

Name	Location	Written or oral testimony?	Family Caregiver or Professional?	Caregiver Situation	Professional Background	Professional Comments		What would have helped?	Respite/Adult Day Services	Dementia competency training for family caregivers, home care workers, residential care workers, and medical professionals	Affordable LTC	Dementia-capable transportation	Rural provider incentives
Susan Hoffecker	Carson City	Oral	Family Caregiver	Susan cares for her mother with vascular dementia at home.			Susan's mother has many difficult behaviors that include hitting and throwing objects such as TV remotes at Susan. Even though she's at risk of being injured, she must never leave her mother's house or she will wander the neighborhood, sometimes late at night, or leave stove burners on. Susan has chronic pain from fibromyalgia and recently had surgery on her leg. Now she desperately needs surgery on the other leg, but she used up her Alzheimer's Association respite grant on the first surgery. Susan needs funding for respite, so she can have her much-needed knee operation and get a break from her mother's dangerous and challenging behaviors. Susan desperately needs respite to get her leg surgery and relieve her from her mother's difficult and dangerous behaviors.	Respite	X				
Julia Greenan	Sparks	Oral	Family Caregiver	Husband Gary was diagnosed with mixed dementia at 55 and is now 62; Julia cares for him at home.			Gary is very paranoid and this makes it almost impossible for her to leave the house. He frequently suffers from episodes that resemble psychotic breakdowns. She once had to call the Sparks Police because he became a danger in public during one such episode. Thanks to the training the officers had received, they were able to calm Gary down, allowing Julia to safely take him home. However, Gary once had a similar episode where the couple used to live. Those police were not well trained, and arrested Gary and placed him in jail where he then suffered a severe cardiac episode and had to be hospitalized for 2 weeks.	Respite; affordable LTC; dementia competency training	X	X	X		
Cathy Maupin	Reno	Oral	Family Caregiver	Caring for mother with Alzheimer's for 21 years; first 10 years were at home; mother now resides in a SNF			Cathy's mom used to wander late at night and ring her neighbors' doorbells, causing them to become frustrated. Cathy wanted her mom to stay at home and explored options, but she didn't know where to look or where to start. She wanted her mother to remain at home for as long as possible, which would only have been possible with a live-in caregiver. However, that would have cost \$84,000 annually 10 years ago. Despite Cathy's wishes, Cathy moved her mother to a memory care facility because it was actually cheaper than home care. Cathy's mom did very well in the memory care center but she later broke her hip, necessitating a move to a SNF. The staff were not well trained, and consequently Cathy noticed a sharp decline in her mom's condition. Not only were the SNF staff not well trained on dementia but it was significantly more expensive as Cathy's mom did not qualify for Medicaid. She is now on Medicaid because they spent down nearly all of her savings, over \$500,000.	Dementia-competency training; affordable LTC		X	X		
Diane Ross	Sparks	Oral	Professional		CEO of The Continuum, an ADC in Sparks.	Lack of awareness of community resources; stigma and resulting		Statewide dementia awareness campaign in partnership with other NGOs					
Sarah DeLaughter-Crawford	Las Vegas	Oral	Family Caregiver	Lives with mother and husband who both have Alzheimer's. Husband is middle-stage and mother is late-stage.			Sarah's biggest behavioral challenges with her husband include: constantly following her and clinging on, wandering outside the home and getting lost, and constant angry outbursts which her mother only makes worse with derogatory remarks. In 2015 Sarah's husband worsened dramatically, and a psychiatrist mistakenly diagnosed him with depression and put him on an antidepressant. He was also put on Aricept and Namenda by a neurologist, and the two were clearly not talking to each other. Sarah takes comfort in her caregiver support group because they remind her to take care of herself. She would like to enroll both her mother and husband in adult day care, but can't afford it. Her local center is a very nice facility that provides round-the-clock activities, and she wishes she could take advantage of it.	Respite; care coordination	X				
