Approved: January 25, 2011
Date

MINUTES OF THE HOUSE CHILDREN AND FAMILIES COMMITTEE

JANUARY 18, 2011

The meeting was called to order by Chairman Kiegerl at 9 a.m. on January 18, 2011, in Room 142S of the Capitol.

All members were present except: Representative Roth (excused).

Committee staff present:

Martha Dorsey, Kansas Legislative Research Department
Renae Jefferies, Office of the Revisor of Statutes
June Christensen, Committee Assistant

Others attending: See attached list.

Conferees Appearing before the Committee:

Lurena Mead, Johnson County Disability Services
Tim Wood, Manager, End the Wait Campaign
Rocky Nichols, Executive Director, Disability Rights Center of Kansas
Matt Fletcher, Interhab

Ms. Mead presented testimony (Attachment 1) regarding the number of Kansas individuals on the waiting list for services—3,391 per SRS data. Of those, 2383 are unserved while 1008 are underserved.

She stressed that attention to the increasing numbers of those who are waiting for services is needed and that the state portion of the annual cost of $40,000 is about 40 percent, or $16,000.

Mr. Wood presented testimony (Attachment 2) with similar numbers of those needing services and informed the committee that the average waiting time was 31 months for for adults and 29 months for children. Those included on the underserved list often have an additional wait time of approximately 32 months for adults. Children are not included in this list, as most receive supportive home care. A chart was included showing the numbers for each committee members' district.

Mr. Nichols presented testimony (Attachment 3) and reported that the proposed closures of Kansas Neurological Institute and the Parsons facility would create a method for increasing revenue into the DD waiver services if those funds were diverted to it.

He stressed that in-home care can be provided at a considerably lesser cost than those in institutions, and generally, the clients would get more individualized services.

Mr. Fletcher presented testimony and also stressed that the waiting list for all Kansans has increased from virtually nothing in 1996 to over 4500 as of January 7, 2011. He encouraged members to enact a multiyear plan to eliminate all waiting lists.

Chairperson Kiegerl thanked the conferees for their information. He announced that the Thursday, January 20, meeting will not be held because of the representatives' trip to

Leavenworth. The next meeting is scheduled for 9 a.m., Tuesday, January 25, 2011, in Room 142S.

The meeting was adjourned at 10:22 a.m.

CHILREN AND FAMILIES
COMMITTEE GUEST LIST

DATE: January 18, 2011

NAME	REPRESENTING
Tim Wood	END THE WAIT
Rocky Nichols	DRC Kansas
Steve Solomon	TFI Family Services
LURENA MEAD	JCDS
Ray Dalton	SRS
Gary Haulmark	SRS
MATT FLETCHER	INTERHAB
Katrina Abraham	intern for Kelly Meigs
GinaMeier-Hummel	KVC Health Systems
Heather Morgan	United Methodist Youthville
Dave Ranney	KHI
Mike Hutfles	Community Living Opportunities
maury L. Thompson	J.C.D.S.
Keith [illegible]	DD Council
April Holman	Kansas Action for Children.
Kari Presley	Kearney & Associates

Johnson County
Developmental Supports
Building Resources for People with Disabilities

January 18, 2011

To: Children and Families Committee

From: Maury L. Thompson, Executive Director
Johnson County Developmental Supports (JCDS)

RE: Community Developmental Disabilities (DD) Waiting List

Chairman Kiegerl and members of the Committee, I appreciate the opportunity to speak with you today, to provide information regarding the community DD waiting list. Before I begin to address the waiting list, I believe a primer of the community DD system may be helpful in establishing a context for a waiting list discussion.

JCDS is one of twenty-seven (27) designated Community Developmental Disabilities Organizations (CDDOs) in the State of Kansas. These organizations are dually designated by the Kansas Department of Social and Rehabilitation Services (SRS) and county commissioners. CDDOs contract with SRS to perform the duties of a CDDO which are delineated through the DD Reform Act. These duties are to:

- Serve as a single point of application,
- Determine eligibility for services,
- Provide either directly or by referral (subcontract), services to persons with a developmental disability, and
- Ensure the quality of services being provided.

Through this contractual relationship all federal and state funds for community-based DD services are to be allocated to and through the CDDO. By subcontract, CDDOs are to establish a network of Community Service Providers (CSPs). CDDOs are to oversee this network of providers and are responsible for managing the allocation of funds to this network of providers as specified through contract with SRS, although providers of Medicaid services directly bill the State for services provided. In Johnson County this network totals more than 350 providers of service.

CSPs provide some or all of the following three primary community-based services: Day and Employment services, Residential services, including services in the family home, and Case Management services. Case Management services are funded through the Medicaid State Plan. As such there is no wait for Case Management services in Kansas.

Unfortunately, the same cannot be said for Day and Employment and Residential services. These services are primarily funded through the Home and Community-Based Services/MRDD Medicaid waiver. These services are, as the name implies, paid for by Medicaid, a federal-state cost sharing

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program, approximately 40% state, 60% federal. With a waiver the federal government "waives" Medicaid requirements, permitting these funds to be used to purchase community-based services versus traditional, medically-based institutional care, at a much lower cost per person, and in the person's home community versus a state institution. And unlike Case Management services, under a HCBS waiver, the State can establish a waiting list for these much needed services and supports, which Kansas has done.

This waiting list has now grown to include more than 4,000 plus Kansans! To narrow this list a bit – if we look to only those who needed services by the end of last year – December 31, 2010, the number is reduced to 3,391.

Of these 3,391 individuals, 2,383 are unserved, while 1,008 are underserved.

We define these populations in this manner:

Unserved: receiving no waiver services

Underserved: receiving at least one service, but needing an additional service
(One example of being underserved is an adult attending a day employment program while continuing to live at home through adulthood, with parents who have now aged to the point where they can no longer physically care for him or her in the home, and desperately need assistance.)

These 3,391 can be further examined by age: 5-17: 1,413, 18-64: 1,965, 65+: 13

Many individuals on the waiting list have been waiting for service for more than five years.

The cost to remove an individual from the waiting list varies based upon the individual's needs. However, on average the cost per person is approximately $40,000 per year, of which the State would contribute 40%.

I can provide a more thorough analysis of the numbers of individuals waiting and the dollars needed to provide these critical services, and would be happy to do so. However there is one number I cannot provide.

The waiting list records the number of individuals with a disability waiting for services, but it does not, and most likely cannot, reflect the "hidden number". That is, every number on the waiting list represents an individual, who has a family, oftentimes in crisis, because our only response to their need has been to add their name to a list, and hope that someday we'll be able to meet their needs. There are truly thousands of Kansans impacted by our failure to provide essential services to those in need.

Many of you have heard directly from families impacted by "the wait". During the interim the Joint Committee on Children's Issues heard several heart-breaking stories of families struggling under the daily pressure to earn a living for their family, while figuring out how to care for a child with a disability. The Committee heard from some who had been successful – so far – and some who hadn't.

Families are eager to speak, to share their struggles, and ask for your help. I appear before you today as their representative, to ask for that help.

END
THE
WAIT

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

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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.

Unserved Waiting List Statewide Numbers – The most current numbers show that there are 1440 children and 960 adults on the Unserved 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 "Unserved" 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 Unserved 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 Unserved 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 Unserved 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 Unserved 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 FR	35 15	64 9	63 12	0 0	162 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	**ALL**	**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.

