**Living in the Community in Nevada: Challenges, Gaps and Barriers for the Medically Complex Adult with Cognitive or Communication Challenges.**

Presented by Stephanie Schoen, B.S., M.A., OTR/L

A 10-minute presentation cannot give this topic full justice. It’s a conversation that is in infancy stages. Thus, consider this to be an over-simplified introduction to the challenges, gaps, and barriers to finding, accessing, and maintaining community-based support services to the small (yet financially significant) population of adults Nevada who experience the co-conditions of being unable to direct their own care and having complex medical care needs. These are people who easily qualify for nursing facility care, need 24/7 oversight or eyes-on, and have frequent in-patient hospitalization because group institutional care cannot always meet their long-term needs. When they live in the community, it is family and close family connections that take on the lion’s share of care giving responsibility. That is the focus of today’s presentation.

**Contents:**

Introduction Page 1

Target Population for this discussion Page 2

Main points “Elevator Speech” Page 2

Definitions of terms Page 2

Context and content Pages 3-4

Sources/References Page 4

Possible areas for exploration Page 5

APPENDIX I: sample list of out-of-pocket expenses Pages 6-9

APPENDIX II: Presenter Bio Page 10

**Introduction**

1. This presentation is based on the following: the presenter’s academic (graduate) research and forty years of personal & professional experiences in the health care fields; information available at https://www.medicaid.gov; recent informal interviews of various stakeholders.
2. An attempt has been made to give the most accurate information possible, yet everything is open to question and fact-checking.
3. Please be curious and open-minded during the discussion phase and try to focus on the target population (as defined below) . Expanding or changing the focus population changes the key factors and it becomes a related, yet altogether different, conversation.
4. “Politically” and socially correct terminology is rapidly changing and subjective. Please do not take offense if the terms used are not “perfect”. There is no disrespect intended.
5. Common abbreviations for some terms are found parenthesis the first time the term is introduced. Subsequent uses of the term will be abbreviated.
6. You are being provided this handout for preview purposes and as a note-taking guide only. The presentation will give more detail. This is a work in progress and therefore far from complete. Your input will be added after the discussion segment of the presentation. Citations might be out of order and there will be typos (guaranteed). Kindly point them out.

**The Target Population for this Discussion:**

**ADULTS**. 18+ years old. *Not children*

**UNABLE TO DIRECT THEIR OWN CARE.** This implies the inability to either express wants and needs, or an inability to recognize what the needs are in the first place, or both. This situation is the main feature, not the diagnosis or reason for that inability. The causes for this situation can vary – intellectual or developmental disability (I/DD) or a related condition like Autism, brain injury (TBI), stroke (CVA), ventilator use without the ability to speak/write instructions to a care giver, or dementia.

MEDICALLY COMPLEX (aka, medically fragile, complicated, intense, involved...) enough that the care recipient QUALIFIES (via PASRR Screening1,2) for NURSING FACILITY (NF) LEVEL OF CARE (LOC). (the ICF/MR LOC is not part of this discussion).

**Main Points (i.e., the elevator speech):**

1. There are major challenges, gaps and barriers to living in the community for adults in Nevada who are unable to direct their own care and who otherwise qualify - through a nationally accepted screening tool (PASRR1,2) - for nursing facility placement.

2. Nevada needs to find ways to provide HCBS for medically involved individuals WITHOUT the assumption that those who care about the recipient of services will also be the primary person to care for the recipient in the absence of a skilled practitioner.

3. Current service models for the population of medically complex service recipients in Nevada and elsewhere are heavily reliant upon families without consideration for the long-term consequences and impact on the economic, mental and physical health of the caring family.

