**This document and its content were shared by Long-Term Services & Supports (LTSS) Subcommittee member and FREED Center for Independent Living Executive Director Ana Acton during the 7/17/2020 LTSS Subcommittee meeting, which was convened to discuss the proposed Long-Term Care at Home (LTC@Home) Benefit.*

LTC@Home: Designing Systems Around the Person

- The LTSS Subcommittee believes that meaningful change can only be brought about by addressing the needs of the whole person. This means providing coordinated access not only to medical care and related therapies, but the critical home and community-based services that people need to live with dignity and independence.
- In this time of COVID, we feel that it is important to highlight three stories- of real people- who have been impacted by COVID and who have relied on HCBS to transition to the community or remain at home.
- Any meaningful system change cannot do away with the HCBS infrastructure, but must instead build upon and innovate it to meet our most urgent needs now.

These stories illustrate the following important principals:

1. *We cannot address this crisis with a medical model. We have to rely on strong foundation of HCBS, and especially housing*
2. *We must rely on providers who are experienced and knowledgeable of these services and supports and this population's needs.*
3. *Any benefit must rely on coordinated, integrated care with flexibility to design care plans that meet consumers' individuals needs*
4. *It will take time and resources to do it right*
5. *We cannot forget focusing on providing a high quality workforce, which means paying better wages.*
6. *How transition is being impacted by COVID*

SNF Transition Story #1: From SNF to Home for a Quality End of Life

During COVID, Sally went to a Skilled Nursing Facility (SNF) to recover from a stroke. She received rehab and then Hospice care. In the current environment there was no direct support of loved ones. The consumer was alone, without support for decisions about care and changes in treatment plans, without trusted eyes on quality of care. The joy and incentive that the world outside of medical care offers was missing. All information was loaded toward the medical model, tailored to insurance coverage, and the needs of an efficiently run SNF.

Her spouse was in a state of ‘not knowing’, waiting by a window to see if they would bring her. He could not support her decision process, was not informed of changes in treatment plan, did not interact with her day to day caregivers and had difficulty connecting with someone at the SNF for information.

The consumer became depressed, progress stalled. She was lonely and disconnected from her life.

There was no doubt this consumer knew she would not live to ‘recover’ from her stroke but it was clear she wanted to spend her remaining time in the home she loved, in the comfort of her life’s accumulations, surrounded by people she shared love with.

Along with home health and Hospice we were able to support this consumer’s safe transition home. We worked with the consumer, her husband and the facility to identify her needs and accessed existing funding and community services and supports including Assistive Technology (hospital bed, rolling shower chair, and Hoyer lift), home modifications, Department of Rehabilitation Transition grant provided funding for initial medical supplies, home set up items, a manual wheelchair and, most important, transitional in-home personal care support.

It took extensive service coordination pre and post transition including assessing needs; developing a person-centered plan, identifying community-based services and support options, and support navigation through the processes.

She was able to transition home and within a couple weeks, died in her home with appropriate care and support surrounded by those she loved and who loved her.

SNF Transition Story #2: At risk of Institutionalization

Laura has been a FREED consumer for several years. FREED had assisted this consumer through the CCT program to transition into the community from a skilled nursing facility several years ago and the consumer has been living independently since that time.

During the month of May, Laura's care provider support began to dwindle, leaving her with very minimal support for her personal care and activities of daily living. Laura contacted IHSS and they told her that because of COVID19 restrictions, they were not bringing on any new workers. Finally, in June, Laura's main support staff had to leave due to a family emergency. When that happened, the existing providers were unable to increase their hours of service and Laura went to the local hospital to ask for help. There was a systemic shortage of care providers available through the IHSS system and even through private pay. This was extremely distressing and traumatic for Laura.

Laura ended up back in a skilled nursing facility to get her personal care needs met. Laura was struggling with isolation due to COVID while in the community and found even more intense isolation while in the facility. There was a coordinated effort among various agencies to transition back to the community before she lost her housing. At the beginning of July, four care providers had been interviewed and hired, 2 through IHSS and 2 through FREED's personal attendant registry, by Laura and she was able to return to her life in the community.

SNF Transition Story #3 Long-Term SNF to Home

Ann has been in a skilled nursing facility (SNF) for several years. She has been ready to live independently for some time but has no relatives or friends who can help with this process. FREED has been assisting Ann in getting a Section 8 voucher, which she now has, and arranging to get a certified birth certificate for further documentation for the Regional Housing Authority. Due to COVID-19, she cannot leave the SNF without having to spend 14 days in quarantine upon her return. So Ann and the FREED

have been working to secure permission from the SNF for a mobile notary to come to the facility and notarize her application; Ann has set up an appointment with the notary. This process has slowed down her ability considerably to get her birth certificate application in the mail. Securing housing is also going to be adversely affected by COVID-19 due to the quarantine. FREED staff are developing a system so that available apartments can be viewed by a staff member or volunteer, pictures can be taken and sent to Ann, and then, if the landlord has not already accepted Section 8 in the past, working with that landlord to attempt to get their approval for the voucher. We are not sure how this will play out, but will continue to support Ann in her efforts to live independently.

Thank you for the opportunity to begin this discussion focused on what matters most to people, and not forgetting the role that critical HCBS play in meeting the populations' needs. We look forward to an engaged discussion – and now I will ask that my colleague, Catherine Blakemore, provide the LTSS subcommittee statement.