

Respite Work Group

October 14, 2016

10:00 a.m. – 1:00 p.m.

HARMS Advanced Technology Center and via Go To Meeting

Present: Melissa Santana (Northfield Retirement Communities), Natasha Clark (Regional West Garden County), Lana Parmenter (DHHS A&D Waiver – Respite Advisory Member), Kathy Bridge (Caregiver), Jill Selvey (Caregiver- Respite Advisory Member), Gloria Kennedy (Caregiver- Respite Advisory Member), Maria Alvizar (CAPWN – Respite Advisory Member), Carol Enderle (Caregiver), Joan McVay (Friends of Alzheimer’s and Dementia), Steve Trickler (Aging Office of Western Nebraska – Respite Advisory Member), Linda Redfern (Region I Office of Human Development – Respite Advisory Chair), Helena Janousek (Respite Coordinator Southwest Area), Jay Everhart (SPEAK OUT), Sherri Blome (Respite Coordinator Western Area)

We began the session with the Long Term Care Services and Supports Power Point. The Power Point was followed by specific respite questions. The agenda is attached. Here are the items discussed.

- **Problem** - Access Nebraska has made access more inaccessible.
 - Many families in the Frontier areas of Nebraska do not have access to the internet or their internet service is not reliable.
 - Families often have pre-paid cell phones and they run out of minutes waiting to talk to someone.
 - There is a training issue. Families calling in are often told “If you don’t like the answer you get the first time you call, call back and you’ll get a different answer.”
 - The system is not relationship based so families are often not comfortable using it.
 - When asked if the family member has a “disability” families may not perceive impaired development to be a “disability.”
 - Navigating the system is difficult due to all the “jargon” used
- **Solution** – Strengthen access by having personal service in the different areas of the state. Be sure the individuals who work at the call centers all have the same training. Encourage the individuals who are at the call centers to not use jargon for example MHCP should not be used but instead say the Medically Handicapped Children’s Program offers ...
- **Problem** - With regard to respite, providers are “siloed”. Multiple programs have respite providers such as the Aging Offices, DHHS, Respite Coordinators, Waiver workers, yet there is no one place to access providers so each list may have the same or different providers. A provider on one list may not automatically be eligible to provide respite for a particular funding source.
- **Solution** – Develop one online location that all providers are entered. Require the same qualifications for all programs. This allows families looking for providers to have a comprehensive pool and to know that the provider will be allowed to be paid by the funding source they are eligible for.
- **Problem** – With regard to the Developmental Disabilities System the Waiting List does not need to be so long.
- **Solution** – Currently if an individual is on the Waiting List then they cannot be served until they reach the top of the Waiting List. For example: the person at the top of the waiting list is from Omaha and the services in Omaha that can serve them are full. The second person on the waiting list is from Scottsbluff. There are openings in the Scottsbluff program, however, that person cannot be served until the person from Omaha is served.

- **Problem** – Caregivers need to be educated on a plan to transition to a nursing home when the time comes. Currently many caregivers do not know what steps need to happen before entering a nursing home and then something happens and nothing is taken care of ahead of time so they have to wait until they can complete the steps needed.
- **Solution** – Anyone working with elderly should be talking to them about what would need to be done in case they need to go into a nursing home at some point.

- **Problem** – Nursing homes have limited or no Medicaid eligible beds. Some families who rely on Medicaid may not be able to get into a nursing facility with open beds because all their “Medicaid beds” are full.
- **Solution** –

- **Problem** – There are now 2 intakes for Medicaid. One for medical and one for economic assistance. This just requires additional paperwork from already stressed out families.
- **Solution** – DHHS programs in general should be able to pull any information from programs individuals have already applied for to decrease duplication. For example a Respite Subsidy applicant who qualifies for Medicaid should not have to send in financial information because Medicaid already has it.

- **Problem** – Spanish applications don’t always make sense even when the families are Spanish speaking.
- **Solution** – Having an actual translator who understands the program helps. Often meaning gets lost in translation. Access to bilingual workers also helps such as the Language Line but only if they are familiar with the “jargon” and intent of the program.

- **Problem** – Assessments are not standardized.
- **Solution** – Assessments should be standardized as much as possible and shared any time possible to assist families.

Barriers

- Nebraska chose not to expand Medicaid which has caused a great deal of access problems.
- Many people do not access respite because out here “we do it ourselves”
- People needing respite often feel there is a stigma to seeking assistance
- Many family caregivers feel it is their “burden to bear” and won’t ask for help.
- Often there are no providers who have higher level of care options available for individuals who need respite but have high medical needs.
- Maximus – a system used by DHHS has been taking up to 5 months to get a new provider approved.
- Often families do not want to use nursing homes for respite. Those who do often find an easier transition when the time comes to use a nursing home but many families refuse this option.
- There are limited day services available in the rural part of the state.
- Respite services serve a narrow window of people and services because of funding structure. Although families can access providers, most cannot access funding assistance which makes them unable to use respite. Families who are not Medicaid Eligible often cannot access funds.
- Provider reimbursement rates make it difficult to get good providers. Currently many systems are allowing \$9.16 for a basic provider and \$10.36 for a skilled provider. Providers can make more money at McDonalds than caring for someone with disabilities.

- Recently respite through the Disabled Children’s Program dropped back down to \$75.00 per month for families.
- The Lifespan Respite Subsidy Program has offered a maximum of \$125.00 per month since it’s inception. This is a very small amount of respite hours.
- Some DHHS programs do not allow family caregivers to private pay to supplement the funds because they make providers sign something stating they will work for the amount paid by the program.
- The reimbursement rate leads to a lack of qualified providers.
- Some nursing homes will only take people 55+, so if you have a 20 year old who is nursing home level of care you can’t use that facility for respite.
- Individuals who can afford Home Instead can still receive only limited services. Home Instead will not do lifts or transfers or do medication.

Summary

In general our group felt that when local workers were taken out of communities, service decreased significantly. When working with DHHS you are never given a “menu of services”, instead you have to guess what is available and then maybe you can find out if you qualify. Often families are not even told of resources that can help them.

Some resources that are available locally include:

- Aging and Disability Resource Center – housed locally at the Aging Office of Western Nebraska – Mandy Fertig – 635-0851. She can assist with resources for individuals with disabilities across the lifespan.
- We seem to have lost the “No Wrong Door” in a lot of areas. We need to get back the idea of I can’t help you but I will find someone who can.
- Peggy Mills at the Gering DHHS office can still meet with elderly in person which helps them to be able to access needed programs.
- Meals on Wheels through the Senior Center and through Regional West would be a good place to share information.
- The Respite Coordinator can do outreach presentations to support groups.
- Flyers and email seem to be a good way to reach out to people.

In a perfect world we would like to see respite funding based on need more than resources, easier to receive the help you need and adequately funded. By offering respite funds to those who need them you avoid more expensive options such as nursing home facilities.