

## Lifespan Respite Summit Notes

July 16, 2015

Lewiston/Clarkston

### Caregiver Panel:

- Pam – cares for son who suffered broken neck (18 years ago). Has done the same thing for 18 years, but under many different programs: Katie Beckett, CNA, LPN, CFH. Loves doing what they do. One thing to change: **Would love to have insurance. Would love respite. Respite providers need a lot of skill. Less regulation; fewer hoops to jump through to defend/maintain nursing license to care for a single person.** Pam became an LPN two years ago at 58 years of age. It is a lonely journey, being a caregiver, in spite of all of the support from church and friends.
- William – Cares for wife of 65 years. Wife has Alzheimer's/Dementia. "Knew nothing about what he was headed for"; has been a caregiver 7 years. Friend gave him copy of *The 36 Hour Day* and discovered he was suffering depression. "I didn't know what I needed so didn't ask until it was dire". Amazed to discover all of the avenues for support. Limited funds; on Social Security. Hopes to glean some places to go for education to help their children understand and adapt. One thing: Changing wife's lifestyle is very difficult. Wife wants things exactly the same as yesterday. Creates roadblock. **Wants to encourage others to seek help. "Don't be discouraged. There's hope."**
- Marian – Cares for husband. Both Marian and Eric are under 65 years of age. Eric's issues were not diagnosable for years. Currently he has a form of sleep paralysis. Discharged from hospital with little support. Works full-time. Friends and family took shifts providing support. Book: *When Bad Things Happen to Good People*. Journey has been one of survival. Marian needs to keep working to provide insurance for Eric. Marian works as a nurse in home health and hospice. Eric is still active so because Marian works full time transportation for Eric is difficult.
- Sandy – cares for husband who is veteran. Receives 3 hours of home care from VA and respite every other Friday for 6 hours. Sandy has been blind since birth. Learning to do things differently. Looking for tips to help husband get the exercise he needs, because he is a large man with mobility issues. Doesn't know how anyone can do this without Faith and Church. **Would like to see other insurances pay for home care (ie Medicare). In home care is more cost effective than hospitalization. Wouldn't get any help if not for the VA.** (Didn't call emergency services recently when husband fell at night, because she thought VA will not pay. Pam Catt-Oliason will have AAA follow up with her.)
- Karla – Cares for young granddaughters. Daughter suffers from post-partum depression. Receives help through kinship grant (\$301 per month). Granddaughters both have ADHD. Makes too much to receive help from the state. Works fulltime. Husband has two jobs. Mom has Parkinson's and is in assisted living facility. Chaos when she has both mom and granddaughters at same time. Does not receive respite care because she only has legal guardianship. **Biggest challenge is trying to find resources.**

- Jennifer – Husband is medical director. Have 7 kids (ages 3 – 12) and 4 have mental health challenges. Has deep understanding of systemic challenges and mental health diagnoses as “invisible disabilities”. Qualify for respite but there is a lack of providers who can adequately deal with children’s’ challenges. Accessing funding was taking too long. Grandparents provide respite. Took 7 weeks to get daughter into facility. Caused disruption with other 6 children who could not be in the home at the same time and had to temporarily stay with grandparents in Texas. **What they needed was crisis respite - some place for daughter to go while they worked through paperwork. Wish that they can decrease barriers (financial, systemic, stigma) to accessing respite. Because these are mental health issues and the child looks normal the intensity of the issues are misunderstood; when you suggest respite, people think you need a baby-sitter.**

“Communities of Caring”

Focus on developing caregiver support networks within geographic areas.

Questions about Emergency Respite Program:

- How do you define crisis?
- Is it available to Certified Family Homes?
- Do caregivers need to preregister?
- Is it for urgent or emergency need?

One Wish

- Affordable accessible respite
- Fewer regulations for providers
- More information about resources
- More information about how to provide care
- How do we make it easier to ask for help?
- Better transportation options and hours
- Financial support/options for caregivers – insurance
- Meaningful activities for care receiver
- Help finding balance
- Respite
- Specialized, qualified respite providers
- Crisis respite; safe and appropriate care for care receiver
- Decrease barriers to access respite (Financial, stigma, system)

*What are the barriers to accessing respite?*

*What are the strengths in your community to accessing respite?*

*What are the opportunities in your community?*

### Barriers and Gaps

- Funding
- Resources that are centralized
- Knowing how to access
- Navigating resources
- Regulation
- Random rule changes
- Rural access to service
- Acceptable trained personnel
- Easy to access roadmap
- Limited understanding among policy makers
- Too many hoops to jump through
- Inconsistent information
- Distance to local office
- Not enough staff to meet the needs of homebound and their families
- Communication among stakeholders
- Technology/access to internet
- No diagnosis for illness
- Not enough support groups
- Not enough trained volunteers
- Care receiver resistance to accept help
- Program sustainability
- Education of caregivers
- Need champions to help break down stigma and resistance
- Lack of appreciation and training for replacement caregivers
- Perception that there is not a need for support
- Resistance of care receiver to replacement caregiver
- Need one number to call (takes a lot of time to locate appropriate resource)
- Caregiver accountability/quality assurance (for both paid and unpaid caregivers)
- Education to help learn how to provide good care
- Limited political/cultural understanding of the problem
- Lack of information in community about what help is available
- Poor pay