Paul Bailey	Las Vegas	Oral	Family Caregiver	Wife Dixie was diagnosed with Alzheimer's in 2014; lives at home and requires constant supervision			Dixie spends large parts of the day tearing the house apart "looking for something", and has taken to packing away as many household items she can find into laundry baskets. When she uses the bathroom, she puts the stopper in the sink and leaves the water running and has flooded their bathroom twice. Dixie also asks the same question over and over again, and Paul gets so frustrated that he exclaims to her that she'd just asked that question. This only makes Dixie angry. Thankfully, Dixie attends the Adult Day Care Center of Henderson 6 days a week. He says they have a caring staff with lots of activities and even live entertainment! He can afford it because of a grant he received from Nevada Senior Services in which only pays \$300 out of pocket as opposed to \$75 per day. Paul is looking into residential care options, but \$4,000+ per month is way out of Paul's budget. Paul uses paratransit to get Dixie to and from the adult day center, but there's a 2 hour window for pickup each direction and he must sit with her the whole time.	Respite; dementia-competent transportation; affordable LTC	X		X	X	

Alonzo Thornton	Las Vegas	Oral	Professional		Psychiatric nurse with ASD	Alonzo sees a lot of people with dementia who also have a co-occurring mental illness. In these individuals, depression worsens due to the dementia		More geropsychs to address mental illness and dementia combined						
Patty Jones	Winnemucca	Oral	Family Caregiver	Patty is a 68 year old woman caring for her husband Harold of 45 years at home who is in late stage Alzheimer's.			Harold is very aggressive, physically and verbally, and doesn't like to be touched. He will hit Patty and hold her down any time she tries to touch him. Harold is also afraid of using the toilet, requiring Patty to keep him in diapers. His reaction to being touched makes it difficult for Patty to bathe him and change his diaper without getting injured. Harold is a veteran and has received some services from the VA. Patty needs to place him, but the closest facility that the VA will cover is in Henderson, a 12 hour drive from Winnemucca. There is a new memory care facility in Winnemucca, but Patty can't afford to place him there because the VA won't pay. Patty used to have respite services but the nurse whom Harold liked has moved away, and Patty won't subject other workers to him because he's prejudiced and doesn't like anyone of color.	Respite; expansion of VA LTC benefits	X					
Robin Gillis	Winnemucca	Oral	Professional		Director of Nursing for Quail Corner and Harmony Manner. They have an 8-bed memory care facility in Winnemucca.		Barriers to families that Robin addressed include: lack of dementia education for caregivers and families, lack of dementia-competent professional in the community, and lack of resources to pay for dementia-competent care. Robin also said when her residents exhibit difficult behaviors, they have nowhere to send them and under-trained staff have to do their best to manage these behaviors. Furthermore they must turn new residents away even when beds are available due to the nursing shortage in rural Nevada. Robin also shared that there's a respite program in Winnemucca with no clients, because the community doesn't know it exists.	Develop statewide volunteer or consumer driven respite program; incentives for healthcare providers to practice in rural areas; statewide directory of resources; hospital-based home care	X					X
Ellen Davidson	Elko	Oral	Family Caregiver	Ellen is a 70 year old woman and cares for her 83 year old husband at home in Elko. They have been married for 2 years, and it was only months after their wedding that Ellen started noticing cognitive changes.		from paranoia and has constant panic attacks. He obsessively drives to a house that he owns every day just to check on it, making Ellen unable to rent it out to supplement their income. He also panics whenever she tries to leave the house, making it impossible for her to attend her local Alzheimer's Association support group even though she found it helpful when she went. Thankfully, Ellen has a friend from her church who comes and watches her husband so she can make it to Bible Study once a week, which is her biggest support system right now and only relief. Ellen is forced to		Respite; dementia training for family caregivers and providers	X	X				
Kerry Aguirre	Elko	Oral	Professional		Kerry is in her fifth year as director of Elko Senior Center. They provide meals, socialization, and health screening.		She has found out from her work that many local providers do not accept Medicare, which forces them to travel 3 hours to Salt Lake City or 4 hours to Reno to get care. Kerry pointed out that family caregivers who must still work have three choices: quit working to care for their loved one and jeopardize their financial wellbeing, hire someone to come in, or move to a new area altogether where greater respite services may be available, allowing them to find work.	More ADC; affordable home care	X			X		
