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March 22, 2016

RE: Public Comments for the A & D Waiver Renewal

The Nebraska Statewide Independent Living Council (NESILC) has a mission to partner with the Independent Living Network and other organizations to promote Independent Living and facilitate systemic change that promotes independence, inclusion, non-discrimination, and dignity for all people with disabilities in Nebraska. The Nebraska Home and Community Based Services (NE HCBS) Coalition is composed of a broad and diverse group of stakeholders representing aging, physical and developmental disabilities, traumatic brain injuries, mental health, independent living, self-advocates and other groups who are interested in Medicaid long-term services and supports within the community. The HCBS Coalition was formed as one means to address the new CMS regulations redefining HCBS but also to acknowledge the recent incorporation of the federal Aging, Independent Living and Intellectual and Developmental Disabilities offices into the Administration for Community Living. NESILC has helped facilitate the Nebraska HCBS Coalition. The Home & Community Based Waivers are a very large component of this. They allow people with disabilities to remain active and participating members of their communities. The following are members of the NE HCBS Coalition's comments, compliments and requests for clarification regarding Nebraska's renewal of the Aged and Disabled Medicaid Waiver. We look forward to the Department's responses.

First of all, the undersigned organizations would like to thank the Nebraska Administration, the Division of Medicaid and Long-term care, and the Division of Developmental Disabilities for their work, transparency and efforts to engage with stakeholders and obtain public comments for Waiver renewals and redesign efforts. We recognize the significant time and energy that is going into the A&D Waiver renewal and the 3 Developmental Disabilities Waiver renewals. Additionally, we would like to recognize the improvements in Access Nebraska, Nebraska's Medicaid and economic assistance intake system. We hope to continue the dialogue to work together to innovate and improve Nebraska's systems –specifically as it relates to long-term services and supports; programs critical to individuals with disabilities and their families.

The items outlined below relate directly to the Summary of Changes in the A&D Waiver and other items we would like comment on. We provide the states proposed change and the HCBS' comments to the change.

### **Appendix A:**

1. *Previously, Resource Development staff were responsible for all activities related to provider enrollment. In December 2015, a Provider Enrollment Broker was added to execute the Medicaid Provider Agreement. The waiver application has been modified to reflect this change.*

**HCBS Coalition Comments:** There are delays with Maximus, the Provider Enrollment Broker, and this has a negative impact on the individual receiving services, the providers are required to meet deadlines when submitting their required paperwork but Maximus is not required to respond in a timely manner with authorization of a provider. The impact is that a provider works with no guarantee of payment or the consumer loses their provider of choice.

**Recommended Language: The Provider Enrollment Broker will execute the Medicaid Provider Agreement within 30 (thirty) days of the submission deadline or be assessed a penalty.**

We are also concerned with the fact that the Provider Enrollment Broker does not seem to be consistent in what levels of background checks must be completed.

Our main concern is the welfare of the consumer. We want to know what remediation is available?

1. *Data aggregation and analysis for Local Level Complaints and Local Level Incident Reports has been changed from quarterly to annually.*

**HCBS Coalition Comments:** People with disabilities have some of the highest rates of abuse and neglect, and thus, we are concerned about decreasing the frequency of aggregation of complaints and analysis of incidents and ask that the state clearly identify the process for insuring safety and quality within the HCBS Waivers. Further, we ask that you also incorporate and reinforce these processes within the state's transition plan for Home and Community Based Services.

1. *The current waiver application states participant/family surveys are conducted on a 3 year cycle and does not specify the reason for the surveys. The new waiver application indicates the surveys will be completed to measure satisfaction and outcome needs. The 3 year cycle was changed to "every 3 years or as needed at the discretion of the department".*

**HCBS Coalition Comments:** We like that the reason for the survey be for satisfaction and outcome needs. One of the basic tenets of the Disability Community is "Nothing About Us Without Us," therefore, we suggest that there be language stating that the survey will be developed and results evaluated by individuals who receive waiver services and their families. Further, we suggest the 3 year cycle be changed to read "every 3 years or increased at the discretion of the department."

2. "Continuous and ongoing monitoring of execution of Medicaid provider agreements" changed to "continuous and ongoing monitoring of participant enrollment" to reflect the changes made in regard to use of a Provider Enrollment Broker.

**HCBS Coalition Comments:** Again, as we identified in item 1, we would like to see further language and clarification about the Enrollment Broker, specifically, if enrollment is negatively impacting the individual receiving services and what the remediation process would look like.

7. A performance measure to address compliance with HCBS setting requirements was added.

**HCBS Coalition Comments:** We compliment the administration for planning for and incorporating changes related CMS' rule for HCBS.