MR/DD HCBS Waiver Waiting List

	Persons on the Unserve		Persons on the Underserved Waiting List	
County	Adults	Children	Adults	Children
Allen	8	8	4	0
Anderson	3	3	1	0
Atchison	5	0	7	0
Barber	3	2	3	0
Barton	10	10	14	0
Bourbon	7	8	5	0
Brown	4	5	6	0
Butler	22	33	19	0
Chase	0	0	3	0
Chautaqua	0	2	1	0
Cherokee	7	10	10	0
Cheyenne	4	0	0	0
Clark	0	1	0	0
Clay	1	2	5	0
Cloud	10	10	1	0
Coffey	1	5	3	0
Comanche	0	0	0	0
Cowley	11	15	14	0
Crawford	9	19	14	0
Decatur	2	0	0	0
Dickinson	5	12	4	0
Doniphan	4	0	2	0
Douglas	35	64	63	0
Edwards	3	1	1	0
Elk	1	1	0	0
Ellis	1	2	2	0
Ellsworth	3	5	3	0
Finney	35	78	14	0
Ford	19	17	12	0
Franklin	15	9	12	0
Geary	1	9	3	0
Gove	0	0	0	0
Graham	1	0	0	0
Grant	0	6	4	0
Gray	0	2	2	0
Greeley	0	0	0	0
Greenwoo	1	1	1	0
Hamilton	1	2	0	0
Harper	2	6	3	0
Harvey	14	22	13	0
Haskell	1	2	0	0
Hodgeman	3	0	1	0

Jackson	3	5	2	0
Jefferson	2	7	10	0
Jewell	2	0	1	0
Johnson	125	248	274	0
Kearny	4	6	2	0
Kingman	4	6	1	0
Kiowa	5	1	0	0
Labette	14	11	3	0
Lane	2	4	0	0
Leavenwor	20	18	11	0
Lincoln	1	1	1	0
Linn	3	1	3	0
Logan	1	0	1	0
Lyon	19	23	16	0
Marion	3	12	6	0
Marshall	2	0	1	0
McPherson	3	20	23	0
Meade	0	1	0	0
Miami	7	20	6	0
Mitchell	1	3	1	0
Montgome	19	20	11	0
Morris	4	2	0	0
Morton	4	3	0	0
Nemaha	2	3	6	0
Neosho	3	10	4	0
Ness	2	3	0	0
Norton	0	1	0	0
Osage	0	6	12	0
Osborne	1	1	0	0
Ottawa	2	4	3	0
Pawnee	7	1	2	0
Phillips	0	1	0	0
Pottawato	6	6	5	0
Pratt	4	3	1	0
Rawlins	0	0	0	0
Reno	31	21	19	0
Republic	1	2	1	0
Rice	3	0	1	0
Riley	7	8	9	0
Rooks	1	1	2	0
Rush	2	0	0	0
Russell	3	1	0	0
Saline	18	46	33	0
Scott	1	12	0	0
Sedgwick	219	300	153	0
Seward	13	34	1	0
Shawnee	59	105	64	0

Sheridan	2	0	0	0
Sherman	2	0	1	0
Smith	1	1	0	0
Stafford	0	1	0	0
Stanton	1	2	0	0
Stevens	3	3	2	0
Sumner	12	11	8	0
Thomas	0	1	0	0
Trego	0	0	0	0
Wabaunse	2	10	1	0
Wallace	0	1	0	0
Washingto	0	0	0	0
Wichita	0	3	2	0
Wilson	1	5	2	0
Woodson	0	2	4	0
Wyandott	51	47	54	0
Totals	**960**	**1440**	**1013**	**0**

3413

Data is for all persons who have a request date of December 1, 2010 or earlier
Children are not on the underserved list.

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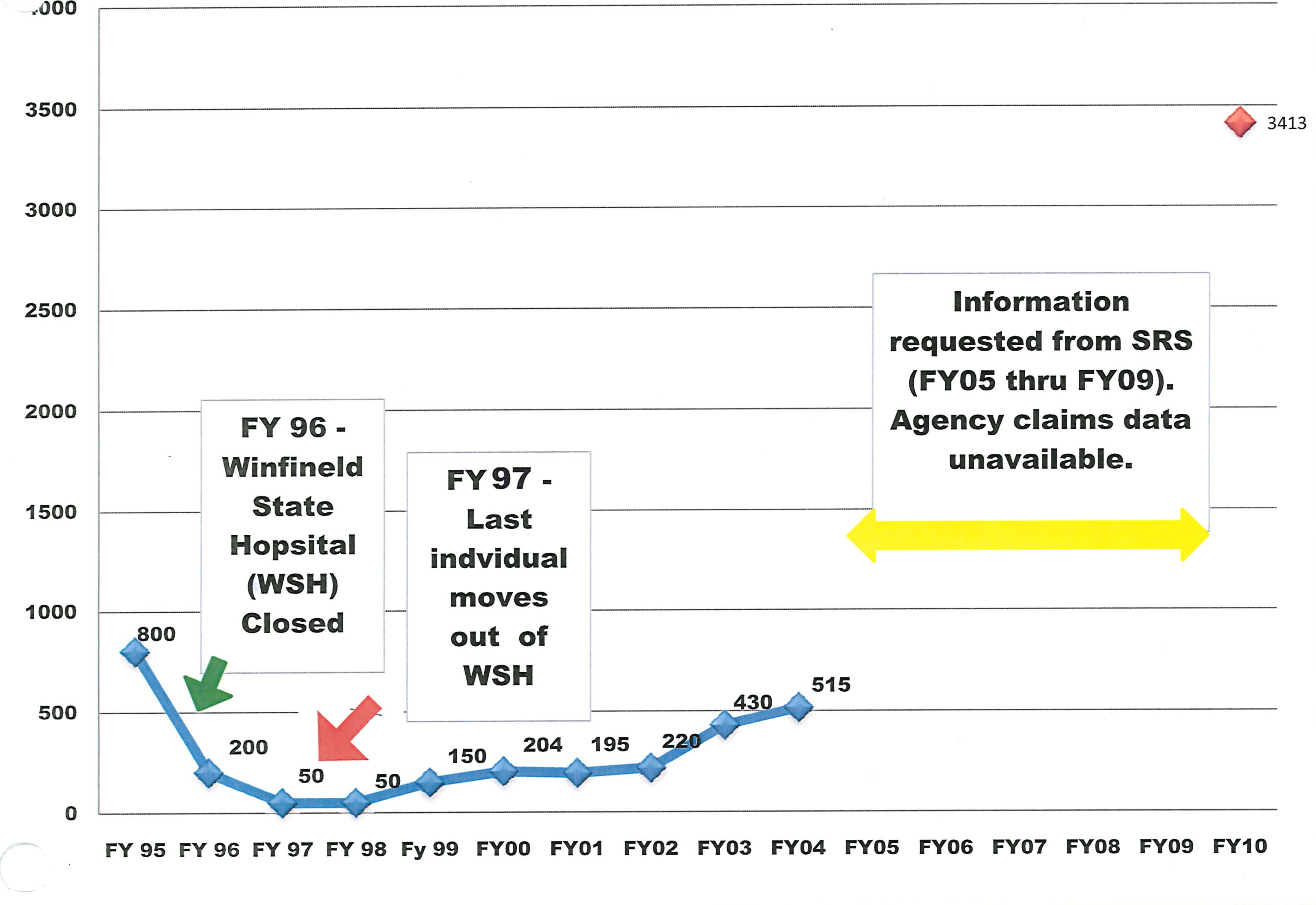
HCBS DD Waiting list (Unserved & Underserved)



FY 96 - Winfineld State Hopsital (WSH) Closed

FY 97 - Last indvidual moves out of WSH

Information requested from SRS (FY05 thru FY09). Agency claims data unavailable.

D DISABILITY
R RIGHTS
C CENTER of KANSAS
EQUALITY ♦ LAW ♦ JUSTICE

House Children & Families Committee – Revenue Neutral Ideas to Fund the HCBS DD Waiver Waiting Lists through DD Hospital Closure

Chairman Kiegerl and Members of the Committee, my name is Rocky Nichols. I am the Executive Director for the Disability Rights Center of Kansas (DRC). DRC is the federally mandated, officially designated protection and advocacy organization for Kansans with disabilities. DRC is a 501(c)(3) nonprofit. We are not a provider of any of the HCBS DD Waiver services. We stand to gain nothing from the closure of DD institutions.