Debbie Anderson	Elko	Oral	Professional		Director of Case Management at Northeastern Nevada Regional Hospital			Dementia-competency training for hospital staff and community providers; respite; incentives for healthcare providers to practice in rural areas; affordable healthcare-related transportation; greater care coordination through managed care	X	X			X	X

Alda Breunig	Sparks	Written	Family Caregiver	Used to provide care to a loved			Greater access to dementia-capable care	Dementia-competency training		X				
Julia Greenan	Gardnerville	Written	Family Caregiver	Monica cared for her father at home			Monica's father would forget he could no longer drive when his driving privilege was revoked. He became very angry and aggressive during bathing, feeding, and when being spoken to. His incontinence caused Monica to never get any sleep at night, making it even more difficult for her to cope with her father's combative behaviors. Hired home care was unable to handle the behaviors; this defeating the purpose and not giving Monica any relief. Hospice was great but kicked him off after 6 months even though he was nearly in a vegetative state for his last 22 months of life.	Respite; dementia competency training	X	X				
Bette Prietti	Las Vegas	Written	Family Caregiver	Bette, her father, and her siblings cared for her mother with Alzheimer's at home			Bette's mom was incontinent and therefore needed to be bathed every day. Bette and her siblings took turns giving their father a break. The home care worker felt her mother was too difficult to care for and stopped showing up for work. Adult Day was great, until they could no longer manage her level of care. They tried a SNF but she was left sitting in a chair all day without getting her diaper changed which resulted in a UTI, and Bette care for her at home until she passed away.	Respite; dementia competency training; more ADC	X	X				
Carolyn Lancaster	Minden	Written	Family Caregiver	Currently provides care to a loved one			Carolyn finds herself unable to manage being asked the same question over and over again, and anger is also an issue. She needs respite to get a break and ease her frustrations.	Respite	X					
Connie Fruge	Fernley	Written	Family Caregiver	Connie cares for her mother at home			Connie struggles with getting her mother to shower. She would like to have someone as a resource to give her mother a shower, or teaching her ways of doing it to make the person with dementia less combative and more relaxed.	Dementia competency training		X				
Jake Wiskerchen	Reno	Written	Professional		Marriage and Family Therapist President, Nevada MFT-CPC Board of Examiners Owner and Clinical Director Zephyr Wellness	MFTs and CPCs cannot bill Medicare. That is my (our) field's singular frustration with being able to serve older citizens and it has been held up in Congress for years, despite multiple attempts to change legislation dating back to 2004. The most recent one was in the form of H.R. 3032, the								
Adina Archibold-Bugett	Las Vegas	Written	Professional		Social Worker	<b>Barriers:</b> Access to services, working with protected people, placement and after care <b>Solutions:</b> New								
Sarah Deardorff	Truckee	Written	Professional		Meals on Wheels to Truckee and North Lake Tahoe	<b>Barriers:</b> Lack of skilled health care providers <b>Limited options for care</b>								
Susan Haas	Carson City	Written	Professional		Nevada Rural Counties RSVP Program, Inc. Social Work	<b>Barriers:</b> Not knowing what services are available and understanding the importance of asking for help. Lack of resources			X	X				
Anna Olsen-Figueroa	Reno	Written	Professional		Social Worker for 24 years	<b>Barriers:</b> Lack of awareness of available spreadsheets, high turnover rate with staff, agencies cannot provide care in support in short timeframe/ emergency situations, families may not have established medical				X				
Craig Lowe	Carson City	Written	Professional		Law enforcement	<b>Barriers:</b> Lack of immediately available resources for an acute situation. Lack of after business hours resources. <b>Solutions:</b> On Call Elder Protective Services personnel or case workers. Senior								

								Easy access support system at all times of day and night. Maybe a helpline with immediate resources for advice, provider care, training, etc.					
Patricia Sohn	Reno	Written	Family Caregiver	Cares for her mother at home						X			
Sandra Atkinson	Carson City	Written	Family Caregiver					Respite care	X				
Roger Carl	Sparks	Written	Family Caregiver	Cares for mother			Frustration from his mother	More information and resources					
Jake LaFleur	Carson City	Written	Family Caregiver	Cares for his wife			It became impossible to leave her alone and he is the only family member with her in the city. She had to go on all the errands, shopping trips, appointments, etc.	Better sources of information as to help options that are available. A clearinghouse of sorts to get proper access to any and all organizations that exist to provide assistance.					
