

Idaho Caregiver Alliance Case for Sustainability



More than one in four adult Idahoans (more than 300,000 people) assume critical responsibilities that make it possible for children and adults living with disabilities, long term illnesses and frailty to live in their home and community. These “family caregivers” are parents, grandparents, spouses, adult children and other family members who contribute over **201 million hours of uncompensated care annually** at an estimated value of **\$2 billion to Idaho’s economy**. This is equivalent to Idaho’s current budget for all publicly-funded long-term care services.

Family caregivers coordinate and provide complex medical and mental health services and navigate financial and legal challenges. The essential role of these caregivers is often overlooked, as are the negative health, employment, and emotional impacts experienced by caregivers. The Idaho Caregiver Alliance serves as a statewide voice, convener, and catalyst for sustaining and supporting these essential providers of care.

The Alliance brings together more than 50 public and private organizations and 200 individual members, including caregivers. The Alliance has accomplished significant work since its inception in 2013:

- Completed a statewide caregiver needs assessment and respite capacity report;
- Engaged caregivers and communities in northern and eastern Idaho through Caregiver Summits;
- Incorporated the voice of family caregivers in innovations underway through the State Healthcare Innovation Plan (SHIP), Idaho Healthcare Coalition, 2-1-1-Careline, and No Wrong Door;
- Implemented an Emergency Respite pilot program with the Idaho Federation of Families for Children’s Mental Health;
- Implemented the evidence-based Powerful Tools for Caregivers program in five regions of the state;
- Championed the passage of HCR 24 endorsing the Idaho Caregiver Alliance in 2015;
- Convened a 50 member Task Force to craft the Caregivers in Idaho report presented to the Health and Welfare Committees of the 2016 Idaho Legislature. Report available at: <http://hs.boisestate.edu/csa/caregivers-in-idaho-report-2016/>
- Authored the Idaho Family Caregiver Action Plan in 2016 to insure that awareness, information, supports and policies are created and sustained to buttress caregivers. Plan available at <https://hs.boisestate.edu/csa/idaho-lifespan-family-caregiver-action-plan/>

Members of the Idaho Caregiver Alliance understand the urgency to do much more. Not only are there unmet needs, but as we look to the future, the importance of the caregiver in delaying or eliminating the need for institutional care will grow exponentially. For example, in 2014 Idaho spent \$271,522,099, 48% of its Medicaid budget, on care provided in nursing facilities, intermediate care facilities, and inpatient psychiatric hospitals. Imagine if families did not provide home-based care—Medicaid costs would be unsustainable.

The Alliance has created an effective, collaborative infrastructure that is addressing this urgency, however without sustainable funding this innovative work will end in 2017.

Going Forward

The Alliance seeks a public-private partnership and a sponsoring agency to maximize the critical convener role it serves and implement the following goals and objectives identified in the Idaho Family Caregiver Action Plan.

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

- *Develop statewide respite resources.*
- *Ensure culturally appropriate information and resources are available to caregivers across the lifespan.*
- *Establish training resources for family caregivers on caregiving responsibilities, techniques, and strategies for self-care.*
- *Establish a statewide network of experts equipped to serve as information and support navigators or guides for family caregivers across the lifespan.*

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

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

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

- *Recognize family caregivers as part of their family members' health care and social support team.*
- *Embed family caregiver perspective and involvement in Idaho's efforts to transform its primary care, long-term care, and behavioral health systems.*
- *Include family caregivers in Idaho's efforts to enhance employment opportunities and tax policies that support families and the state's economic vitality.*

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

- *Build on the established foundation of the Idaho Caregiver Alliance and ensure that the Idaho caregivers across the lifespan have a coordinated voice.*
- *Assure data are available to inform decision-making related to family caregiver supports and services.*

In addition to establishing a public-private partnership and sponsoring agency, the Alliance projects that \$100,000 a year will be needed to continue this important work. This is based on the following projections:

- \$55,000 annually to support a Project Coordinator. This dedicated staff member will coordinate the results-focused goals of the Alliance, connect agencies and professionals with information about best practices, catalyze collaborative grant writing and program development opportunities, and provide a leadership role in identifying opportunities for Idaho to shine for its efforts to support family caregivers.
- \$25,000 annually to support a Quality Improvement/Data Manager. These funds will be used to support an external evaluator responsible for the development and implementation of process and impact evaluation activities. Evaluation results will be used by the Alliance and sponsoring agencies to inform project activities.
- \$20,000 in annual operating budget to provide communications, materials for education and outreach, and support regional and statewide meetings of the Alliance.

Funding will also be needed to implement action items outlined in the plan. The Alliance will continue to work collaboratively with public and private agencies and organizations to solicit support and resources.

It is in the best interests of individuals and the state of Idaho to invest in the well-being of family caregivers. They serve a critical role as "gatekeepers" and invest exorbitant amounts of their personal energy to delay or eliminate the need for state funded institutional care. For that reason, and based on the rationale outlined in the Action Plan, we are requesting the above stated support for sustaining the impact of the Idaho Caregiver Alliance.