**Definitions:**

* Service recipient – this is the patient, client, care recipient or person served. Choose the verbiage you prefer.
* Visit nursing vs. private-duty (shift care) nursing:
	+ Visit nursing: a nurse comes to the home to do a limited number of skilled tasks, usually no more than 2 hours. Visits are often paid by the visit, not the hour, so nurses are motivated to take as little time as possible to conduct their services and move on to the next patient. This may or may not impact quality of care.
	+ Private duty nursing: when a nurse comes for several hours to provide on-going daily skilled assessment and services. Situations for this service include: dependence on medical breathing equipment, IV hydration, or continuous feeding; frequent & severe seizures, apnea or other serious conditions; polypharmacy that is best dispensed over the course of the day (and not all at once); medically fragile, unstable or unpredictable from hour to hour, such that their condition can and does change frequently or quickly; and more. [This can also mean hospice care, however for the purposes of this presentation, hospice is not included].
* Medically complex - a service recipient whose health/medical condition
* requires the assessment and evaluation skills of a registered nurse on a daily basis for more than a simple “visit”.
* Requires timely access to the input or services of their primary care physician (MD or DO) or and advanced practice nurse (APN) frequently and in a very timely way for which office visits are impractical.

|  |  |  |
| --- | --- | --- |
| **Challenges** | **Gaps** | **Barriers** |
| Finding doctors, therapists, and supply vendors who take Nevada Medicaid. | No provision for relief to family members who provide the bulk of the care and then serve also as the primary on-call staff when providers take time off. | Transparency – difficult to ascertain what services are available and to whom. |
| Inconsistency of information provided by the agencies, vendors and providers, including 211.  | When level-of-care determination (i.e., PASRR1) is for NF2, the person’s needs for support don’t change just because they move to a community setting, yet often the money does not follow them into the community. | Labeling and dividing people into “categories”. |
| Quality of products covered.  | Needed DME not covered | Transportation |
| Lack of Providers – shallow talent pool or rural areas without professional depth | Developmental Services for adults is focused on behavioral services\* | 24-hour services are not available when adults with I/DD live with a family member; but 24-7 services ARE available when that same person lives in a group home. Translation: family takes up the slack. |
| Limited or prohibitively costly respite workers who are qualified to provide the LOC needed. | For young adults, limited daytime facilities and programs that employ or have ready access to a nurse and provide age-appropriate activities.  | Lack of flexibility in person-centered planning due to labeling and categorization. |
| Presumption that family will include the person in the everyday life of the family, which in reality translates to being the 24/7 back-up or on-call caregiver when care from other sources cannot be found (or they call in sick, go on vaca, leave their job, etc.).  | Short-sighted view with bias toward children, failing to realize that if you do a good job during childhood, the kids grow up to be adults. Yet adults do not get the same level of funding or services. In-home services limited to early intervention; but in-home services could benefit health of many fragile adults and should again pick up after school eligibility ends when there is difficulty finding appropriate providers and/or transportation is problematic. | Funding – affects how much providers are paid, and therefore the availability of needed service providers |
| Deficits in choice and lack of control over who enters the home to give care. | Few resources to help families to learn to care for the medically complex patient. | Poor rating system for who gets which services and how much they get, as well as waiting lists. |
| Natural supports are often insufficient and inappropriate for the level of care (LOC) need by people who are medically complex. | In-home OT/OT/ST services limited to early intervention; many fragile adults could benefit from in-home therapy and if fragile should not be expected to travel to a clinic to receive therapies. |  |
| Administrative burden on both the recipient/recipient’s family as well as state case workers |  |  |

**Possible areas for exploration:**

Ideas that could be explored to serve the very few people in this population:

Is it time to finally merge I/DD waiver into the other combined waivers?

Voucher system model for those who fall outside the norm or needs.

Medical Home model.

In-home services, including concierge model of medicine.

Flexibility in how services are combined.

Plan for services that are not reliant on family always carrying the time and cost burdens.

Utilize Community Health Worker Model.

Work with AG’s office to find ways to limit State liability through legal releases, etc.

Work with Nevada systems of higher education to utilize internships and prepare health care professionals and social workers to assist families in planning for long-term care.

Formulate some sort of disability and long-term care network (similar to the Human Services network) to bring all stakeholders to one table for comprehensive planning within the State of Nevada instead of the piece-mill, pilot-study, catch-as-catch can system of resource grabbing we see today.