As you examine the HCBS DD Waiver Waiting Lists, you will find that in order to reduce the waiting lists that you will have to find millions of new dollars. Hospital closure can help make that happen.

- **If Kansas were to close both KNI and Parsons it would create a revenue neutral way to pump millions of dollars into new HCBS DD Waiver services, and help dramatically reduce the DD Waiting Lists.** We do not take the idea of closing both large-bed DD Institutions lightly. To close both institutions is a major task. It should be done carefully, over a reasonable period of time, and every dollar previously spent in the institutions must flow to the DD Waiver. Over a dozen states have closed either all their public or private DD institutions.

Let's get Beyond the Myths about DD Hospital Closure … The Facts are Clear:

- ***Those with greatest disabilities are already in the Community on the DD Waiver***
    - ***For every 1 person at KNI with the greatest need, there are 30 with the same level of need in the community***
    - ***For every 1 person at Parsons with the greatest need, 45 are in the community***
- ***Closure of both KNI & Parsons would free up between $25 and $40 million to be transferred for new services on DD Waiver. You can greatly reduce the Waiting Lists with these new dollars from hospital closure.***
- ***People experience better measurable outcomes in the community vs. institutions.***
- ***This Legislature should follow the lead of the Facilities Realignment and Closure Commission's Report. That recommendation took ALL the savings from closing hospitals and transfers it to the community DD Waiver. Also, the Commission took extraordinary measures to ensure all the dollars go to the Waiver.***

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ATTACHMENT NO. 3-1

MYTH BUSTERS

MYTH – "KNI & Parsons have the hardest people to serve with DD. They can't possibly survive in the community. Kansans on the DD Waiver don't have the same severity of disability as those in the institutions."

FACT – For every 1 person at KNI with the greatest need (Tier 1), you will find nearly 30 people in the community with the same need (Tier 1).
For every 1 person at Parsons who is a Tier 1, you will find 45 in the community.

The severity of a Kansan's developmental disability is determined by a thorough and complex assessment that gives each person a "Tier score." The Tier levels of persons being served in large-bed DD institutions are strikingly similar to the Tier levels of those being served in the community. Key to keep in mind, the lower the Tier number the greater the severity of the disability and greater the need. The higher the Tier number, the lower the level of severity of the disability and the less assistance needed. Tier 1 are individuals with the greatest needs.

- **DD community services = 2,160 Tier 1 individuals**
- **KNI = 74 Tier 1 individuals**
- **Parsons = 47 Tier 1 individuals**

MYTH – "People with special DD needs do much better in an institution like KNI and Parsons. The DD Waiver doesn't obtain good outcomes for them. The institution is the best place for them."

FACT – People get far better outcomes after institutional closure. Winfield proves it.

- **Winfield Study = Better Outcomes After Leaving the Institution** – Research proves that the former Winfield residents obtained better outcomes and were far happier and healthier in the community.
    - "The Kansas experience of the closure of Winfield has been far more successful than this consulting team predicted," from the Winfield closure report, *"Are People Better Off?"*, 1998.
- The Winfield Report, funded jointly by the Legislative Coordinating Council and the KCDD, surveyed all Winfield residents before closure and 1 year after they were placed in the community. The results:
    - Individualized Plan services – 57% increase (up sharply from 5.2 to 8.2 services)
    - Family Contacts More than DOUBLE – Up from 7 to 18 contacts per year
    - Day Program Services QUADRUPLE – up from 4 to 18 hours per week
    - Integration – very significant (ten times) increase from 3 outings to 31 outings per month
    - Choicemaking scale – 50% increase (up from 27 to 40)
    - Days Sick, Dramatic Drop – Down from 3.2 days sick to only 0.8 (every 28 days)
    - Adaptive Behavior – "Significant gain" of 5%
    - Quality of Life Rating scale – 15% increase (from 68 to 78)
    - Staff Job Satisfaction scale – up 1.2 points (out of 10)
    - Need for Psychotropic Meds Plummet – Down from 18 people to 6

one year after

it works better even after 15 years

MYTH *– "If DD Hospitals are closed the money can't follow the person into the community. We learned that lesson when Topeka State Hospital was closed."*

FACT – Topeka State Hospital was not a DD Hospital. It had vastly different federal Medicaid rules that prevented dollars from going into the community. Federal law REQUIRES that money from DD Hospitals (like KNI & Parsons) must follow people into the community.

- KNI is not comparable to Topeka State (they are like apples and oranges). Topeka State was a psychiatric institution. Medicaid does not allow its dollars to fund psychiatric institutions (by law individual Medicaid money cannot follow a person leaving a psychiatric institution, because there is not Medicaid money in the institution). KNI & Parsons are DD institutions, where by law the Medicaid dollars MUST follow the person into the community onto the DD Waiver.

MYTH *– "The DD Hospitals will be closed to balance the budget on the backs of the residents."*

FACT – ??????????? Unfortunately, I can't bust this myth ... yet. This is still "To Be Determined."

- **It is unclear what Governor Brownback's recommendation would do with the savings from closure of KNI. It's unclear if all the savings would go to the DD Waiver.**
- **This Legislature should require (by law) that ALL savings from DD Hospital Closure are transferred to the DD Waiver.**
- **When Winfield was closed, all the savings transferred to the DD Waiver.**
- **The Facilities Realignment & Closure Commission recommended all the savings to go to the DD Waiver.**
- **Closure Creates Capacity (which we desperately need)** - When Winfield was closed all the savings went to new DD Waiver services. Before closure we served 5,500 people per year on the DD Waiver; now we serve 10,000. The infusion of the new dollars is needed to keep up with the capacity needs in the community.

Why should Kansas close both KNI & Parsons transfer the savings to the DD Waiv

We have three answers to that question:

1) **40 million new dollars**
2) **358** DD Parsons KNI
3) **3,400** Waiting List

<u>I will explain each answer below:</u>

Upwards of 40 million dollars = As I will show in this testimony, Kansas is spending 40 million <u>more</u> dollars on KNI and Parson on average than if the people there were served on the DD Waiver.

150,000 177 KNI 120 Parsons

358 = 358 Kansans are served in KNI & Parsons. The overwhelming research and real-life experience with Winfield Hospital closure clearly proves that the 358 people currently served at KNI and Parsons will receive better care and better outcomes if proper funding is provided in the community.

3,400 = Over 3,400 Kansans with developmental disabilities forced to wait for community services. If the extra 40 million was transferred to HCBS DD Waiver community services (along with the untold millions from the sale of the property, buildings, etc.), think of how many of the nearly 3,400 people waiting for services would get the life-saving, community based DD Waiver services that they need.

358 people (KNI/Parsons) = costs $40.4 million MORE than if in community

Place	Ave. # persons	Ave Cost per person	Total Cost
Total Average cost at KNI & Parsons	*358*	*$148,526 (ave of KNI & Parsons)*	*$53,172,308*
Total Average HCBS Costs for serving the 358 in the community	*358*	*$35,663 (ave cost to serve on DD HCBS Waiver)*	*$12,767,354*
Disparity & Higher Cost of Institution	**N/A**	**Institution is $115,626 MORE per person**	**$40,404,954 MORE is being spent in institutions**

Imagine if KNI and Parsons were both closed, just like Winfield was successfully closed well over 10 years ago. That's upwards of $40.4 million <u>more</u> that can go to the DD Waiver to reduce the Waiting Lists.

The final amount saved that can then be transferred to the DD Waiver depends on the total number of consumers who need so-called "super tier" rates (or extraordinary funding). When Winfield was closed, we believe the state was inefficient in setting up mini-institutions and funded too many consumers at super tier rates. Depending on the numbers that are granted a super tier rate, the final savings can still be somewhere in the $24 to $40 million range. That means that $25 to $40 million could be transferred to the DD Waiver to dramatically reduce the waiting list.

