Katrina Hoff Idaho Area Health Education Center	Marilyn Sword The Frontier Group (Task Force facilitator)
Stephanie Hoffman Behavioral Health, DHW	Victoria Thompson St. Luke's, Mountain States Tumor Institute
Roger Howard Living Independence Network	Pamela Thorson Caregiver/LPN
Monique Johns Blue Cross of Idaho MMCP	Sarah Toevs Center for the Study of Aging at BSU
Courtney Keith 2-1-1 Careline	Shawna Wasko CSI Area Agency on Aging
Oni Kinberg I-CARE/State Veterans Home	

CAREGIVER CONCERNS (from members of the Family Caregiver Task Force)

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
- 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