POLICY ANALYSIS! Using various models before presenting anything to the legislature!

**APPENDIX I**

Information that the families need to know before accepting the key responsibility of caring for someone at home.

In planning for transition of service recipients from institutional care to community settings, the person or persons who are being asked to take on the primary role of caregiver, host home, or responsible party might need to have a full understanding of the costs and commitments that they are likely to incur by agreeing to provide in-home care. Sometimes these costs of time and money exceed what people think before they get into it.

The potential responsible party/care giver needs to be given realistic information about duration of care, alternatives to their immediate presence, budgets, resources, back-up plans, etc. Social workers at hospitals and NF’s are not in a position, nor is it usually their job, to provide the gritty or unpleasant details associated with finding community “placement”. Yet to be fair to families taking on the responsibility for a medically complex loved one, those details may impact their future economic, mental, emotional, social and physical health.

Time is a hug commodity. We all get the same share of time, and there are plenty of studies coming out demonstrating the strain and burdens of caregiving3, 5.

Some supplies are very costly and not paid by any type of health care coverage. Some things can be paid by insurance or Medicaid if the doctor is invested and willing to provide the time and effort needed to write a sufficient justification for the item(s) (known as a Prior Authorization Request, or PAR). For any physician, this is a big demand on their time and the PARs do not always get the attention they require for approval. Furthermore, not all physicians are very good at this and the family/responsible party must resort to the “appeals process”. This process is scary for people, as it sets up an “us vs. them” scenario.

**Expenses that are generally out-of-pocket**

**Hygiene and Grooming** (costs that we all cover for ourselves):

* Shampoo/hair care products
* Hair cuts
* Shaving supplies
* Deodorant
* Lotions, powders
* Acne/skin treatments that don’t require prescription
* Nail care (and someone to do it)
* Oral care (toothbrushes, toothpaste, denture cream & cleanser, floss, mouthwash)
* Soap, antibacterial soap, no-touch soap dispensers
* Hand sanitizer
* Make-up, cologne, after-shave, perfume, if applicable
* Grooming implements (combs, brushes, clippers, etc.)
* Paper goods like paper towels, toilet paper, tissues, cotton swabs, etc.

**Hygiene and grooming supplies outside what most non-disabled people use:**

* PPE – gloves, masks (not sure about gowns in the event of contact precaution requirements).
* Oral swabs for the person unable to spit or participate in standard oral care
* Bed bath supplies like microwavable bath wipes and no-rinse shampoo caps
* Incontinence care (the things that drain the budgets of many elders these days):

[Sometimes, and with effort, these items can be covered, however people report inconsistencies in approval as well as finding a vendor. It’s a common topic among those in the field doing any sort of home care].

* Personal hygiene wipes for incontinence management (i.e. baby wipes for adults)
* Peri-area cleanser (formulated specifically to remove odors associated with bowel and bladder incontinence)
* Washable incontinence pads for the bed (range in cost from $5-15 for minimum absorbency, ½ size pads, which is usually not sufficient. $25-45 per full size pad for the bed with moderate-high absorbency, with a life ranging from 4 months to 2 years. Brands vary in backing and quilting quality).
* Disposable incontinence pads (i.e. Chux)
* Incontinence garments (such as Depends)
* Some catheter supplies

**Over-the-Counter (OTC) Medications**

* OTC Medications\*–common for the complex patient, and many essential medications are now considered OTC. Medicaid allows coverage for 3 OTCs per month. OTCs include pain relievers, cold remedies, allergy relief, and the types of things that all people buy without a prescription.
* Vitamins and herbals
* A note about CBD products: CBD can be covered by Medicaid under certain circumstances. Details should be investigated separately if CBD is part of a person’s treatment plan (as in for seizure control, spasticity, pain, etc.). It requires an assessment by and prescription from a doctor who has specific credentials.

