

Senate Public Health & Welfare Committee Informational Testimony Tuesday, March 12, 2013 SB 194

Good afternoon Madam Chairperson 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 appear before you today regarding SB 197.

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 End the Wait Campaign is concerned about SB 194. By and large, the current system of assessing people with DD is working. The assessment system is not the problem. The real problem within the DD system is the crisis that exists with the DD waiting list. There are currently over 5,000 Kansans waiting for DD Waiver services, and the system has been chronically under funder for decades. We would like to point out that this proposed legislation does nothing to address the needs of the system and the thousands of people it serves on a daily basis, nor would it do anything to save the state money. More importantly, Madam Chair and members of the committee, this legislation would not move one person off of the waiting list.

Kansans with Developmental Disabilities who go onto the DD waiting list end up waiting upwards of 8, 9 and even beyond 10 years before they are able to receive services. This issue is not going to solve itself; therefore the Kansas Legislature must act to address this crisis. Otherwise, we are leaving a huge burden on future generations. This is why we would recommend that this committee consider developing a long-term comprehensive plan to address the real issues within the DD system, which include a waiting list that has reached over 5,000 and capacity of the HCBS waiver to meet the needs of citizens of our state who have 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.

635 SW Harrison, Suite 100 Topeka, KS 66603 www.endthewaitks.org One of these STCs can be found on page 31 of the 109 page document (No. 46), which calls on the state to "earmark cost savings". Below is an excerpt 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, End the Wait and the families we represent believe that this required "earmarked cost savings fund" is the best opportunity for the Kansas Legislature to take bold action to eliminate the HCBS Waiver waiting lists. We recommend that the Kansas Legislature include in the budget bill a muti-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. This can be done with a multi-year proviso dedicating a sufficient percentage of future KanCare cost savings to create an "Earmarked Cost Savings HCBS Slot Expansion Fund," with the sole purpose being to increase the number of slots on the HCBS Waivers in order to eliminate Waiting Lists over the next 5 years. This would carry out this requirement of the STC with the federal government, and allow the Legislature to establish a policy to expand slots and eliminate the waiting lists over the next 5 years with the future cost savings of KanCare. Then from that special fund, the Legislature would appropriate dollars to increase slots on the different Waivers with Waiting Lists, including the DD Waiver.

End the Wait proposes that this Committee leave the DD Reform act unchained (as it is not the problem creating the Waiting List) and instead pass an amendment to dedicate future KanCare savings toward HCBS Services and Waiting Lists, including the 5,000 (and growing) DD Waiting Lists.

Thank you, Madam Chairperson and members of the committee. Our agency stands ready and willing to assist you in any way we can to develop a plan to accomplish this goal.