



## RECOMMENDATIONS ON THE LTSS (LTC) REDESIGN

The following letter is being sent to respond to the state's request for feedback for Long-term Services and Supportive Redesign. The comments are from a Workgroup composed of 15 individuals representing (some parents and some representing various agencies and organizations supporting persons that are aging and/or have developmental and physical disabilities) as well as a Respite Advisory Committee. We have been meeting over the course of several months to discuss issues related to the individuals served and what their experiences have been in accessing programs and services to meet their-and their family's needs for care and support. Our group believes that families are the backbone of Nebraska's long term care system and they require support in order to continue providing care in their homes. Families frequently have to adjust their work schedules or leave the work force entirely in order to provide for the caregiving needs of their loved one. There are increasing numbers of families caring for children and grandchildren with either high medical or severe behavioral needs and these families need support services like respite. However, these services are not often available to them due to high costs to obtain services and lack of trained providers to address these needs.

One overriding concern is in the area of **navigational support for individuals** who have disabilities or families of children with disabilities. Many shared frustrations of the lack of navigational support available to assist them in finding programs and services. In one case a family member had questions about her daughter potentially requiring nursing care services and was told by her state services coordinator to call Medicaid directly. She was given the number of who to call only to be referred back to the service coordinator to get the answers by the Medicaid representative. An additional area of concern was with those individuals with disabilities who have been served by the public school system not being guided into what to expect or how to reach adult services their children will require.

In many cases, families are discouraged because they must know the name of the program they are seeking, the name of the coordinator they must reach and often what the income guidelines are for eligibility for the service requested. Families often report they do not know enough about the programs and services they may have access to, making navigation a continual frustration.

The following are examples of calls that Respite Network Coordinators often get asking for assistance:

- A mother is seeking a facility for her 15-year-old son to go. She doesn't want Respite in her home—she wants her son to go somewhere. He has behavior issues and has been diagnosed with Oppositional Defiant Disorder (ODD) and Reactive Attachment Disorder (RAD) and has been violent in the past. He doesn't qualify for the only program in town that has an out of home Respite option because of his volatile behaviors. Even if he did qualify, this agency is only

open M-F, 8 am to 6 pm which does not offer support to the mother during the time she needs them (like evenings and weekends.)

- A grandmother (non-English speaking) is seeking Respite services for her very high medical needs grandson. None of the providers that we have in our data base would be comfortable providing Respite in this case.
- A mother calling seeking a facility that her special needs daughter could stay while the family goes out of town for a family event. Omaha does have facilities that offer respite to older family members with special needs if there is availability, however, this service is non-existent in Western Nebraska.

We need to address the pay scale for respite care providers as these individuals make about \$10/hour. One provider stated “why would I work at \$10/hour to support someone that punches holes in a wall, hits and kicks me when I can work at McDonald’s and get paid the same or more and not have to worry about the liability or medical expenses of myself or the individual I am supporting”. **A high level of care, also needs a higher funding level.**

Our group was focused primarily on **respite services**, which are those services designed to enable to family caregiver a break from the demands of providing care. These services are often unknown to families and/or are not adequate to meet their family’s needs.

The following are recommendations that our Work Group feel are important for consideration in the LTSS Redesign:

- Increased training opportunities need to be available to enable respite providers to more adequately be able to care for the needs of individuals with high medical or behavioral issues.
- Address the way that families would have greater access to Medicaid as these families may have higher incomes but also have high medical needs that should be considered in determining eligibility.
- Crisis respite funding needs to be more readily available and timely to families.
- The state of Nebraska needs more crisis respite centers available for drop off when a family is in a significant crisis and in-home respite is not appropriate.
- There needs to be more information available defining what types of respite are available to families, as there are many definitions for respite being used across the state.
- Across the state, there needs to be an increase in training for staff on cultural competency for professionals and direct-care support staff.
- Increase the number of Spanish-speaking respite providers and agency personnel to help these families navigate the service delivery system.
- More emphasis could be addressed on securing professionals in medical and behavioral issues that can work with Hispanic families specifically.
- Look to making priority those aging families that are caring for their adult children with Intellectual and Developmental Disabilities who will eventually be in need of LTSS when the again parent/caregiver passes away or had to move to a nursing home themselves.
- Expand access to respite services to provide family caregivers a break from the demands of caregiving, especially in times of crisis. Families of children and young adults with high behavioral needs frequently experience limited opportunities for a break and enter into crisis situations, calling to find a place to drop off their loved one because they “can’t take it

anymore.” **The state of Nebraska needs more crisis respite centers available for drop off when a family is in a significant crisis and in-home respite is not appropriate.**

- Consideration made to offer respite support services to families on an individualized basis, considering the special care needs of the person requiring care. Some families require more assistance than is generically provided.
- Encourage utilization of online registry that lists all respite providers in Nebraska, regardless of who they work through and require that all providers have the same qualifications. There is too much confusion because there are multiple respite programs and confusion on what definition is being used for respite care services.