\*Some OTC drugs are not compatible with some common enteral feeding systems (such as a MicKey button) and require a different formulation of the drug than what is approved for OTC sale. These can be covered by most insurances with adequate justification by the prescribing doctor. Sometimes it requires an appeal

**Cleaning supplies and equipment** (or a cleaning service)

* + trash bags
	+ cleansers
	+ broom, dustpan, mop, vacuum
	+ rags or cleaning cloths
	+ laundry products

**Household set-up, maintenance and associated products** – varies greatly depending on type of housing, location, and ownership of the property. Potentially could include:

* + Furniture
	+ Bedding, linens, towels
	+ Kitchen implements and small appliances
	+ Disposal services
	+ Power (and sometimes Gas)
	+ Water services
	+ Cell or other phone services
	+ Light bulbs
	+ Air filters for furnace
	+ In Nevada, often a humidifier
	+ batteries
	+ Flashlights
	+ Fire extinguishers
	+ Emergency supplies
	+ Yard maintenance, if applicable
	+ HOA fees, if applicable
	+ Parking spot (some apartments charge for this)

**Personals:**

* + Clothing & footwear
	+ Gifts to others
	+ Computer or tablet
	+ Rec & Leisure costs: Books, magazines, hobbies, cable TV, movie rentals/tickets, videogames, plays, concerts, special events, classes, adaptive sports expenses (like ski tickets) and fees to recreation departments (like for Quad Rugby, swimming pool use, etc.), specialized equipment for use on beaches and other soft and uneven surfaces, memberships or season passes (museums, the gym, water parks, ski areas, tennis center, etc). There are costs even if the person is bed-bound. Netflix, Hulu, and Prime are not free.... and neither is the internet service that supports them.

**Pets and pet care products, particularly when a service dog is in the mix**

* + Veterinarian
	+ Medications
	+ Licensing
	+ Toys
	+ Food and snacks
	+ Equipment (leash, bowl, vest, etc)
	+ Grooming supplies or grooming service
	+ Walking service, as applicable
	+ Daytime boarding, as applicable

**Transportation – varies by location of housing and the individuals need for a) accessible service or vehicle, and b) attendant care during transportation other than just the driver.**

If a person lives outside the area served by a regional transportation, the responsible party needs to find an alternative, which might include one of or a combo of the following:

* Wheelchair cab service
* Uber or Lyft (accessible or not)
* Friend or volunteer from other social connections
* Non-emergency medical transportation services
* RTC Access or equivalent, depending on the community.
* A privately owned vehicle
	+ Van conversions are not covered in NV by the State so the conversion to a wheelchair accessible vehicle is incurred by the individual or family unless they can get some sort of funding (i.e., grants, independent living, charities, go-fund-me, etc.).
	+ Somebody has to buy, insure, smog, register, maintain, and fuel thevehicle.
	+ Someone needs to be allowed to transport the client in that vehicle if the family is not available to do so.

**Dental Care** (non-medical for cleaning, prevention, x-rays and general oral health)

**Vision Care** (non-medical, for glasses or contacts, general eye check-ups)

**Hearing Aids**

**Dentures (??)**

**Respite care**

The target population is not always able to participate in all the “normal activities of family life” because of their underlying health condition, intolerance of weather extremes, difficulty traveling, sensory sensitivities, or limited tolerance for out-of-bed sitting/activity (to name a few reasons). Yet there are dozens of reasons that a caregiver is likely to need to be unavailable, even if they are at home.\*

The only way a care giver can take a true respite from the 24/7 obligation for someone in the target population is to find a person with the skills necessary to replace them without worry. For the medically complex population, care giving is not simple and requires a reasonable level of expertise. So, when someone says, “what about someone from your church”, or “what about a neighbor”, the answer is often “they don’t have the necessary skills, nor the comfort level to learn them”. And when someone cannot direct their own care, the State does not cover the service of someone without what is considered the appropriate credentials (i.e. nursing). Thus, the expense falls partly or entirely on the family.