- List of independent providers
- Gaps in cultural and generational understanding of caregiving
- Not enough specialized training
- Geographical barriers (rural)
- Lack of trust in resources
- Connectivity

### Strengths in Community

- Community centers
- AARP
- Senior Centers
- Area Agencies on Aging
- ADRC
- Idaho Caregiver Alliance
- National and local support (Interlink volunteers)
- Just Serve
- Certified Family Homes
- Idaho Medicaid staff
- Faith/Church communities
- Family supports
- Increased awareness
- Compassionate community
- Aging and long term care (Clarkston)
- Hospice
- Emergency Respite Program
- 2-1-1 CareLine
- Idaho Department of Health and Welfare
- Human Needs Council (Moscow)
- Service Learning Programs at Colleges and Universities
- Universities and High Schools that require community service (intergenerational support)
- Large and growing population of retired people who are looking for opportunities to volunteer
- Alzheimer's Association and other disease specific groups
- IDHWBlog.com
- Local listings in newspaper about support groups
- Improved timeliness of caregiver background checks
- Senior programs, meals on wheels
- Advocacy groups (ie League of Women Voters)
- Daybreak Center at Senior Center for those with Alzheimer's (Sandpoint)

- Navigation Services through DHW
- Public School Districts required by law to provide services up to age 21
- Nursing program at Lewis and Clark State College and Walla Walla Community College
- State plan for Alzheimer's
- No Wrong Door
- Kincare
- To be able to work for family or friends
- Can network well in a small community because people know each other
- Rural community has a lot of caring, helpful volunteers
- Respite-trained caregivers
- Word of Mouth
- Caregivers are resilient and resourceful
- Jeff D settlement
- Us! (seeing ourselves as assets to create change; "I am an asset; change happens with me.")

### Opportunities

- House Concurrent Resolution 24
- Creating online blog/facebook/website support groups (opportunity to connect with others)
- 6 week respite course to train providers (through colleges)
- Caregivers should take the opportunity/accept help. Make commitment to yourself to accept help.
- Capitalizing on volunteer resources: AmeriCorps VISTAs, Project Grace, etc.
- Connections at local churches
- County Extension agencies
- Regence Service directory
- Look at funding for reimbursement of quality caregivers
- Remembering: When the Caregiver's done, everybody's done
- Senior Companion Program
- Engaging retired people as volunteers to help with
  - meal prep
  - laundry
  - calling families to see how they're doing
  - create toolkit of resources to rural areas
- Expand concept of Adult Day Centers
- "Sick" daycare
- Case managers
- Train individuals pursuing human services field

- Train other senior centers in “Riggins” model
- Involving/training faith communities
- Put champions to work
- Include children and adults in care settings
- Public Service Announcements/Public education
- Creating a roadmap for caregiving; creating centralized directory of services to ensure that you’re connecting with the right people/agencies
- Keeping loved ones at home rather than institutionalize
- Respite Camp (Families Together)
- Create an “Angie’s List” for caregivers; searchable data base
- Access to quality, accurate, appropriate information
- Develop skills and education to overcome resistance and denial
- Churches sending 2 volunteers to homes; recruiting kids/teenagers
- How do we help families develop a good back-up plan with informed choices
- Rosalyn Carter Institute’s REACH
- Networking events for caregivers
- Group training for families
- Create a backup plan for emergencies
- Respite provider registry
- Utilizing media/advertising to raise awareness
- Centers for Independent Living
- Expanding 2-1-1 CareLine (easier access and more informed staff)
- Connection with Idaho SHIP
- Respite training in nursing programs
- Empower caregivers
- Celebrate community-based living
- Promote volunteerism as opportunity for “healthy aging”
- Developing a directory like AARP Wyoming Caregivers Guide
- Bring more people to the “party”
- Create opportunities for productive conversations with State and Medicaid
- Creating Public Service Announcements to help educate about behaviors
- Develop task list for family members who would like to help
- Challenge Faith Communities to mobilize
- Educate public service workers (police, EMS, Postal workers about behaviors)
- Putting strengths and assets to work to overcome resistance and stigma
- Student community service
- Developing caregiver co-ops
- Peer-to-Peer training and registry
- Respite for CFHs providing 24/7 care
- Encourage HS youth to assist caregivers for extra credit/community service

- Free training opportunities for ongoing education
- Scholarships
- Identify family caregivers specific skill sets and offer training to new caregivers (peer to peer)
- Engage Home health agencies as respite providers and partners
- AAA respite offered for residential facility/adult daycare
- Computer labs
- Web-based support groups
- Day care centers provide respite
- Seniors helping seniors
- Preventative health care
- Care “guides”
- Buddy System of support
- Increasing government programs ie ACA, AAA, True Blue, FQHC/CHAS
- Interfaith volunteer programs (ie Habitat for Humanity)
- Medical education programs
- Training program for parents who ‘age out’ of being a caregiver
- Transition planning
- Vocational/Technical caregiver option in High Schools
- Create better policies for supporting caregiver
- Streamline services
- Give caregivers a platform to express individual experiences
- New designated provisions in Medicaid for client with 24/7 care needs (ie more care hours)
- Allow those caring for spouse to qualify as Certified Family Home
- Tax homeowners and use money for caregiver resources
- Waive monthly fee for CFHs caring for family member
- Improve education about hospice
- Utilize non-violent prisoners as workers to obtain skills
- Educate caregivers about community resources
- State scholarships for home caregiver/respice education
- Improved support from State in implementing regulations

### Synergies, Strategies, and Solutions: Addressing Gaps

What do the outcomes look like if what we’re proposing comes to be?

