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Survival Coalition of Wisconsin Disability Organizations and Family Voices of Wisconsin appreciates the opportunity to comment on the renewal application for the Children's Long-Term Supports waiver. We recognize the attempts DHS used to obtain stakeholder input including virtual listening sessions with families and input from the DHS Council on Children's Long-Term Supports. The CLTS waiver and current application reflects extensive collaboration between DHS, families and stakeholder groups. We believe this application represents the outstanding evolution of the support Wisconsin provides to families and children with disabilities.

We support the clarification on eligibility for children 0-5 and expect this will lead to greater consistency statewide. These years are critical for young families to receive access to supports and service coordination, particularly for children with medical complexity, severe disability or challenging family circumstances. We also support the proposed new services and the consolidation of select existing services. The additional focus on planning for the future and transition supports reflects the evolving priorities of waiver participants as they age out of the children's waiver. Similarly, the additional focus on family and participant directed supports and a more robust infrastructure to actualize these services is encouraging. The addition of Remote Supports and Equipment reflects at least some of the challenges brought to light during the pandemic. We would like to see DHS, to the extent which CMS allows, reduce technology access disparities for families and participants unable to afford technology and broadband access for those living in rural areas without broadband access.

Given Wisconsin's county-based system for implementing the CLTS waiver, we strongly recommend DHS continue to invest in a robust infrastructure to assess and assure uniform, statewide access to CLTS services. This includes comparative county data collection, technical assistance, and training to address variability that results in disparities. Additionally, part of the intent of the waiver is to support families as well as the eligible child. It is important to continue quality improvement efforts that reinforce the focus on supporting families by assuring both the array of services and the process to develop and implement a service plan keeps family support in the forefront. The DHS has a critical role to reduce variability between counties and assure families have the information needed to participate in the process. Continued effort to provide training and technical assistance to counties remains important.

One of the stated goals for the waiver renewal is to make the program more accessible. Disparities in access to both the CLTS program and the full range of services remains concerning. There are several aspects we are concerned about:

1. In order to access the program families need to know it exists. Wisconsin has no defined pathway for families to find out about long-term supports nor how to begin the process to access services. Instead, families find out through chance encounters with other families, or providers who might have some information about supports and services. Many families report taking months to years before they hear about and are connected to the CLTS program. We recommend a focused, intentional, and continuous outreach campaign so that professionals, including primary care providers, serving families who have children with disabilities are well informed and know where to direct families they serve who might need additional supports and services. This campaign should include specific strategies to reach under-represented and under-served populations.
2. To access program supports and services, families need to know how to connect what they need to an available service. The supports and services coordinators are critical to helping families access the full array of services in the program. There exists a high degree of variability in the skills and knowledge of staff in this role. We believe that professional qualifications and a brief orientation to those serving in this role is not enough to assure families statewide have equal access to services. We recommend DHS take a stronger quality assurance role in assuring service coordinators have the skills and knowledge needed by communicating with counties their expectations for staff competencies and the provision of training, coaching or mentoring strategies to promote staff development.
3. Another critical role for service coordinators is to educate and help families access other programs for which they or their child are eligible. Like the previous statement, this aspect of service coordination varies greatly from family to family. Families struggle with obtaining Medicaid state plan services and many providers and families are unfamiliar with the EPSDT benefit. We believe clearer expectations and additional information about coordination with other services is needed to assure that families have equal access to Medicaid, other DHS, community, and school-based programs families may need. Supports and service coordination needs to go beyond sharing a phone number but rather include substantive navigation assistance. We recommend DHS develop resource materials and training for this purpose.
4. The array of CLTS benefits is well designed to meet the anticipated needs of families. Yet many families can not find providers for needed services. While the provider registration directory is designed to help families find a provider, it remains under populated, particularly by non-traditional providers who might be most appropriate to provide a service such as home modifications. We recommend a coordinated and focused effort with county waiver agencies to increase the number of providers available to families. Similarly, information should be developed and directed to families

to support them to find providers and help explain why they might become Medicaid certified.

5. As the new waiver service definitions are operationalized, we encourage DHS to continue to utilize family, provider and county partners to obtain feedback from stakeholders in order to maximize the usefulness and access to the new services.
6. To the extent CMS allows payment to families providing care to children under 18, we strongly support the continuation of this benefit after the public health emergency is lifted. Children who are not able to be vaccinated due to health concerns or are not eligible to be vaccinated remain at high risk. These children need a caregiver at home which means that families will continue to have to reduce work hours or are unable to work. Strategies to prevent financial hardship and crisis for these families need to be continued.

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