



**House Committee on Aging and Long-Term Care
Tuesday, February 22, 2011**

Good morning Chairman Bethell and Members of the Committee, my name is Tim Wood. I am the Campaign Manager for the End the Wait Campaign. 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. Thank you for allowing me to appear before you today in support of HB 2296.

The End the wait Campaign is not here to speak about the closure of KNI. We are here to educate Members on the significant need for funding for the DD Waiver. HB 2296 is consistent with the recommendations of the Kansas Facilities Closure and Realignment Commission by ensuring that every dollar saved in closure will stay in and be tracked within the DD Waiver budget. With the proposed amendment, which we support as well, it would also capture proceeds from the sale of real estate, surplus property and all other savings and require that those proceeds be place into the KNI community conservation conversion fund.

To help illustrate this great need I would like to share a few of the personal stories that were shared with us when Kansans signed up to join our campaign to End the wait.

Nancy Zimbeck of Olathe, KS writes: My son was diagnosed at age 3 with autism. We frantically sought help from the start.....we were told about the HCBS waiver grant and had to wait until he was age 5 to be considered and receive services. Although there were only 2 "slots" open for children the year he turned 5, we did receive a slot. The services that we have received over the years have literally been a life changer for my

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autistic son. While doctors told us he may never speak again, say "I love you" or have any sort of life, with the services we were able to obtain (EARLY INTERVENTION IS THE KEY) our son now leads a full life. He speaks, reads and writes, holds a small part time job, participates in special olympics and obtained his EAGLE SCOUT in boy scouts.....NONE OF THIS WOULD HAVE EVER BEEN POSSIBLE without our funding. We continue to set more goals for our son in order that he may achieve his highest potential. We could not even fathom where he would be at this point had we not had early intervention and continued support through our hcbs funding. Waiting for these children is not acceptable and in the long run not cost effective for our state!

Kim Ferguson of Pittsburg, KS writes: I am a single mom of two boys with Down Syndrome. Cory was on the waiting list for a long time, then started receiving Family Subsidy. He had that for a little bit, then KS stopped all support. Andrew has been on the waiting list for 3 years and who knows when he will receive any support. My boys love school (Kindergarten and 1st grade), but I know we would benefit as a family if the support would start up again. Being a single mom for two kids with disabilities is a struggle at times and the support would help me, as well as my boys.

Vicki Dieterman of Olathe, KS writes: Hi, my name is Vicki and I have 3 nearly grown children. My 2 girls, one who is 17 and about to go off to college, and the other, 21, and about to graduate from college and begin her new life as a teacher.

And then there's my 20 year old son, Sam, in the middle. Sam has autism, and over the years, doctors have also talked about OCD and ADHD issues as well.

Sam is what I call high functioning, but high maintenance. He is verbal, but sometimes difficult to understand by those who are familiar with him. He is also somewhat predictable, until you try to rely on that predictability. Then he will change his routine, if he thinks he can get one over on you. He's very smart. He's somewhat independent within our household, but I monitor him periodically all day long, as he can easily become over stimulated when left to his own devices for too long.

I would never leave him at home alone-he's too impulsive. He could (and has, recently) opened the door to anyone, stranger or not, and invited them in. We have awakened in the past, early in the morning, to find the front door wide open and wondered if Sam had actually been out, or just looked out. He may wander away - he did this once when he was 2 and I was alone with him and his baby sister, getting ready to pick up the oldest from preschool. I was terrified for the next 20 minutes that it took me to find him. He was around the corner, approaching a neighbors' dog. Mind you, I'd left him in the house while I was buckling his sister into her car seat, and he slipped past me in the garage! In the past he's attempted to cook something in the microwave unassisted, to awaken the rest of the household to the smoke alarm. For quite awhile after this incident, I began unplugging the microwave before going to bed. As a result of these incidents when he was young, plus the fact that I tend to be a bit of a control freak, I was always very gun-shy of trying to teach him to be too independent.

We have spent years working with school personnel, trying to teach Sam things that he needs to learn to be a little bit more social and independent, to be able to maybe be employed at a sheltered workshop, or participate in a day program, even go into a residential program eventually and make a few friends with some peers. And he's made great strides, huge progress.

Now, as he approaches his 21st birthday, I am in the position of having to try to find a specialized "sitter " for my son for a couple days per week and try to keep my foot in the door as a sub in my current part-time job with the school district.

(And, please note that I've always only been able to work part-time in order to be home when Sam was not in school.) Otherwise, I will have to quit my job altogether, not something I really want to do in the current economy, to stay at home with Sam, my beautiful young man with the social and emotional development of an 8 years old. This is all due to the dreaded, ever growing, "waiting list".

And what of all of that hard work that we did home and in school to get him ready for the next step in his life, only to be put on hold indefinitely? I have to say, it is so frustrating. It seems like such a waste, all of those years of IEPs and community outings and parent-teacher conferences and speech/language therapy, and then, suddenly, nothing. Sit at home with your mom and let your brain rot away.

I will do my very best to try to help Sam to maintain what he's learned, and, hopefully, maybe even continue to grow, but I am one person, and I am not a professional. I am his mother, and I have limited resources.

Hopefully, when the inevitable budget cuts are made, they won't keep picking on the folks, like my son, and those even worse off that he is, those who can't defend themselves. And, hopefully, Sam's name will come up on the 'magic list' before he regresses too far to reach.

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.

Chairman Bethell 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 you support HB 2296. 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.

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

Member	Co.	Adult Unserve d	Children Unserv ed	Adults Unders erved	Children Unders erved	Total
Rep. Bethell	RC	3	0	1	0	4
	BT	10	10	14	0	34
	RN	31	21	19	0	71
		44	31	34	0	109
Rep. Worley	JO	125	248	274	0	647
Rep. Flaharty	SG	219	300	153	0	672
Rep. Henderson	WY	51	47	54	0	152
Rep. Hill	LY	19	23	16	0	58
Rep. Kelly	EK	1	1	0	0	2
	CQ	0	2	1	0	3
	MG	19	20	11	0	50
		20	23	12	0	55
Rep. Otto	AL	8	8	4	0	20
	AN	3	3	1	0	7
	CF	1	5	3	0	9
	FR	15	9	12	0	36
	WO	0	2	4	0	6
	27	27	24	0	78	
Rep. Schwab	JO	125	248	274	0	647
Rep. Vickery	MI	7	20	6	0	33
Rep. Weber	FO	19	17	12	0	48
Rep. Wolf	JO	125	248	274	0	647
Rep. Wolf Moore	WY	51	47	54	0	152
Committee Total	18	531	736	585	0	1852
Statewide	ALL	960	1440	1013	0	3413