- As one example, let's look at KNI. Even if you assume "super tier" reimbursements for 75% of the former residents at KNI Institutions (which is the inflated percentage that received super tiers when Winfield was closed), SRS estimates that at least *__$14 million in savings__* would be transferred to the HCBS DD Waiver if you closed KNI.
- The $40.4 million in savings is based on the assumption that none of the former residents at KNI and Parsons are provided super tier rates, and that they are served for the average cost in the community.
- **The actual savings from closing both KNI and Parsons will likely be somewhere between $25 and $40 million.**

DD Hospital Closure should not be about saving money for the State General Fund:
__That is why any closure of DD hospitals must be contingent upon having ALL the money flow to the community.__

- **ALL the money means not just the programmatic money … it means the sale of any real estate, buildings or other surplus property from KNI and Parsons.**
- **All the money means all the money.**
- **We support the Facilities Realignment and Closure Commission recommendation which calls for ALL the savings (programmatic, sale of property, etc.) to go to the DD Waiver. This recommendation was made by a motion of Rep. Bob Bethell on the Closure Commission.**
- If you want to close institutions as a catalyst to improve community-based services for the 358 Kansans being served in DD institutions and the 4,000 forced on waiting lists by ensuring all the dollars flow into the community, then you will have DRC Kansas and many disability advocacy groups ready to help you. If, however, you want to close DD hospitals to save money and help the budget crunch, then we frankly don't want any part of that.

Thank you for the opportunity to provide information on this topic of revenue neutral ways to enhance HCBS DD Waiver services.

A ional Information and Background on this issue:

Community Capacity Must Expand in Kansas; Kansas has the Lowest DD Waiver Spending in our Region - Kansas is last in our surrounding five-state region in the average amount spent per person, per year on DD HCBS Waiver services:

- Oklahoma $47,700 per person, per year
- Nebraska $44,500 per person, per year
- Colorado $40,200 per person, per year
- Missouri $36,700 per person, per year
- *Kansas $32,500 per person, per year*

(source: 2008 State of the State in Developmental Disability Services – a 50 State Comparison; David Braddock, University of Colorado; using 2006 numbers, the latest year for comparative data)
[NOTE: This national report uses 2006 numbers and a uniform method by which to calculate the average to ensure that they can compare the states.]

Oklahoma spends nearly 50% MORE per person, per year on the DD Waiver than Kansas. Is it any wonder that we have a need to increase capacity at the community level in Kansas?

- The State of Kansas spends dramatically more per person on institutional services than community-based services, even when the level of support needed for the person is the same.
  - **Kansas spends $35,663 on average per year to serve a person with DD in the community on HCBS DD Waiver** (source: 2009 Gov. Budget Report, performance measures; comparison on costs & numbers served).
  - **Kansas spends on average nearly $150,000 to serve that SAME person with DD in state DD hospitals ($125,195 in Parsons State Hospital, $177,390 in KNI).** (sources: GBR, comparison on costs & numbers served).
  - **How does spending upwards of nearly FIVE TIMES the amount for Institutional Care vs. Community-Based Care deliver on the promise of the ADA? It does not.**

- Nearly 4,000 Kansans with Developmental Disabilities (DD) are waiting for some type of service while Kansas continues to overfund expensive DD institutions at KNI & Parsons.
  - HCBS DD Waiver Waiting List may grow to over 1,800 people without action by this Legislature, many of whom wait years for life saving services.
  - There are an additional upwards of 2,000 Kansans with DD on the "under"-served waiting lists, who though they may have cleared the initial waiting list, are provided *some* of the services they need, but put on a secondary waiting list for care that they absolutely need according to the results of states own assessment.

More Data on Tier Scoring:

- From 2004 SRS Study - Average Maladaptive Scores also show that people with severe disabilities are being successfully served in community-based HCBS services (Maladaptive score is a number from 0-200 – the higher the number, the greater the severity of disability). KNI = 40.8; Parsons = 71.16; Private large-bed ICF/MR = 74.79; Community Services = 66.44.
- From 2004- Average Adaptive Scores (0-500; higher the score, greater the severity of disability). KNI = 399.83; Parsons = 209.70; Private large-bed ICF/MR = 227.95; Community Services = 210.73
- From 2004 - Average Health Score (0-30; higher the score, greater the severity). KNI = 11.57; Parsons = 7.8; Private large-bed ICF/MR = 7.72; Community Services = 8.31

Subrankings of States in Four Key Outcomes And Data Elements

Allocating Resources to Those in the Community (Non-ICF-MR)

% of ID/DD Expenditures on non-ICF-MR		Rank
100%	Alaska	1
99%	Vermont	2
99%	New Hampshire	3
99%	Michigan	4
98%	Oregon	5
98%	Arizona	6
97%	Rhode Island	7
95%	Colorado	8
94%	Hawaii	9
94%	New Mexico	10
93%	Maryland	11
90%	Minnesota	12
90%	Montana	13
89%	Alabama	14
88%	California	15
87%	Kansas	16
86%	Nevada	17
86%	Wisconsin	18
86%	Wyoming	19
84%	Maine	20
84%	Georgia	21
84%	South Dakota	22
83%	West Virginia	23
82%	Missouri	24
82%	Connecticut	25
82%	Massachusetts	26
82%	Washington	27
82%	Delaware	28
80%	Florida	29
78%	Pennsylvania	30
78%	Idaho	31
75%	Ohio	32
75%	Nebraska	33
75%	Oklahoma	34
75%	Tennessee	35
74%	Dist. of Columbia	36
73%	Indiana	37
73%	South Carolina	38
72%	Utah	39
70%	Kentucky	40
70%	New York	41
70%	Virginia	42
70%	North Carolina	43
66%	North Dakota	44
66%	Arkansas	45
63%	Iowa	46
61%	Illinois	47
61%	New Jersey	48
59%	Texas	49
53%	Louisiana	50
30%	Mississippi	51
77%	US Average	

Supporting Individuals in the Community and Home-like Settings

% Living in Settings with 1-3 Residents		Rank
98%	Nevada	1
98%	Vermont	2
95%	Arizona	3
95%	New Hampshire	4
93%	Idaho	5
90%	California	6
90%	Kentucky	7
89%	Washington	8
89%	New Mexico	9
89%	Alaska	10
88%	Hawaii	11
87%	Georgia	12
85%	West Virginia	13
85%	Colorado	14
81%	Delaware	15
81%	New Jersey	16
81%	Florida	17
81%	Ohio	18
80%	South Carolina	19
80%	Maryland	20
80%	Tennessee	21
80%	Montana	22
79%	Alabama	23
79%	Oregon	24
79%	Virginia	25
78%	North Carolina	26
78%	Michigan	27
78%	Massachusetts	28
77%	Missouri	29
76%	Iowa	30
76%	Utah	31
74%	Connecticut	32
73%	Maine	33
73%	New York	34
72%	Kansas	35
71%	Louisiana	36
71%	Indiana	37
69%	Pennsylvania	38
68%	Oklahoma	39
67%	North Dakota	40
67%	Nebraska	41
66%	Wisconsin	42
66%	Dist. of Columbia	43
65%	South Dakota	44
65%	Minnesota	45
63%	Texas	46
62%	Rhode Island	47
59%	Wyoming	48
54%	Arkansas	49
50%	Illinois	50
44%	Mississippi	51
81%	US Average	

