



**House Health and Human Services Committee
Wednesday, February 13, 2013
HCBS and KanCare Oversight**

Good afternoon Mr. Chairman and members of the Committee. My name is Tim Wood. I am the manager of the End the Wait Campaign. Thank you for the opportunity to submit written remarks regarding the Developmental Disabilities (DD) waiting List, as it relates to HB 2025.

The End the Wait Campaign is a statewide issue campaign working to educate the public and policymakers about why Kansas needs to take bold action in order to end the Developmental Disability (DD) Waiting List. The End the Wait Campaign is a collaborative project of the Disability Rights Center of Kansas (DRC) and numerous stakeholders, funded through a generous grant by the Kansas Council on Developmental Disabilities (KCDD). The ultimate goal of the End the Wait Campaign is to successfully eliminate the waiting list for the Developmental Disability (DD) Waiver.

The DD waiting list has reached a crisis level for Kansas families and the time is now for the Kansas Legislature to take bold and effective action by developing and moving forward with an effectively working plan to move individuals off of the DD waiting list at a reasonable pace and ensure that Kansans with DD obtain the high level and quality of services that is indicative of our history and experiences in Kansas. ***Now is the time for the Kansas Legislature to take a comprehensive look at the DD system and develop a long term plan that will eventually eliminate the waiting list.***

If HB 2025 is enacted, the HCBS and KanCare Oversight Committee may very well be the most appropriate committee to carry this task out, by first engaging in a comprehensive study of the DD system and then reporting back to the legislature with a recommendation on how to implement a long term effectively working plan to end the waiting list.

In December of 2010 the State of Kansas reported there were 4,573 Kansans on the DD Waiver waiting list, with an average waiting time of over 7 years. This figure represents both categories of the DD waiting list (Unserved and Underserved).

Today, we cannot know for certain exactly how many Kansans are waiting because KDADS no longer publishes a monthly DD summary report. I can, however, report to you that according to the last report published by SRS (May 3, 2012) there were **4,994 Kansans on the DD waiting list. We know of multiple families who have been waiting for over 8 years.**

635 SW Harrison, Suite 100
Topeka, KS 66603
www.endthewaitks.org

Funded through a generous grant of the Kansas Council on Developmental Disabilities

When the Centers for Medicare and Medicaid Services granted the State of Kansas approval of the KanCare section 1115 demonstration waiver, it did so under a set of “special terms and conditions” (STCs), which set forth a number of requirements and limitations that the State of Kansas is obligated to adhere to for the life of the demonstration.

One of these STCs (STC 46) can be found on page 31 of the 109 page document, which requires the state to “ earmark cost savings”. Below is the language of this specific STC:

46. Earmarked Cost Savings. The State Medicaid Agency will designate a portion of savings achieved through the implementation of the KanCare 1115 to increase the number of slots in the 1915(c) waivers to move individuals currently on the waiting list to HCBS, subject to state legislature appropriations. The state shall report to CMS on the progress of individuals receiving HCBS services in their annual report pursuant to STC 77. In this report the state must include: the total number of individuals on the waiting list; the number of people that have moved off the waiting list and the reason; the number of people that are new to the waiting list; and the number of people that are on the waiting list, but receiving community-based services through the managed care delivery system.

Given the projected savings of \$1 billion from KanCare over the next 5 years and the requirement for the State to earmark a portion of the savings to waiting list reductions and the potential to significantly reduce the waiting lists, **End the Wait and the families we represent believe that this required “earmarked cost savings” is one of the best opportunities for the Kansas Legislature to take bold action to eliminate the HCBS Waiver waiting lists. We recommend that the Kansas Legislature either: 1. Include in the budget bill a multi-year proviso that sets aside a sufficient percentage of the future KanCare costs savings to eliminate the DD Waiting List (as well as other HCBS Waiting Lists) over the next 5 years or 2. Amend HB 2025 to create an “Earmarked Cost Savings HCBS Slot Expansion Fund” to fund additional slots on HCBS Waivers with waiting lists as part of a long term effectively working plan that moves individuals off of the waiting lists at a reasonable pace.** Regardless of the approach the legislature takes to accomplish this task, there must be an effectively working plan developed that moves individuals off of waiting lists at a reasonable pace.

The “Earmarked Cost Savings” STC represents one way among others that the legislature could deploy to address the crisis situation that exists for Kansans with disabilities who are waiting up to and over (in some cases) 10 years for services through the DD Waiver. The task of addressing this issue is too large to put it off any longer.

Thank you Mr. Chair and members of the committee for allowing me to address the issue of waiting lists. Our agency stands ready and willing to assist you in any way we can to develop a plan to accomplish this task.