## Appendix C

1. *Assistive Technology and Support previously identified a \$5,000 cap for assistive technology supports and home modifications. This amount was set in 1998 and restricts modifications to return home. This has been removed*

*and replaced with the State establishes an annual maximum for each of the two service components for Assistive Technology Supports and Home Modifications.*

**HCBS Coalition Comments:** We are pleased that the current cap for home modification and assistive technology is being eliminated to recognize increases in costs since 1998. However, we have concerns that not setting an amount is not transparent and removes the knowledge base of individuals receiving services to know what both the home modification and assistive technology amounts would be. The language we would suggest is:

**Recommended Language: The Department will meet with Assistive Technology Partnership (ATP) at least annually to negotiate the cap for home modification and assistive technology to be reflective of the market and not going below the average of the total costs for waiver projects for the previous 12 (twelve) months.**

Further, we would like to add that ATP funding is critical to individuals in need of long-term services and supports and that the current eligibility levels for Nebraska's Waivers do not meet the needs of many individuals who need ATP services. Further analysis of this is needed in the state's redesign to prevent institutionalization and promote home and community based services and remove ATP's waiting list.

*2.) Criteria for precluding school attendance by the parent(s)/guardian as a reason for child care to be authorized were updated from post-graduate to graduate studies.*

**HCBS Coalition Comments:** This is very nice. Thank you!

3.) The requirement for meals to be delivered daily was removed from the General Service Specifications for Home Delivered Meals.

**HCBS Coalition Comments:** We have some real concerns about this. Specifically, how the nutritional needs of people with disabilities will be met with this change? Will meals still be delivered on the weekends? Will individuals who need assistance with meal preparation have the supports they need? Please clarify the changes.

*4.) The bulleted list of crimes that would disqualify a person from being a provider was removed.*

**HCBS Coalition Comments:** Please describe the process of screening for providers. How will the state determine what crimes disqualify a person from being a provider versus crimes committed where they could still be a provider? Is there a statute of limitations that the state uses? We believe that the bulleted list should be updated by remain to protect the individual receiving services from between crimes of violence /safety and financial exploitation.

## **Appendix G:**

1.) APS Information was updated to reflect current APS/CPS regulations, policies and practices.

**HCBS Coalition Comments:** Please provide additional information about the updates with APS/CPS. Nebraska has historically had the highest national rates out of home placements in foster care and we know that individuals with disabilities are at a high risk of abuse and neglect. Additionally, if programs/medical supplies are too costly for families to afford, is their training for APS and CPS to recognize the difference?

- Specifically, does Medicaid or other Divisions within DHHS, do training to APS/CPS workers on the waiver programs? How does Adult Protective Services and Child Protective Services collaborate with the Division of Medicaid –specifically within the Waiver programs?

2.) The performance measure regarding Participant/Family Experience Surveys was deleted due to

reliability issues with data.

**HCBS Coalition Comments:** If the Participant/Family Experience Survey was eliminated, what was replaced to insure that the involvement of individuals who receive waiver services and their families remain?

**Other HCBS Coalition Comments:**

- We ask the department to clarify the process for determining a child who has previously been eligible for the A & D Waiver to be found ineligible for A& D Waiver services.
  - Many concerns have been shared by families who have children that are on a 'G-button' and are being tube fed to insure proper nutrition, that once they hit a certain level of oral intake that they are no longer eligible for the A&D Waiver. We understand that children can improve to the point of not requiring the Waiver, but we also want to insure that they are stable enough and have enough time to demonstrate stability of their oral intake. Does the Department take this into consideration? If so, please describe.
  - The A & D Waiver also provides coverage of the intensive therapies required to help improve the child's growth and development. Once the child loses coverage of the A & D Waiver, they also lose coverage of the corresponding services and are at risk for regression and failure to thrive. How does the Department and the state Medicaid system provide other services and treatments to insure the health and well-being of the child when the child who previously was eligible for the A & D Waiver is found ineligible?
  - How does the A & D Waiver support the requirements of Early Periodic Screening Diagnosis and Treatment (EPSDT)?
- Currently Nebraska does not allow for personal assistance supports (PAS) to be paid when an individual on the A&D Waiver is in the hospital. We are concerned that this places the individual who needs assistance in danger as hospital nurses are not always and immediately available.
  - Please respond to the feasibility of providing reimbursement for PAS during hospitalizations
- Please clarify the timelines and processes for collaboration within the Nebraska Department of Education and Vocational Rehabilitation and who supports a youth on the A & D Waiver as they transition from school.
  - If the child is eligible for special education is he/she required to remain in the school-supported transition program until age 21?
  - If the child graduates at 18, can the A& D Waiver support the youth as he enters employment and/or college?
  - Can a child on the A & D Waiver, move into the DD Waivers?
  - How does the A & D Waiver support socialization and inclusion for youth/young adults?
- Please clarify the difference and similarities between independent skills training, adult day services and habilitation within and between the A & D Waiver and the DD Waivers.
- How will the Department advertise and promote future Waiver renewals and amendments?
- Has the Department considered offering a stipend to individuals and families who participate in the stakeholder process or quality assurance processes?

Again, thank you for your work on the Waiver renewals. We look forward to your responses and the on-going collaboration to improve Nebraska's long-term services and supports programs.

Sincerely,