Keeping Families Together through Family Support

Families Supported with Family Support per 100k of Population		Rank
537	New Mexico	1
348	New Hampshire	2
309	Arizona	3
308	Montana	4
261	South Dakota	5
228	Alaska	6
228	New Jersey	6
227	Connecticut	8
224	California	9
216	Massachusetts	10
216	New York	10
214	Vermont	12
213	Hawaii	13
211	South Carolina	14
206	Delaware	15
199	Wisconsin	16
199	Wyoming	16
185	Pennsylvania	18
181	Louisiana	19
157	Minnesota	20
139	Maryland	21
139	Mississippi	21
131	Oklahoma	23
129	Kansas	24
129	Missouri	24
123	West Virginia	26
117	Washington	27
113	Florida	28
113	Michigan	28
105	Ohio	30
105	Tennessee	30
103	Nevada	32
100	Texas	33
95	North Dakota	34
87	Illinois	35
76	Georgia	36
74	Colorado	37
69	Rhode Island	38
67	Iowa	39
66	Indiana	40
62	Alabama	41
52	Utah	42
50	Idaho	43
49	North Carolina	44
42	Kentucky	45
41	Maine	46
38	Virginia	47
35	Oregon	48
32	Nebraska	49
28	Arkansas	50
0	Dist. of Columbia	51
144	US Average	

Supporting Meaningful Work

% in Supportive or Competitive Employment		Rank
77%	Oklahoma	1
61%	Washington	2
51%	Connecticut	3
48%	Vermont	4
45%	Louisiana	5
44%	Massachusetts	6
38%	Maryland	7
38%	Pennsylvania	7
35%	Alaska	9
35%	Colorado	9
34%	New Mexico	11
34%	Oregon	11
32%	Utah	13
30%	South Dakota	14
29%	Nebraska	15
29%	New Hampshire	15
28%	Iowa	17
26%	Delaware	18
26%	Georgia	18
24%	Michigan	20
23%	Virginia	21
22%	Florida	22
22%	Indiana	22
22%	Ohio	22
21%	Kentucky	25
21%	Maine	25
21%	Wyoming	25
20%	Rhode Island	28
20%	Tennessee	28
20%	Texas	28
19%	North Carolina	31
16%	Nevada	32
16%	Wisconsin	32
15%	Idaho	34
15%	Minnesota	34
15%	Mississippi	34
15%	North Dakota	34
14%	Arizona	38
14%	Montana	38
14%	New Jersey	38
13%	California	41
13%	Illinois	41
12%	New York	43
12%	South Carolina	43
11%	West Virginia	45
10%	Dist. of Columbia	46
10%	Kansas	46
9%	Missouri	48
8%	Hawaii	49
5%	Alabama	50
2%	Arkansas	51
21%	US Average	

INDEPENDENCE
INCLUSION
INNOVATION

INTERHAB

January 18th, 2011

TO: Mike Kiegerl, Chair, and
Members of the House Children and Families Committee

FR: Matt Fletcher, Associate Director, InterHab

RE: Waiting List Issues for Kansans with Developmental Disabilities

Thank you Representative Kiegerl, and members of the Committee, for the opportunity to speak with you today regarding the fifteen year legacy of waiting lists for Kansas children and adults with developmental disabilities. These waiting lists are the most visible symptom of the chronic underfunding that plagues the Kansas community developmental disability service system, and threatens the future viability of community-based supports for Kansans with developmental disabilities.

The last time the State of Kansas could boast it had no DD waiting lists was 1996. Since that time, the number of children and adults with developmental disabilities needing help has inched forward to a total of 4,576 today.

The State actually maintains two waiting lists. One for those who receive no services (the 'unserved' waiting list); and one for those who receive some basic level of service, but who have identified need for additional support (the 'underserved' waiting list). The numbers for each of those waiting lists? As of January 7, 2011 – 2,908 children and adults on the unserved waiting list, and 1,668 children and adults on the underserved waiting list. You might hear different numbers from others providing testimony today. The numbers above represent the widest portrait of those waiting for help; that is, all who have been identified as waiting for service.

Over the years, legislators and governors have made attempts to address these waiting lists. However, amounts appropriated have done little more than attempt to balance out the numbers of new individuals who every year are added to the list. In the last legislative session,$3.3 million SGF was added to the FY 2011 budget in order to remove an estimated 145 individuals from the DD waiting lists. However, in spite of these new dollars the waiting lists are larger than they were this time last year (4,249 individuals in January, 2010). Clearly the approach of the last two administrations has made it impossible for the legislature alone to remedy these unmet needs.

Legislators must begin work on a multi-year plan to **eliminate** the DD waiting lists.

HOUSE CHILDREN AND
FAMILIES
DATE: JANUARY 18, 2011
ATTACHMENT NO. 4-1

2006 Legislative Budget Committee Recommendations:

Your peers have already done the hard work and drawn up a blueprint for eliminating the DD waiting lists. In 2006, the Legislative Budget Committee recommended a three-year plan to both build the needed human service capacity and provide funding to eliminate the waiting lists. We encourage the Legislature to dust off that blueprint and re-commit itself to the recommendations of the report. While the budget numbers would need to be updated, and perhaps even the number of years outlined in the plan modified, the recommendations contained within the report are a solution for ensuring that the Kansas community-based system of supports remains viable for Kansans with developmental disabilities in the future.

Quality-Based Community Expansion:

The 2006 Legislative Budget Committee's recommendations were built upon the belief that DD service capacity must be increased in conjunction with efforts to eliminate the waiting lists. The philosophy that these two issues (service capacity and waiting lists) must be addressed in a unified manner that acknowledges the vital interconnectivity of the two was given the name "***Quality-Based Community Expansion***", or "***Q-Base***". The membership of InterHab was instrumental in the development of the philosophical framework of ***Q-Base***. I have attached a summary document to my testimony on ***Q-Base*** that explains the importance of building capacity while addressing the waiting lists.

The membership of InterHab believes in a simple but critical premise – that waiting lists and service capacity must be addressed in tandem if the State and its community partners are to be successful in ending waiting lists for Kansans with developmental disabilities.

Proposing new resources to fund the waiting lists without also providing funding to build up the human resource infrastructure required to serve those new individuals ignores the current reality of the community DD system. Consider the following indicators of a stressed community DD system:

- *In several areas of the State, providers are unable to hire staff to serve new consumers due to low starting wages.*

- *Other providers are without enough supervisory staff, due to turnover, to safely oversee an expansion of services required to address the numbers of individuals on the waiting lists.*

- *Requests that a provider serve a person with challenging behavioral issues may be turned down due to the relative inexperience of existing staff, or*

- *Other requests that a provider serve a person with challenging medical issues may be turned down due to a shortage of persons on staff with adequate training to safely provide the ancillary support tasks of tube feeding or tracheotomy-cleaning.*

To provide increasing amounts of services requires the State/community partnership to expand service capacity and enhance service quality in amounts commensurate with the needs of persons to be served, **ahead** of any increase of service delivery that would be required in ending the waiting lists.

To attempt to increase service delivery without this consideration invites further quality erosion and exacerbates safety risks to all consumers, not just consumers funded by new waiting list dollars.

Capacity Expansion:

Community service providers have few tools with which to develop the human resource capacity needed to serve significant new numbers of persons. These providers find themselves in a constant battle to overcome high turnover and staff shortages that arise as a direct result of low wages for the direct-care workers who are so vital to the community support of Kansans with developmental disabilities.

True capacity building can only result from significant upward adjustments in the HCBS DD Waiver reimbursement rate in order to provide a competitive wage that would reduce the stigmatization of vital direct-care jobs as low-wage, no-advancement jobs. Reducing such stigma removes the initial barrier faced by these providers in attracting staff, i.e. that persons entering the job market routinely do not apply for our jobs because they are known to be hard jobs with low pay.

The State must provide resources adequate to enable service providers to recruit, train, and retain high-quality direct-care staff. Current reimbursement rates are not adequate to make better wages and benefits possible.

