

## Idaho Caregiver Summit

Twin Falls, CSI

July 7, 2017

**Introduction: Sarah Toevs** Caregivers, medical, social service agencies, CFH, grandparents raising grandchildren, AAAs, coroner, etc.

**Care Mapping: Marilyn Sword** Begin to draw your map and then refer to packet for complete instructions and examples. How to use the product to pave the way to achieving respite for you. Who is not on the map who should be? Look for the voids in support. Use it to have important conversations with your family so you don't burnout and are able to stay healthy.

### **Caregiver Panel: Mary Holden, Dr. Harry Geist, Beverlee Frandsen**

*Beverlee:* She and her husband raised 7 children while she worked. She fell and broke her knee and retired. Husband's youngest son abused a granddaughter and that son is now in prison. The children were removed from the home and put in DHW custody. To avoid foster care, the grandparents became guardians of 5 children between the ages of 5-11 plus an older child. Mom is unstable, which caused problems between the kids and grandparents. All children are food hoarders and one older child with ADHD runs away. That child is now being cared for by Beverlee's son in Kimberly. The LDS church has been supportive, but they could use more respite. This Summit is Beverlee's respite while her husband has taken kids to camp for 5 days. The AAA has helped and "Cooking Matters" a class through the Food Bank, has helped Beverlee stretch her food budget and serve healthier food. Now Beverlee has been recruited to help with classes. Also *Just Serve* has been initiated; it is an app to help anyone who needs it—we can help one another.

*Harry* – born and raised in northern NY state; wonderful parents and teachers; drafted and served in Alaska (he and his wife were square dancing at 72 below zero!). They moved to Twin in 1971; first pediatrician trained in neonatology; practiced for 30 years. Met his wife Dorothy in high school; married almost 58 years; 5 children, grandchildren and in-laws. Now a caregiver instead of a physician. Dorothy was diagnosed in 2012 with Alzheimers. Could see that it had been progressing when diagnosis was made. Grieving process ongoing; 2013 was the worst year of his life. Harry's parents came to live with them during the last years of their lives so he had experience with dementia. Also lost his favorite dog and his cat of 18 years. Lived in Hagerman Valley in beautiful setting among nature for many many years—loves nature and animals. In 2013 lost his desire to run (long-time long-distance runner; had run the Boston Marathon at 50). He could no longer commit to church activities. He copes through reading. Shared the names of two books he found helpful: Option B by Sheryl Sandberg and Pilgrimage into the Last Third of Life by Jane Marie Thibault and Richard L. Morgan. Harry's children are supportive. He is a cook now—daughter who is a chef brings food with her when she visits from Eugene. Harry is scared and anticipated the unknown. Concerned about his incapacitation before Dorothy dies because that would be a huge burden on children. Harry and his wife just celebrated the 39<sup>th</sup> anniversary of their 39<sup>th</sup> birthdays.

*Mary* – originally cared for aunt and mom and realized she didn't know what she was doing. Went through BSU program in gerontology. Learned information does not prepare you for caregiving. Worst year was 2015; lost 47-year-old brother, dad had a heart attack; mother moved in with Mary and she saw how bad the dementia had become. Mary and her husband had to work so could not stay home and care for her mom so she moved into a facility. Mary's dad died in September. Mary's brother Tom was diagnosed with colon cancer and he lived for 4 years and died in January, 2017. Challenging to care for brother who resisted help; difficult to talk about effects of colon cancer with sister. He worked until two

weeks before he passed away. Brother had many crises in that time and wound up in ER many times. Advance Directives are important! Her brother was 2 years into his cancer before he completed all of his end-of-life paperwork. Mom (87) and hoarder aunt (94) are now both in same memory care facility. Lots of support from husband, attorney; she is concerned about her ability to retire due to lost years of employment. Mary discovered a blog about taking care of yourself so you can care of others: *Daughterhood.org*. Your days are not predictable. Learn a lot about the people you cared for after they have passed in going through their things.

