



**House Children & Families Committee
Tuesday, January 18, 2011
HCBS DD Waiver Waiting List Data**

Good morning Chairman Kiegerl and Members of the Committee, my name is Tim Wood. I am the Campaign Manager for the End the Wait Campaign. Thank you for allowing me to appear before you today.

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 end all Waiting Lists for the Developmental Disability (DD) Waiver.

There are currently 3413 adults and children on the DD Waiting List.

What we define as the DD Waiting List really consists of two separate lists. The first list – called the “Unserved” Waiting List – is where an initial request for services has been made, but the person is not receiving any services. This “Unserved” Waiting List has an average wait time of 31 months for adults and 29 months for children. The second waiting list – called the “Underserved” Waiting List – consists of those who have cleared the first waiting list, start receiving *some* of their services only to find that they are put on a *second* waiting list for the rest of the services they need. The services are not “extra” or luxury-type services. These are services that according to their individualized assessment and plans of care are absolutely necessary, however, they are forced to wait on an “Underserved” Wait List anyway. This second “Underserved” Waiting List has an average wait time of 32 months for adults. It is important to note that because children in need of services have largely been limited by the State to receive only Supportive Home Care – the state does not provide

an effective or accurate estimate for children with DD on the Underserved Waiting List. The data I have for you today is for all persons who have a service request date of December 1, 2010 or earlier.

Unservd Waiting List Statewide Numbers – The most current numbers show that there are 1440 children and 960 adults on the Unservd Waiting List (total of 2400). These are Kansans who receive no DD Waiver services.

- ***It's important to note that according to the latest SRS data, the person who is next in line on the "Unservd" list to receive services has been waiting since May 1, 2006 (55 months).*** Let me let that sink in for a moment. That means that the "lucky" person at the front to the Unservd Waiting List line has been forced to wait without any DD Waiver services for over 4.5 years!

Underserved Waiting List Statewide Numbers – According to SRS, the number on the Underserved Waiting List is 1013 adults. As previously mentioned, because of the way SRS tracks the data we cannot provide an accurate estimate for children with DD on the Underserved Waiting List.

- To put into perspective how utterly cruel this second Underserved Waiting List is, let's take the example above of the person at the front of the Unservd Waiting List who has been waiting without services for over 4.5 years. Let's say that person clears the waiting list today. They think to themselves "great, now I can get the services I have been waiting nearly 5 years for." Not so fast. Their individualized plan of care may say that they need both day and residential services. When the magic date happens and they clear the Unservd Waiting List, they may be offered only day services and they are then put on a second Underserved Waiting List for residential services. So, they still have nowhere to live. They will then wait on this Underserved Wait List on average for an additional 32 months! This is on top of the over 55 months they waited on the Unservd Wait List. All total, this "lucky" person with profound Developmental and Intellectual disabilities who is at the front of the line will have been waiting for over 7.5 years just to receive the services they need to accommodate their disabilities.

In the chart below I have provided for each of you the number of individuals on the Waiting List specific to your home counties. If you would like to see statewide data (by county) please refer to the attachment provided in your packet:

Number of Kansans on the DD Waiting Lists In Your Home Counties

Member	Co.	Adult Unserved	Children Unserved	Adults Underserved	Children Underserved	Total
Rep. Kiegerl	JO	125	248	274	0	647
Rep. Wolf	BT	10	10	14	0	34
Rep. Gatewood	SN	59	105	64	0	228
Rep. Brunk	SG	219	300	153	0	672
Rep. Gregory	DG	35	64	63	0	162
	FR	15	9	12	0	36
Rep. McCray-Miller	SG	219	300	153	0	672
Rep. Meigs	JO	125	248	274	0	647
Rep. Roth	SA	18	46	33	0	97
Rep. Rubin	JO	125	248	274	0	647
Statewide	AL L	960	1440	1013	0	3413

The final chart I want to explain is attached to my testimony – titled “HCBS DD Waiting list (Unserved & Underserved).” This chart tracks the DD Waiting List over the past 16 years. As you can see, the last time the waiting list was virtually eliminated was right after the closure of Winfield State Hospital. That’s because all of the dollars from the savings of the closure of Winfield stayed in the DD system in the form of new dollars to the HCBS DD Waiver. As you can see, the waiting list was 800 in FY 95 and it plummeted to around 50 in both FY 97 and FY 98. The savings stayed in the DD Waiver, and the waiting list was next to nothing. A waiting list of 50 means that you are waiting a few weeks or a couple of months for services, which is reasonable and manageable for Kansas families. The current reality is neither reasonable nor manageable. Today a person can be waiting for 5 years to clear the Unserved list and maybe an additional 3 years to clear the Underserved list. Today the Waiting List has ballooned to 3413. We must work in a concerted effort to reverse this trend and eliminate the DD waiting list.

Naturally, you may be wondering how an individual comes off of the Waiting List. There are two primary ways in which an individual can access services through the HCBS DD Waiver: either through the appropriation of additional funding or due to a crisis situation. Since FY 2006 (which are the only numbers available according to SRS) there have been 1348 people who have moved off the Waiting List because funds became available (either through appropriations or because someone else transitioned off the Waiver) and 1895 who moved off because they were determined to have been in crisis.

Number of Kansans with a DD who have moved off the Waiting List

FY	# of Unserved Accepting Waiting List Funds	# Underserved Accepting Waiting List Funds	Total Persons Accepting Waiting List Funds	# of Unserved Determined in Crisis	# of Underserved Determined in Crisis	Total Persons Determined in Crisis
FY06	*	*	262	**	**	295
FY07	288	107	395	**	**	256
FY08	315	120	435	140	148	288
FY09***	0	0	0**	197	225	422
FY10***	0	0	0**	187	253	440
FY11****	196	60	256	80	114	194

** According to SRS the Unserved and Underserved numbers for the waiting list funds were not tracked*

*** According to SRS the Unserved and Underserved numbers for crisis were not tracked in FY 06 and FY 07*

**** Waiting list funds were not appropriated in FY 09 & FY 10*

***** As of December 1, 2010*

In his Inaugural Speech, Governor Brownback spoke of the core virtues Kansans hold most dear. The Governor said that Hope, Freedom, and Opportunity are central to the Kansas experience and that as Freedom expands so does Opportunity. Kansans with Intellectual or Developmental Disabilities and their families share those values. Freedom to make important choices about their own lives. Freedom to be included in every segment of society that anyone without a disability would be able to participate in. Opportunity to do things that they or their families may have

never thought possible. Hope to live in their own apartment or to hold a job. They want to have friends, socialize freely, and pursue their own dreams. The DD Waiver gives them the Freedom and Opportunity to live their lives with Hope, dignity and respect.

Mr. Chairman and Members of the Committee, in the same spirit of Hope, Freedom, and Opportunity Governor Brownback expressed in his Inaugural Speech, I respectfully ask that that you seriously examine ways the Legislature could significantly and aggressively address the needs of this population. Doing this will give some of our most deserving citizens the same Hope, Freedom, and Opportunity we all seek for ourselves, our families, and our friends.

I thank you for this opportunity and I look forward to working with each of you to find real common sense solutions to End the Wait in Kansas.