We could get a jump start on initiating a new revised version of the Legislative Budget Committee's recommendations, with the Legislature's passage of provider assessment legislation this year. The legislation will enable the State to take advantage of expected changes at the federal level, which would allow additional federal dollars to be drawn down for the HCBS DD Waiver through a provider assessment mechanism. DD providers in Kansas are in favor of the proposal, which has been estimated to bring an additional $25 million into the DD waiver in its first year of implementation.

Any serious effort to eliminate the waiting lists must first ensure that adequate service capacity exists in the community.

Why begin the process of eliminating waiting lists this year?

I know that, given the current fiscal climate the state faces, legislators may ask "why now?" Compelling arguments can be made to make ending waiting lists a priority for this legislative session:

- ***Kansas taxpayers' investment in the Community Service Model has been allowed to erode*** – Anyone who has owned a home knows that you must continue to invest in the property if you want to ***protect*** the value of the property. Kansas taxpayers have invested millions of dollars in the belief that supporting a person with a developmental disability in the community is the most cost-effective choice. And it has been. However, the State has not implemented a systemic approach to ensure that the community DD system would receive incremental increases that reflected increased costs of doing business. In fact, in the last 15 years, increases in the HCBS DD Waiver's reimbursement rate to providers have not even kept pace with inflation.

- ***Institutional care costs more*** - If the community network is allowed to erode further, the only other option for persons with developmental disabilities will be institutional care – a model which will continue to be significantly more costly to Kansas taxpayers. FY 2011 annual cost of care at Parsons State Hospital: $135,415. FY 2011 annual cost of care at KNI: $169,725. Estimated average annual cost in the community: $35,663. Further, with Governor Brownback's indication of the intent to close KNI within 23 months, the capability of the institutional system to serve any increase in its population will be severely curtailed. Any attempts to increase that institutional service capacity in the future will require massive investments of State dollars.

- ***"Graduating to the living room" squanders tax dollars -*** Imagine paying for special education services for a child with a developmental disability through two decades of schooling, from pre-school to high school graduation. Now, imagine throwing much of that investment away because supports aren't available to that child once they graduate from school. This example is, in fact, repeated every day in Kansas. To find multiple examples, one can look to the State's DD waiting lists. The skill sets learned through years of special education can be quickly lost, if not reinforced once the child leaves the special education system. With no funding for these ever-growing waiting lists, more and more Kansas children "graduate to the living room" while they wait for services to become available. While they wait, the investment Kansas taxpayers have made in them erodes. It's a shameful thing to do to a human, and it's a shameful waste of Kansas tax dollars.

- ***Making a child or adult with a significant developmental disability wait for help is morally unjustifiable -*** We, as a State, must determine what the primary outcomes of our collective investment in government will be. I would argue that providing help to our most vulnerable citizens should be a primary focus of government.

Conclusion:

The members of InterHab stand ready to work with the Kansas Legislature, should it choose to prioritize the formation of a multi-year plan to address the capacity needs of the DD system and eliminate the State's waiting lists. We are excited and encouraged by these hearings, and hope they signal the beginning of a significant recommitment to ensuring the future viability of community-based supports for Kansans with developmental disabilities.

Thank you for the opportunity to speak with you today.

Legislative Budget Committee

PUBLIC DEVELOPMENTAL DISABILITIES SYSTEM

CONCLUSIONS AND RECOMMENDATIONS

The Legislative Budget Committee recommends that the Legislature establish a phased-in effort to accomplish the programmatically linked goals of community capacity expansion and the elimination of the waiting list for services from Home and Community Based Services waiver for persons with Developmental Disabilities (HCBS DD). This effort would consist of the following:

- Expand community capacity through rate adjustments to achieve rates which would more closely reflect a parity between community wages and state institutional wages by adding $15 million SGF in FY 2008 and $10 million SGF in FY 2009 and FY 2010; and
- Eliminate the waiting lists for developmental disability (DD) services by adding $10 million from the State General Fund in both FY 2008 and FY 2009, and $15 million in FY 2010.

Additionally, the Committee recommends that the Senate Ways and Means and House Appropriations Committees request information during the 2007 Legislative Session on items including but not limited to the following:

- To assure that all programs are designed to meet the intent of the DD Reform Act for greater emphasis on independence, inclusion, integration and productivity;
- To examine, and replicate if appropriate, models in other states which are better designed to assist families of dependent children, rather than relying solely on the current HCBS DD waiver;
- To establish minimum standards for all persons and entities who provide services to persons with DD;
- To assess current capacity planning at the Department of Social and Rehabilitation Services to upgrade the State's ability to provide monitoring and oversight for the expanded numbers of community service providers; and
- To propose ways by which to upgrade employment related services for persons with DD, including providing the Legislature with a fiscal estimate on unbundling supported employment services so as to allow providers of such services to build employment service capacity in the community, and therefore be able to reduce reliance on facility-based employment services.

Proposed Legislation: None.

4-4

BACKGROUND

The Legislative Coordinating Council directed the Legislative Budget Committee to study the state's system for serving individuals with developmental disabilities. Specifically, the Committee was directed to review the updated Department of Social and Rehabilitation Services' (SRS) strategic plan and quality assurance and enhancement activities. In addition, the Committee was to examine current and proposed models to meet the demand for community based services.

COMMITTEE ACTIVITIES

At the September meeting the Committee heard full-day testimony from nearly 20 conferees regarding the developmental disabilities system. Conferees included representatives of state agencies, consumer organizations, Community Developmental Disability Organizations (CDDOs), Community Service Providers (CSPs), provider associations, and other advocacy organizations.

Staff presented an overview of the developmental disabilities system to orient the Committee and lay the foundation for testimony. Following the staff presentation, SRS briefed the Committee on the number of persons served, or waiting for services, and the impact the additional funding approved by the 2006 Legislature is having on waiting lists. In addition, the agency presented information on the Developmental Disabilities (DD) Strategic Plan, quality assurance activities, targeted case management services, and the Federal Deficit Reduction Act.

Although, many comments and suggestions were made by conferees, testimony centered on the following primary themes:

- Closure of remaining state hospitals and private large bed facilities;
- Reduction of the waiting list for Medicaid Home and Community Based Services (HCBS) waiver services and expansion of community based services;
- Increased wages for direct care professionals;
- Improved quality assurance and monitoring;
- Focus on the vision set out in the Developmental Disabilities (DD) Reform Act; and
- Service requirements for individuals with severe, and sometimes violent, behaviors.

The expansion of community based services and the elimination of the waiting list for HCBS waiver services are underlying themes in nearly all of the testimony. However, cautions were expressed regarding the need for capacity expansion, quality oversight, funding and other measures to ensure the expansion is successful. Conferees commented that a quality system of services requires both access for individuals needing services and service providers reimbursed at levels sufficient to recruit and retain employees with the right skills and abilities.

A number of conferees addressed issues with having adequate direct care professionals in the community. The most common comment was regarding the salary of direct care professionals, especially in relation to what staff at the state hospitals are paid. According to testimony, the current state-wide average wage for direct care staff in the community is $8.83 per hour while the beginning wage for a similar position at a state hospital is $11.81 per hour. According to testimony, the estimated cost to increase community based staff wages to $11.81 per hour is $35 million from the State General Fund. Several conferees commented on the amount of work required from direct care staff and the difficulty in hiring, training and retaining qualified staff to provide around-the-clock services.

The closure of the remaining two state hospitals and private facilities was discussed by two conferees representing advocacy organizations. According to conferees, institutional services are not the most economical way to serve persons with developmental disabilities. Additionally, federal pressure is building to re-balance funding in favor of community based services. Conferees recommended that all savings generated from closing institutions be directed into the community to fully fund services. The suggestion also was made to set a binding date for closure to facilitate the process. Finally, one conferee suggested the Committee review the report on the closure of Winfield State Hospital and Training Center which reported that individuals moved into the community had better outcomes than when they were in the hospital.