Shellie Becker	Carson City	Written	Family Caregiver	Cares for father, but her mother is the			The personality changes, major loss of empathy towards main caregiver.	Much more provider training needed		X			
Virginia Malberg	Carson City	Written	Family Caregiver	Was a caregiver until the last 3			Hospital and rehab center not equipped or prepared to provide needed help and give care. Personnel not well trained.	Provide people to watch him and feed him when family is not there to do so.		X			
Donna DePauw	Carson City	Written	Family Caregiver	Oversees care of husband at the facility. Used to care for him in the			Anger, emotional abuse, domestic violence, mean to the cats unknowingly, carried furniture around the house, tried to leave the house, incontinence, needed constant attention, and didn't want to bathe.	People who cared about what was going on. Caregiver agencies and providers that are more educated on the disease.	X	X			
Lori Draney	Carson City	Written	Family Caregiver	Currently cares for her husband in their home.			Husband accusing her of stealing his money. He is very repetitive. Personality change, he is upset frequently when he doesn't get what he wants when he wants. Also lacks in empathy.	Support group meetings have been a great help. The biggest need is educating people working in care facilities. Care facilities also need to be checked on how they operate.		X			
Rae Waddington	Carson City	Written	Professional		DPBH State Health Worker	connecting to resources, managing condition alone is difficult/impossible <b>Solutions:</b> Community							
Shelly Kamps	Fallon	Written	Professional		Community Health Worker	<b>Barriers:</b> Transportation and fixed income with certain health insurance <b>Solutions:</b> Cart buses						X	
David Kale	Gardnerville	Written	Professional		Mental Health Social Worker, mobile outreach safety team	services, accurate assessment, in-home services, family education, funding, co-occurring issues				X			
Kim Gilbert	Mesquite	Written	Family Caregiver	Cares for a loved one			Stubbornness - unwillingness to do the right thing				X		
Kirstin Malone	Las Vegas	Written	Family Caregiver	Cares for her brother			Anger						
Melissa Hicks	Mesquite	Written	Family Caregiver	Used to provide care for a loved one			Getting him to eat. He would also write things down on sheets of paper and read them day and night. The words would change weekly and he would take the papers everywhere.	Couldn't get people in to help with bathing, feeding, etc. until right before his death. He would sit for hours and not get up for anything. More help was needed.					
Kirstin Malone	Las Vegas	Written			Healthcare professional	families about memory care, the important of engagement, enhancement, and enrichment. <b>Solutions:</b> Education			X	X			
Kim Gilbert	Mesquite	Written			Social Worker	Lack of resources, cost, limited availability of respite providers or			X				
Sundae Orwick	Winnemucca	Written	Family Caregiver	Cares for her mother			Mother has no behavioral issues	Respite care	X				
Christine Bissell	Winnemucca	Written	Family Caregiver	Used to provide care for a loved			Had ulcers, both nose and stomach. One time he thought he was having a stroke, since been shown it was an alcoholic seizure .	Help with some "heavy" house cleaning					

## Agenda Item VII.d - Testimony Notes and Common Issues

Sherry Mock	Winnemucca	Written	Family Caregiver	Used to provide care for a loved			Getting mad and combative	Supportive services					
Gini Cunningham	Winnemucca	Written	Family Caregiver	Used to provide care for a loved			The inconsistency of each day	Better adult day services	X				
Cary Walter	Winnemucca	Written	Family Caregiver	Used to provide care for a loved				More rural services and respite	X				
Anna Krave	Sparks	Written	Family Caregiver	Provides care for her husband			It's like living with a child sometimes; it's difficult to "reason" with my husband and he is "hyper-emotional" and gets angry at the drop of a hat. If he doesn't get what he wants when he wants it, it's not a good day. The world has to revolve around him, like a child.	I would be most helped if people in his situation could still get some kind of financial assistance for the working caregiver. I could use more help with respite funds. It would also be very helpful if the age for medicare and retirement benefits could be lowered and also lower the age for community resource help.	X				
Carol Zadra	Minden	Written	Family Caregiver	Used to provide care for her husband			Husband would get so sad when people would not treat him with respect.	There should be mandatory education for the people dealing with the general public.		X			
Deborah Norrish	Reno	Written	Family Caregiver	Was caring for her mother. Her mother is now in assisted living, but she			Mother did not want to bathe regularly and was not cooperative. The mood swings and acusations of stealing were other difficult factors.	Had so much support with classes, respite care, and the Alzheimer's Association. I was very fortunate.					
Don Colton	Reno	Written	Family Caregiver	Used to provide care			Bathing was stressful. Last two years of her life spent on hospice in a group home. She was nonverbal, bedridden, developed several intestinal blockages, and bed sores.						
Karen Beatty	Minden	Written	Family Caregiver	Caring for her mother			Repetition - Frustrating being asked the same questions repeatlly. Lack of conversation - mother can no longer hold conversation and doesnt comprehend unless it is the simplest of phrases. Mother obsesses over appointments, travel plans, time of day.	More suport group meetings in Minden/Carson City. Would like professional one-to-one session.					