### **Small group work: Barriers, Gaps, Strengths and Opportunities**

#### Barriers/Gaps:

- Lack of workers in rural areas
- Not knowing where to start or who to go to
- Technology and boomers
- Budgets keep getting cut
- People won't ask for help
- Lack of public transportation
- Legal issues – HIPPA, lack of access to info
- Not willing to accept help
- Family cannot get same resources as foster families
- Emotional impact of caregiving
- Complicated/cumbersome application process for services/eligibility
- Social stigma
- Respite to permit attendance at training
- Lack of behavioral health counseling services regardless of age, resources (caregiver or care recipient)
- Language/cultural
- Someone to help you connect dots
- Respite for Certified Family Home providers
- Religion
- End of life navigation (opportunity for training)

#### Strengths:

- Openness to explore alternative therapies and new ways of doing things; being agile
- Office on Aging (CSI) – supports, respite, info
- Certified Family Homes
- Openness to learning
- Volunteer organizations
- Faith-based organizations (Just Serve, started by LDS church; working on app)
- Quality people in local agencies
- Grandparents as parents
- Empathy
- Inclusiveness toward new people
- Community (families, church, grandparents)
- ICCP (Idaho Child Care Program)
- St. Luke's Behavioral Health accepting new patients
- Behavioral Health Crisis Center

- Deseret Industries – job support, counseling, training

#### Opportunities:

- Physicians taking a team approach (patient-centered care)
- Acknowledgement of end-of-life values and wishes
- Innovative treatment opportunities
- Caregiver to gain new friends and build social networks
- Continue networking and communication opportunities
- Use of advanced technology for distance management of health conditions
- Patient Financial Navigator Library on CSI campus
- Idaho Care Line 2-1-1
- Community-based approach to caregiving; capitalize on independence
- Coroner's office not utilized as it could be (end-of-life, hospice, etc.); alleviate liability
- Office on Aging (CSI)
- Taking a step to make a difference
- Public Awareness Campaign (link to Action Plan?)
- Non-profit agencies as community resources (transportation, housing, counseling, etc)

#### **Current State of Respite in Idaho - Pam**

See Power Point presentation

#### **Lunch and Learn Presentations**

AARP – Francoise Cleveland, PP presentation

National and Idaho caregiver data; CARE Act details

D.L. Evans Bank – Joshua Rose, Dana Stewart

Handout

Financial investments re: leaving an employer; protect your assets

- 1) leave assets where they are: do not disturb; easy to do but can be complicated to manage if you have numerous accounts
- 2) rollover to consolidate and simplify; avoid taxes and penalties
- 3) cash out 401 K; mandatory 20% to taxes plus another 10% penalty (if you are under age 59 ½. 42% of people do this

Options: borrow against your 401K but you need to pay it back before you leave

Must start taking \$ out of 401K at age 70 ½ or penalized 50%

Regence Personalize Care Support Palliative Care Program – Leslie Foren, Scott Schlagel

Tips to use when working with an insurance company – public or private

- Case management – telephonic, based in Lewiston; partnering with providers?
- Does your insurance company have case management?
- Pharmacy benefits – what resources available?
- Home health care benefits?
- Networks of providers? Provider search option
- What is the process for appealing decisions?

*What to share*

- End of life documents/advance directive/POST form

- Any other life events
- Caregiver information to be incorporated into member's record; who can they talk to about you?

*For caregivers:*

- Who is coordinating care?
- Are there respite benefits?
- Other caregiver resources? (grief support, stress management)

*When things go wrong:*

- Circle back to your insurer to let them know (billing errors, fraud, etc.)

Regence has a palliative care program.

St. Luke's MV Palliative Care Team – Christina Thongdee

*Power Point presentation on palliative care*

Palliative Care program. Encourage caregiver to be involved. Thorough assessment process and can deliver financial, advanced planning and other associated issues. Want to help coordinate resources. Realize the communication with provider is complicated but essential. Do not provide in home services.