Improving the system for quality assurance and monitoring was cited as a principal of providing quality community services. Conferees indicated that the current system has not kept up with the expanding community system resulting in a concern about whether people are receiving the appropriate services and if state dollars are being spent effectively. Conferees cited the lack of new funding for quality monitoring, both at the state and local level, despite increases in the numbers of consumers, providers and service models. In addition, one conferee commented on the reduction in day-to-day contact that SRS staff have to monitor the provision of services due to staffing reductions and reorganization. Conferees asked for additional resources dedicated to the development of outcome measurements and the establishment of minimum standards for all providers.

A refocusing on the vision of the DD Reform Act, particularly with respect to adult independence, was a key in a number of presentations. Multiple conferees commented on the need for timely transition of services when youth graduate from high school and move into adult services. According to conferees, these services are critical to moving people into the community and out of the family home where their adult independence may be hampered by overly paternalistic families. Integral to this process and to the provision of better services during school age years, is better communication between SRS and the Department of Education about program requirements and service coordination. Another challenge to adult independence noted by conferees was payments made to families to provide care. According to the testimony, paying family members to provide service may provide a disincentive to those families to move the child out of the home for fear of losing a source of income. The result is a lack of independence for the now adult child to gain independence and integrate into the community.

Another piece of the adult independence theme was testimony about the importance of Supported Employment and Supported Living programs. Testimony was presented that stressed the importance of these two types of services to ensuring adults were integrated into the community. Conferees requested additional support for these programs.

Challenges with dealing with developmentally disabled persons who have severe behavioral issues in the community were addressed by two service providers. According to the testimony, service providers have very little ability to reject clients whose behaviors pose dangers to staff or exceed the providers ability to serve the individual. The providers commented that, particularly in light of the relatively low wages, direct care staff were being put in harms way without sufficient recourse. It was suggested that the state needed to look at alternatives to deal with persons who exhibit criminal, predatory, violent or other aggressive behaviors.

Other topics presented to the Committee included the value of consumer self-advocacy; gaps in services for children; and the need for Ombudsman services. With regard to consumer self-advocacy, the following three steps were given to ensure consumer rights: consumer participation in quality assurance; increased opportunities for choice and control of services; and increased education and awareness of service delivery options. In addition, more financial support for statewide self-advocacy training was requested. Gaps in services for young children were identified that results from a system designed to serve adults. These gaps include: the lack of HCBS waiver services for persons under age five; in-home supports not designed to meet families' needs; lack of billing system for mental health services; inflexible systems that do not support community collaboration and limited discretionary funds. Finally, one conferee noted the need for Ombudsman services to support and educate persons with developmental disabilities.

CONCLUSIONS AND RECOMMENDATIONS

The Legislative Budget Committee recommends that the Legislature establish a phased-in effort to accomplish the programmatically linked goals of community capacity expansion and the elimination of the waiting list for services from Home and Community Based Services waiver for persons with Developmental Disabilities (HCBS DD). This effort would consist of the following:

- Expand community capacity through rate adjustments to achieve rates which would more closely reflect a parity between community wages and state institutional wages by adding $15 million SGF in FY 2008 and $10 million SGF in FY 2009 and FY 2010; and
- Eliminate the waiting lists for developmental disability (DD) services by adding $10 million from the State General Fund in both FY 2008 and FY 2009, and $15 million in FY 2010.

Additionally, the Committee recommends that the Senate Ways and Means and House Appropriations Committees request information during the 2007 Legislative Session on items including but not limited to the following:

- To assure that all programs are designed to meet the intent of the DD Reform Act for greater emphasis on independence, inclusion, integration and productivity;
- To examine, and replicate if appropriate, models in other states which are better designed to assist families of dependent children, rather than relying solely on the current HCBS DD waiver;
- To establish minimum standards for all persons and entities who provide services to persons with DD;
- To assess current capacity planning at the Department of Social and Rehabilitation Services to upgrade the State's ability to provide monitoring and oversight for the expanded numbers of community service providers; and
- To propose ways by which to upgrade employment related services for persons with DD, including providing the Legislature with a fiscal estimate on unbundling supported employment services so as to allow providers of such services to build employment service capacity in the community, and therefore be able to reduce reliance on facility-based employment services.

4-8

INTERHAB

Quality-Based Community Expansion - "Q-Base"

The Kansas Developmental Disabilities (DD) Reform Act (KSA 39-1806), passed in 1995, mandates development of a community network of supports that foster independence, inclusion, integration and productivity for Kansans with developmental disabilities. Significant and sustained efforts must be undertaken by the State of Kansas, in partnership with community providers, in order to build the infrastructure required to carry out this commission.

While small increases in needed resources have been championed by the legislature in recent years, no organized effort has been initiated by policy makers to either address the glaring needs of the community DD system or meet the mandates of the KS DD Reform Act. Strong leadership is now needed to steer the State into a new era of sustained investment in a community-based system of supports for Kansans with developmental disabilities that will finally answer the call of the KS DD Reform Act.

The beginning steps of such a sustained effort must include the elimination of the State's waiting lists for DD services, which now number more than 4,000 children and adults with developmental disabilities.

However, policy makers must understand that in order to end the State's waiting lists, community service capacity must be dramatically enhanced - both programmatically and in terms of human resources infrastructure.

The following is a broad proposal that we believe must be embraced if we are to meet the mandates of the DD Reform Act. This proposal is based on a simple but critical premise, i.e. waiting lists and rate increases must be addressed in combination if the State and its Community partners are to significantly expand community services for persons with developmental disabilities.

Proposing new resources to fund "stand alone items" ignores the reality that waiting list funding alone will not enable community service providers (CSP) to meet the needs of persons on the waiting list, e.g.:

- In several areas of the State CSPs are unable to hire staff to serve new consumers due to low starting wages.
- Other CSPs are without enough supervisory staff, due to turnover, to safely oversee a business expansion.

- Requests that a CSP serve a person with challenging behavioral issues may be turned down due to the relative inexperience of existing staff, or

- Other requests that a CSP serve a person with challenging medical issues may be turned down due to a shortage of persons on staff with adequate training to safely provide the ancillary support tasks of tube feeding or tracheotomy-cleaning.

To provide increasing amounts of services requires the State/Community partnership to expand service capacity and enhance service quality in amounts commensurate with the needs of persons to be served, ahead of the curve of service expansion.

To increase service without this consideration invites quality erosion and exacerbates safety risks to all consumers, not just the consumers funded by new waiting list dollars.

Only with sufficient rate increases, in combination with creative and flexible program management, can the State/Community partnership insure a quality-based approach to community service expansion.

InterHab proposes that any new system dollars – for waiting list reduction and rate increases – be creatively utilized to address four program components:

- Stewardship
- Quality enhancement
- Capacity expansion
- Waiting lists

Community Stewardship:

Community leadership have long been tasked with combining state/federal resources with local resources to make community DD programs work to the maximum attainment of the statutory and regulatory expectations of the participating funding authorities. To that extent, the following are the stewardship activities that we believe are vital to assure the long term financial sustainability for the coming years:

- State and community efforts must be increased to assure an expanded effort in the community to promote employment and employment related training for persons with developmental disabilities.

- Programs such as 'tiny-k' infant and toddler services which perform vital early intervention for children with disabilities and their families must be enhanced, thereby ensuring a better quality of life for thousands of Kansas children who could be diverted from further need of State-funded assistance.

- State and community efforts must collaboratively develop new family service models that satisfy basic family needs, in order that families are not diverted into the most available funding stream (the current HCBS DD Waiver) but are assisted by options (including the Family Subsidy model, a new Family Services waiver, or other models).

- State and community efforts must be redoubled to increase the maximization of freedom and control that someone can bring to their life.

- State oversight must position its structure, within the philosophical framework of the Developmental Disability Reform Act, to be supportive of community flexibility in adjusting programs, services and staffing to suit the wide spectrum of both proven current needs and possible future needs of populations served.

