

VAPAW Advisory Committee Meeting Panel Presentation Responses

Topic: Family Caregiver Support in Vermont August 22, 2022

Panelists:

- Janis Appel, former caregiver of spouse experiencing the progressive neurodegenerative diseases of Progressive Supranuclear Palsy and Frontotemporal Dementia
- Lisa Stamatis, caregiver of 6 adult children with developmental disabilities
- Lynn Messier, kin caregiver to great-granddaughter

	How long have you been (or were you) a caregiver? Why did you take on the role of caregiving?	What are the top three things that were most helpful to you or that you think would help caregivers the most?	What is/was your caregiving relationship like? What impacts does/did caregiving have on your life (work, family, health, and wellbeing)?	Other comments by presenters:
Jan	Retired from state position as MSW in 2016 to care for husband as no resources for other caregivers were available. Ken passed in 2018.	Diagnosis misunderstood; once clear, no supports or resources – how to manage things as it progressed? No support groups. No experience w caregiving. Had to educate medical staff, which was stressful. Impact was huge – ex. Jan broke her leg & needed to physically help Ted, resulting in personal injuries. Self-care not met. Needs: support groups, educated medical staff, skilled respite & self-care.	When was caregiver, was also parent of 4 children & supported foster parents & kinship families, childcare providers in her work. Now had FT care of an adult slipping away each day. PST & FTD are horrible diseases. Since Ken passed, Jan is involved in giving back to others. Learned to manage grief. Impact on family – everyone traumatized. Affected income & both became isolated from the community also.	Raising awareness of dementia and recognition of the diversity of the diseases and the resources needed. All caregiving situations are unique and specific, and they all need specific resources & support. Holistic plans specific to each situation needed. What are the services people need and how do you address them for that specific individual? Respite care & adult day services question: Jan looked into it and couldn't leave the house when someone is there, and adult care is focused on different intellectual capacity & no staff to keep him from

				falling – it was a generic program that didn't meet a specific need.
Lisa	Parenting via adoption since 1983 for 6 adult children currently aged 33-38. Diagnoses include Down syndrome, TBI, panic & eating disorders, early Alzheimer's, blind, deaf, Hirschsprung's disease, congenital heart disease, etc.	Medical staff want to medicate to make it easier for caregiver. There is no infrastructure. 1. Personal innocence was appreciated as she did not know what she would face going forward. 2. Ability for one person to be a stay-at-home parent. 3. Financial stability, health insurance, limits, etc. Access & resources such as legal services for estate planning. Had to do court visits for guardianships post age 18. Other caregiver cost is beyond financial possibilities. Need: Support staff; we are at a crisis point with low wages & lack of staffing. Need access to grants.	Every aspect of life is impacted. She & husband work outside the home on different schedules. They are exhausted. Fear about future; need to outlive the children. Had no help the last 3 years, in crisis mode. Husband is SW Case Manager at hospital night shift, caring for others. There is such a huge need for the differently abled population. We are in crisis mode.	Has some respite funds but in negotiations w Howard because will go through funds in no time. Private caregivers charge \$38/hr; can apply for more respite funds; can't find staff or support it financially. Don't want the infrastructure to go away – even if family keeps some funds. Need respite.
Lynn	Elena is now age 8. Cared for her off & on since pre-school, then officially in 2020 due to both parents being incarcerated.	Need: support from experienced, educated, knowledgeable folks. Children do not have consistent services. Lack of support or care. Need therapists that understand the experience of an older great-grandparent doing kinship care. Thankful for school resources, but they are not enough. Ex. Lynn had breast cancer & is going to have shoulder surgery and can't think about herself first.	Retired & thought they would travel and do so many things. Whole life changes – no social life – Vermont Kin as Parents (VKAP) Zoom group for support. Do not have knowledge base and resources to work w traumatized child – no trained & experienced therapists available. Need to find resources. Some folks don't even have transportation or money for medications vs food or services. Must show tax returns to get help with childcare. We are saving the state a lot of money as unpaid caregivers.	Knows someone who has applied since January for respite caregiver – hard to justify why they need it. Unless have a person who is respite-approved, can't go anywhere, or use them. Stressful because never get a break.