- Team based approach
- Applicable to any stage of care, not just end of life
- Focus on quality of life
- List of conditions that can be addressed with palliative care
- Symptom management
- End-of-life planning and preparation
- Resources to support caregivers
- Communication between care providers, care givers, and patients
- Help navigating in-patient services and post-discharge home visits
- Paid for by Medicare, Medicaid, private insurance, VA
- Palliative care would precede hospice

<https://getpalliativecare.org/resources/caregivers/>

**Lifespan Respite: Building and Sustaining Best Practices: Jill Kagan, ARCH**

We do not have a formal LTC system in US. Caregivers are the backbone of the LTC system

See Power Point presentation

Respite is one of the most requested supports. Brings stress level down, can benefit entire family, and can help reduce expensive care. Can also be beneficial to care recipient.

Respite is a preventative service but is generally accessed in a crisis situation

Respite becomes a luxury in a caregiving budget due to the costs of everything else

Most people don't identify as a "caregiver",

**Small Group Work: Synergies, Strategies, and Solutions**

- Liability issues
- See neighbors taking care of neighbors; why don't they anymore? How do we address getting to know one another better and ensuring safety. Who is safe and what is a scam?
- Livable communities from Blaine County into other areas.
- Justserve.org as a local clearinghouse; add local resources to the Justserve app
- One thing everyone needs is doctor. Have a good brochure (about the clearinghouse) about where to go, follow the dots

- Linking existing orgs (Rotary, etc.) to involvement; how do you vet to ensure safety? In small towns everyone knows everyone else and that can be an invasion of privacy. So it is a trying to find a balance. What are the barriers to engaging these clubs?
- POEM by Bill the Adorable Poet
- Churches are key.
- Ideal services? They will be easily accessible; you have supplies, transportation, information from a variety of venues; not everyone has internet service; collaborating with hospital, agencies and get everyone on same page
- Who could we involve? Yard services = alternative high school. What about other high schools and their student volunteers? Man who developed a water park for his daughter with disabilities as an example of community involvement. College students as a community resource?
- Education is power. Agencies go into schools and talk to students about the agency services; caring for other people is a skill to be developed = high school interns job shadowing in the coroner's office. Boise and Girls Club
- How do we get the training? CSI, churches, schools, YMCA. How could 211 be looped in?
- More caregiver support groups. Take a break and share with others
- Nursing and social work students; death and dying classes; what about clinical hours for these students in home care? Involvement of clubs. What about day health center(s) on CSI campus?
- Nurse health occupation programs; training for CNAs, MAs, etc. what about working with those students as volunteer respite providers. Because they are minors, the caregiver could not leave the home, but could be freed up to do other things. Also CNA training programs at the community colleges as source of student volunteers. What about the Elks as a community project across the state. Facilitate community within apartment complexes; barter system.
- Anything that is already single generation, build into multi-generational.
- Home health agency provide training for families who need this to provide care; may not be families that are receiving home health services but provide training.
- Lists available from the Area Agency on Aging

### **Goals for Respite and Caregiver Support Services in Idaho: Next Steps**

Individuals – what can YOU do to make a difference or foster change in your community to move caregiver support forward in Twin Falls, Magic Valley, Idaho?

*Shawna:* recently got services in the home for her parents. Challenge the Senior Centers to contact churches in the area to deliver meals to people. Can make a difference, nutritionally, emotionally, and financially.

*Mike:* niece is going to be NHS president at her high school. He will contact her about having them take on caregiving help for seniors in the area.

*Sarah:* Will connect Gene and Christa with Honoring Choices Idaho.

*Della:* Fourteen points written down through the day that she will commit to doing.

*Sharon:* incorporate respite and other supports into updating caregiver database.

*Steve:* Connect two adult family home providers to provide/receive services.

**ICA commits to:**

- Add your name to our email list and keep you informed in what we are doing
- Submit a strong application to ACL for another grant
- Continue to engage policymakers in what we are doing but this requires your voice
- Use the information generated today to help us move the Action Plan forward