Quality Enhancement:

The State and community collaboration of the past, which ushered in a high degree of professionalism and expertise in all areas of the delivery of community services and supports, has taken a back seat to a struggle to maintain 21st century quality enhancement momentum with 20th century resources. This trend must be reversed.

Further, additional emphasis and resources must be brought to bear on the State's efforts to encourage self-advocacy among Kansans with Developmental Disabilities.

Finally, in order to fill a vital community education and oversight role, the State should pursue creation of a Kansas DD Ombudsman. This ombudsman would provide information to persons served and their families regarding community service and provider options, as well as collect needed data on community provider customer service, quality of service and service access issues.

A significant resource commitment must be made in the following areas of training:

- Training initiatives to assist in the delivery of high-quality services to the increasing numbers of persons with health, behavioral or age-related challenges,

- Training initiatives to upgrade the skill-set of every supervisor of community direct care staff, and

- A comprehensive review must be undertaken to assess the core quality related proficiencies of the current network of service providers.

The expansion of services, the expansion of non-licensed providers, and the lack of adherence to core standards among newly licensed providers – all of these factors give rise to a concern among community leadership that standards of service intended to safeguard the interests of consumers have been sacrificed due to resource shortages. Minimum standards must be established, and reimbursement rate structures must reflect a commitment to such standards.

In the era of increased self-sufficiency among persons receiving service, ensuring the adherence to statutory and departmental quality benchmarks such as the core components of the DDRA (integration, inclusion, independence and productivity) is vital. The State must undertake a development process to implement full oversight of these new service choices, in order to determine that established statutory and departmental outcomes are met.

The State's Waiting Lists:

State and community leaders must better assess and present the characteristics of persons' needs who are waiting for services. Merging the two lists into one list would acknowledge that individuals' needs cannot be arbitrarily prioritized by who is and who isn't currently receiving some services.

State and community leaders must also re-emphasize the generic community supports that do exist, and persons waiting for services, and their advocates, must be assisted in accessing such generic supports. Generic supports can, and often do, mitigate some of the negative effects of waiting for service, and sometimes can become a non-paid alternative to paid services.

Capacity Expansion:

Community service providers have few tools with which to develop the human resource capacity needed to serve significant new numbers of persons, given that the principal energy of human resource professionals in the system is spent in the constant battle to overcome high-turnover and staff shortages that arise as a direct result of low wages.

True capacity building can only result from significant upward adjustments in the wage base to reduce the stigmatization of such jobs as low-wage, no-advancement jobs. Reducing such stigma removes the initial barrier faced by HR staff, i.e. that persons entering the job market routinely do not apply for our jobs because they are known to be hard jobs with low pay.

Obviously, the foundation of HR capacity building is the foundation upon which the community service policies rise or fall. It is critical, but still woefully under-addressed, that the State must provide resources adequate to enable service providers to recruit, train, and retain high-quality direct care staff. Current reimbursement rates are neither adequate nor reasonable to make better wages and benefits possible.

HR capacity building is additionally needed to enable focusing in the following ways:

- To ensure that community developmental disability service providers are reimbursed at a rate which allows them to offer wages and benefits commensurate with attracting and retaining quality direct support staff.

- To utilize higher qualified and/or more experienced staff for the increasing numbers of consumers served whose diagnostic characteristics include (a) significant health needs, (b) increases of the early onset of age-related illness, principally Alzheimer's and other forms of dementia, (c) behavioral challenges of such significance that the failure to provide adequate staff to serve such persons could easily constitute risks to the consumers or the community at large;

- To increase the development of community generic support to help meet individual needs with non-paid services; and,

- To better educate community employers to see workers with DD as a resource to be utilized, and to provide the informal short term assistance to make that happen, as well as the intermittent long-term follow up to assure the viability of those employment experiences.

- To fully-fund supported employment services for persons with developmental disabilities in order to assist them in becoming independent, contributing members of their communities.

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Graduating to waiting

Juliet Banks is pictured here with her son, Brandon.

Students with disabilities age out of public schools and land on a waiting list

BY BARBARA HOLLINGSWORTH

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Juliet Banks wants the same things most mothers want for their children.

She wants to see her son reach his potential and achieve at least some of his dreams, including working and moving away from home. But 21-year-old Brandon is somewhere in a 4,000-person deep line waiting for services offered to people with developmental disabilities.

Banks, who attended his final days at Highland Park High School last month, is among a growing number of Kansans who at 21 have aged out of the public school system to find nothing waiting on the other end. It is a difficult reality for those with disabilities who can find themselves going from the classroom to the couch, and it is a logistical challenge for families that must make difficult decisions about how to care for children that can't be left home alone. They are decisions that can lead some families to leave jobs, sending them into a financial tailspin.

ut there," said Rocky Nichols, executive director of
se families who have fought so hard to get special
dren and fought so hard with Medicaid to get the
re under 21 now get sucker-punched and not only
rick wall, bounce off of it and then find themselves
4,000 deep."

disabled children navigate the system. In those
, years in advance, she put her son's name down,
ed 18. But when funding didn't keep up with
as 21 — the age at which students with special
iting.

"My husband and I will probably have to cut back on work during the day," Juliet Banks said.

Services vary depending on the need of the recipient. They could include around-the-clock care, assistance to live independently with roommates or support for working in a job. Some families are able to pick up the tab for the care — at least for a short time, said Ramona Macek, community developmental disabilities organization director at TARC. Some families face crisis, particularly one-income, single-parent homes. When they are available and able, grandparents can be invaluable, she said.

The Banks are among the families that can count themselves lucky to have two wage earners.

"There are families that have it a lot worse than I do," Juliet Banks said.

Some help is coming, but advocates say it won't be enough. The Legislature restored a 10 percent cut in Medicaid funding that affected both the pay for workers in the field and the quantity of services provided. Lawmakers also added $6.9 million that will be shared to address the waiting list for the physically and developmentally disabled. Tom Laing, executive director of InterHab called the new money a "drop in the bucket" that might take 150 names off the waiting list.

Lawmakers, Laing said, have years of underfunding to address. Although he said it feels like lawmakers turned a corner this year toward addressing funding, "a hell of a lot of people were ignored."

"It's terribly shortsighted," he said. "The responsibility has been passed on from legislative session to legislative session until the current Legislature was faced with a multiyear challenge. It will take us three or four years at a minimum to whittle down the waiting list until it's manageable again."

In the meantime, many of those children will stay in school longer. Anecdotally, school districts like Shawnee Heights Unified School District 450 say they are seeing greater numbers of children with developmental disabilities stick around until age 21 rather than leave at 18 because they are on the waiting list.

Of Shawnee County residents waiting for services, 81 are between the ages of 18 and 21, Macek said. Some, she said, have waited five years for services.

It is a waste, Laing said, to invest in intensive education services while children make their way through public schools and then leave them with nothing on the other end to help them maximize their abilities.

"When you deny them the one path that exists for them to do that you've not only stolen from their lives but you've thrown your money into the fire, so to speak," he said.

The options are limited. Tonia Martin's oldest son Justin White recently finished up at Washburn Rural High School. While Justin is 21, Tonia Martin can't leave him unsupervised. Cooking would be dangerous. He likely wouldn't make a good choice if a stranger came to the door. As is, Justin receives 15 hours of support services during which he works one day and volunteers another.

Martin believes her son is near the top of the waiting list but is planning to spend time at home with Justin in coming months. A recent graduate in social work from Washburn University, she is going to take some time off before returning to school to work on her master's degree. Until he finds his way off the waiting list, she worries he will lose out on the future he had envisioned, including living away from home.

"Everything we planned for and hoped for, now that his time has come, we're uncertain of what is going to happen," she said. "It's not fair to them. They deserve the same opportunities that we have."

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