In No. NV there are some creative methods of using some of the local respite programs, and there was recently a one-year pilot study that engaged families in person-centered model of respite that was focused on the needs of the caregiver, not the care recipient6.

Costs can run from zero to upwards of $45.00/hour, depending on the required LOC that the person being cared for needs.

\*Injury, illness, surgery, appointments, shopping, funerals, weddings, graduations, church, parties and special events, vacations, travel, work, school, tending to other family members and pets, working in the yard, cleaning the house, date nights, participating in support groups, participating in advocacy efforts, taking a shower, using the toilet, or sleeping.

Source References:

1. https://www.medicaid.gov/medicaid/long-term-services-supports/institutional-long-term-care/nursing-facilities/index.html.

2. https://www.medicaid.gov/medicaid/long-term-services-supports/institutional-long-term-care/preadmission-screening-and-resident-review/index.html.

3. https://www.nvchwa.org

4. Levine, Carol. 2004. *Always On Call: When illness turns families into caregivers*. Vanderbilt press, Nashville.

5. Just Google it. There are dozens of scholarly articles on Google Scholar, too many to list here.

6. Source: informal discussion with Cheryl DInnell of the Nevada Respite Coalition, March 23, 2021. She is not at liberty to discuss results of the pilot study, so this is not a formal citation.

**APPENDIX II**

**Stephanie Schoen, B.S., M.A., OTR/L**

**Bio**

Raised in Reno, NV, Stephanie attended local public schools and UNR, beginning adulthood with a Bachelor of Science in Renewable Natural Resources/Forest management. Ten years later, as a newly single mother, she was financially forced to place her daughter into skilled nursing care, allowing her to pursue a career in health care that would later support bringing her daughter back home. She attended and graduated from the University of Puget Sound with a second Baccalaureate of Science in occupational therapy. After practicing OT briefly in Oregon and Washington, Stephanie returned to Reno to fulfill her commitments as a Nevada WICHE scholar and has now been a licensed OT in Nevada since 1996. In 1998 she participated in Nevada’s first class of Partners in Policymaking (an advocacy training program for people or parents of someone with a disability), bringing her daughter back home to live on the day of graduation day of that program. Since then she served two years on the Advisory Committee for Children with Special Health Care Needs (under Maternal and Child Health), and eight years on the Nevada Governor’s Council on Developmental Disabilities (with service on the Executive and Legislative Committees, including re-writing the 5-year state plan during that time)

As an OT, Stephanie has worked in diverse settings with various populations with roles ranging from private practice to therapy supervisor at a major in-patient acute-care facility. She loves to help people “occupy their time” in ways that they find important and personally relevant. She is certified in Skills2Care® (a program for people caring for someone with dementia)

More recently, Stephanie earned her Master of Arts in political science in 2018 with an emphasis in health care policy. Her thesis used Medicaid (as a federal program) as a case study to explain how and why state borders are now a key for factor in the access of services for many people facing disability and poverty. She believes in the use of evidence-based practices combined with both creative problem-solving and a family-centered approach to reach outcomes that are meaningful to each individual and feasible for the family, whether that be through a therapeutic process or policy implementation. She believes steadfastly in community and educational inclusion, life enrichment, and quality of care.

On a personal level, Stephanie continues to manage, coordinate, and provide the bulk of the care that her now-33-year-old daughter requires (the equivalent of intensive-care at a hospital). At this point, Stephanie has had over three decades of care giving and recipient experience with SSI, Nevada Medicaid, and a variety of service entities just for her own daughter, and over two decades of dealing with similar systems for her patients.

She welcomes questions about her education and background, how each stage of her personal and professional development has changed her life, influenced the way in which she practices the art and science of occupational therapy, and how she approaches policy analysis and change at all levels of government and non-governmental service.

Stephanie has been married over 20 years to Erik, is involved in her home church, loves the outdoors, raises chickens for eggs, grows much of her own produce, has two golden retrievers, and enjoys skiing, cycling, kayaking, camping, indoor climbing, and art. And her daughter thrives in the home environment.