- Barrier: Self-Identification as a caregiver
  - Action: Write an article in the Golden Times “You’re a Caregiver If ...”
    - Create a campaign. Involve news channels
  - Possible Result: support groups ;increased calls to agencies; caregiver empowerment

- Barrier: Training Respite Providers
  - Engage families to help train volunteers and professionals so that they'll be ready to provide respite
- Barrier: Caregiver Accountability - Different regions work with agencies in different ways
  - Explore other models
- Barrier: Caregiver Isolation
  - Use existing model of Circles to create "Caregivers Anonymous" – to encourage creation of intentional friendships, networking
  - Put time limit – ask them to commit to 6 months
- Barrier: Accessing Information
  - Understand that different generations have different comfort levels with technology
  - Action: Take "No Wrong Door" or 2-1-1 approach
- Barrier: Comfort level leaving loved one with Respite provider; creating care plan: What will happen to your loved one if something happens to you? Everyone needs an emergency and long range plan.
  - Create a 2 week training course
    - Offered through church
      - Barrier: Getting a foot in the door in churches
        - Utilize church bulletins
        - Contact Administrative assistance of church
        - Provide churches with models
      - Building on existing resources through AAA, Project Grace
      - "Family Promise" faith-based homeless housing model
    - Increase adult day services programs
- Barrier: Preparedness of Caregivers and respite providers
  - Take advantage of existing resources and facilities
    - Hospitals, churches, colleges, required training through home care agencies
  - Affordable liability insurance
  - Requiring 1<sup>st</sup> aid training, CPR, background checks, etc.
  - Keep list of preferred/approved respite workers current and accessible
  - Fair compensation for those who seek it, commensurate with skill level required
  - Offer training in specialized areas
    - Sign language, dementia care, catheter care, developmental disabilities, range-of-motion, body mechanics, patient safety
  - In-home training for family members and friends
  - Require care plans
    - MD, mid-level provider, or family
  - Invite friends and neighbors to participate in process
    - Will help de-stigmatize situation
    - Increase sense of normalcy
    - Lessen mystery of disability and declining health



- Decrease social isolation
  - Provide hiring assistance (not all families understand employment law)

Vision: Respite care becomes familiar to the public, accessible to caregivers, affordable and safe. Lifecycle care becomes the norm (again).

- Barrier: Funding Resources (Creating pathway to sustainability)
  - Propose sales tax to be dedicated solely to respite care
  - Donation box on tax forms
  - Idaho Lottery Money
  - Write to legislators
- Barrier: Lack of knowledge of services
  - Create marketing/media campaign
    - Medical service providers
    - Discharge planners
    - Social services
    - Family education/training
    - Support groups
  - Educate employers
  - Outcome: Free resource guide and directory
    - “ From Frazzled to Dazzled:
    - Free background checks for providers that are non-commercial
    - Free respite registry
    - Free caregiver counseling
- Barrier: Access to information
  - Advertise 2-1-1 CareLine more
  - Link to statewide agencies
  - Make available to faith based and human services organizations in community
  - Create database with interest, age, and experience
- Barrier: Qualified Caregivers
  - Utilize educational institutions, churches, community
  - Educational requirements; community service hours
  - Training courses a requirement
  - Mobile respite (planned)
  - Caregiver planning
  - Utilize nursing home training programs—caregivers attend nursing home training programs
- Barrier: Accountability – Quality Training; What Region?
  - Community Action Partnership Database
    - Overseeing Area Agency on Aging Region 2
    - Is it NIC in Region 1?

- Is it by Region?
    - What happens in border areas? (ie Newport/Sandpoint and Clarkston/Lewiston)
  - Database that includes providers skills/abilities
  - Adapt Agency guidelines and training for private individuals
- Barrier: Trained Respite Providers
  - Caregivers and care recipient are able to provide the most comprehensive training
  - Gather a group of various professionals and volunteers and provide training
  - Develop rating system of respite/care providers based on their level of training and expertise
  - Sufficient time to screen and orient respite providers until client/caregiver/respite provider are comfortable
  - Use AmeriCorps/VISTA program
- Barrier: Self-Identification as caregiver
  - Article/Campaign in *Golden Times* (Lewiston)
    - “You are a caregiver if ...”
    - Sponsored by Dave Pankey, Area Agency on Aging
    - PSA to educate public about inappropriate behaviors