Kim Charles	Reno	Written	Professional		Healthcare Professional	Barriers: Availability of safe housing for those with medicaid; Length of time to complete guardianship process; Prolonged hospital stays due to lack of placement options; Lack of locked facilities; Caregiver burnout resulting in in PWD not being able to return to familiar housing; Refusal of insurance company to pay for hospitalization; and Lack of case management for people without family/friends to							
Mary Lee Fulkerson	Reno	Written	Family Caregiver and an ES PWD herself	Used to provide care			Husband used to argue about everything; had public angry outbursts; wandered into a lake; and became very resentful. Friends no longer came to visit as he progressed and he grew lonely.	More support groups, a hotline for consultation; and more social engagement activity.					
Susan Stewart	Reno	Written	Family Caregiver	Used to provide care			Father's rapid mood changes; from happy to angry to combative.Caregiver could not care for her father, so she sought help through a memory care facility. The ratio of staff to residents at the unit was unbalanced and resulted in one staff for 6 residents.	More quality time between residents and staff at memory care unit.		x			
Sandra Welch	Carson City	Written	Family Caregiver	Currently provide care			Currently caring for a loved on who is rapidly declining and feeling helpless.	Better education and preparation for ho w to care for someone with the disease.		x			
Suzanne Mohr	Dayton	Written	Family Caregiver	Currently provide care			Suzanne finds it challenging to bathe her husband. She tries to give him a bath every 3 weeks but often times its usually 4 or more weeks due to the difficulty of doing it alone. She also does not qualiafy for medicaid which would assist with in home care, based on her income.	Access to dementia capable care.		X			
DeeDee Jensen	Reno	Written	Family Caregiver	Currently provide care			DeeDee provides care for her mother-in-law who is in the begging stages of the disease and has good days and bad days. She was able to be placed in a facility that specializes in dementia care. DeeDee attends suport groups to help her learn how to cope.	Education and information on how to answer her mother-in-law when she repeatlly asks questions or wonders why she cant go home.		x			

### Agenda Item VII.d - Testimony Notes and Common Issues

Vicky Nielson	Elko	Written	Family Caregiver	Currently provide care			Vicky cares for her husband and has challenges finding good medical care in Elko. Her husband was fired from his job as a pharmacist and became depressed. He was misdiagnosed as depressed and put on medication. Her husband has bouts of angry outbursts and it is difficult to communicate with him.	Vicky finds help in support groups and attending education workshops to help her better understand the progression and how she can offer help to her husband.					
William Kramer	Las Vegas	Written	Family Caregiver	Currently provide care			William has challenges with caring for his loved one when it comes to personal hygiene (bathing, using the toilet, brushing teeth,, etc.)	Screening test for those that may be high risk.					
Donald Mcfall	Reno	Written	Family Caregiver	Currently provide care			Caring for wife of over 30 years who was diagnosed 2/15. Her physical condition seems worse than her mental condition and Im her sole caregiver. He is having a hard time accepting the disease and knows the difficult road ahead.						
Hallie Murphy	Carson City	Written	Family Caregiver	Currently provide care			Hallie and her husband both take care of their moms living with dementia, who both still live in their own homes. They have taken their moms to several different doctors over the years, none of whom were helpful and they didn't communicate with each other.	Training for providers on dementia-related behaviors; greater care coordination through managed care		X			
Jolene Holmes	Elko	Written	Family Caregiver	Used to provide care			Jolene lost her father to Alzheimer's in 2016, and she and her mother cared for him. Jolene's mother then became too frail and sick to provide care, so Jolene had to move in and care for both of them. Jolene and her mother struggled the most with their father's aggression. Thankfully Jolene's family got relief from BrightPath, which was an adult day center in Elko of which her mother had been on the board. He went for 2-3 hours 2 days per week. However, they lost funding and closed their doors, leaving Jolene with no other source of respite.	Jolene wished they didn't have to close BrightPath and that the funding could have remained.	X				
Kathy Pantner	Dayton	Written	Family Caregiver	Used to provide care			Kathy cared for her husband at home. His most difficult behavior was not wanting to take a shower or be assisted with toileting. However, Kathy hired in-home care who were able to handle it, but this cost over \$2,000 per month for 5 hours, 5 days per week. Kathy ended up placing her husband into a memory care facility that was understaffed and had poorly trained direct care staff. They didn't change his catheter often enough, resulting in a UTI which went to his brain and killed him in the hospital.	Kathy would like to see stricter training requirements on caring for persons with dementia in memory care.		X			
Juan Molina	Carson City	Written	Family Caregiver	Currently provides care			It was difficult to bathe her because she would not allow him to.	More respite care in Spanish. Not many people or companies can provide these services in Spanish.	X				