Approved: March 15, 2011
Date

MINUTES OF THE HOUSE AGING & LONG-TERM CARE COMMITTEE

The meeting was called to order by Chairman Bob Bethell at 9:01 am. on February 22, 2011, in Room 144-S of the Capitol.

All members were present except:
Representative Scott Schwab – absent
Representative Kay Wolf – excused

Committee staff present:
Katherine McBride, Office of Revisor of Statutes
Iraida Orr, Kansas Legislative Research Department
Craig Callahan, Kansas Legislative Research Department
Estelle Montgomery, Fiscal Analyst, KLRD
Evelyn Walters, Committee Assistant

Conferees appearing before the Committee:

Rocky Nichols, Executive Director, Disability Rights Center of KS
Tom Laing, Executive Director, Interhab, Inc.
Jane Rhys, Executive Director, Council on Developmental Disabilities
Tim Wood , Campaign Manager, End the Wait

Others attending:
See attached list.

Representative Hill moved to reconsider HB 2147, seconded by Representative Gonzales. Representative Moore made comments. **Motion carries.**
Representative Vickrey moved to pass out favorably HB 2147, seconded by Representative Worley. Comments were made by Representative Hill, Representative Weber, and Representative Kelly. Further information was provided by staff. **Motion carries.**

Chairman Bethell opened the Hearing on:

HB 2296 – Establishing the joint committee on oversight of the closure of the Kansas neurological institute.

Chairman Bethell made comments regarding purpose of this bill and the need to stay on task with the purpose of this bill.
Katherine McBride, Office of the Revisor of Statutes, reviewed the bill contents and the two balloon amendments. (Attachment 1) Chairman Bethell mentioned fiscal note attached to the bill.
Proponents:
Rocky Nichols, Executive Director, Disability Rights Center of KS provided testimony. (Attachment 2). Questions were asked by Representative Kelly and Representative Worley.
Tom Laing, Interhab, Inc. provided testimony. (Attachment 3).
Jane Rhys, Executive Director, Council on Developmental Disabilities provided testimony. (Attachment 4). A question was asked by Representative Kelly. Comment by Chairman Bethell.
Tim Wood , Campaign Manager, End the Wait testified. (Attachment 5).

No other conferees on **HB 2296.**

Chairman Bethell closed the hearing on **HB 2296** at 9:50 am.

Chairman Bethell asked for discussion on this bill and how the committee desired to proceed. **Representative Hill moved to pass out favorably HB 2296, seconded by Representative Moore.** Discussion and questions were presented by Representative Gonzales and Representative Kelly. **Representative Weber moved a substitute motion to include the balloon amendments, seconded by Representative Vickrey.** Further discussion and questions by Representative Flaharty, Representative Otto, Representative Kelly, Representative Worley and Representative Hill. Chairman Bethell asked Mr.

Ray Dalton, Deputy Secretary of Disability Determination Services of the Department of Social Rehabilitation Services to clarify how the savings estimates were derived.

Representative Hill restated his move to pass out favorably HB 2296 as amended, seconded by Representative Weber. Motion carries.

The next meeting is scheduled for March 3, 2011.

The meeting was adjourned at 10:04 am.

HOUSE AGING AND LONG TERM CARE COMMITTEE

DATE: 2/22/11

NAME	REPRESENTING
Sara Arif	KDOA
Tim Wood	EndtheWait
Crystal Lu	
Heather DeBusk	
Christina Ray	
Tom Laing	InterHab
Colin Curtis	Sandstone Group
	KCDD
	KCDD
Gary Haulmark	SRS
Rocky Nichols	DRC Kansas
Ray Dalton	SRS

PLEASE USE BLACK INK

transfer certified by the secretary of social and rehabilitation services and the current balance in the Kansas neurological institute community conversion conservation fund of the department of social and rehabilitation services.

(f) Members of the committee shall be paid compensation, travel expenses and subsistence expenses or allowance as provided in K.S.A. 75-3212, and amendments thereto, for attendance at any meeting of the joint committee or any subcommittee meeting authorized by the committee.

Sec. 2. (a) (1) There is hereby established the Kansas neurological institute community conversion conservation fund in the state treasury which shall be administered by the secretary of social and rehabilitation services. All savings resulting from transferring individuals from the Kansas neurological institute to home and community based services shall be ~~deposited in this~~ fund. All expenditures from the Kansas neurological institute community conversion conservation fund shall be in accordance with the provisions of appropriation acts upon vouchers approved by the secretary of social and rehabilitation services or the secretary's designee.

(2) Whenever an individual who is residing in the Kansas neurological institute transfers to home and community based services, the secretary of social and rehabilitation services shall determine the savings attributable to such transfer and shall certify the amount or amounts of such savings to the director of accounts and reports. Upon receipt of each such certification, the director of accounts and reports shall transfer the amount or amounts specified in such certification from the funds and accounts specified to the Kansas neurological institute community conversion conservation fund of the department of social and rehabilitation services in accordance with such certification. The secretary of social and rehabilitation services shall transmit a copy of each such certification to the director of the budget and to the director of legislative research.

(b) The secretary shall certify to the joint committee on oversight of the closure of the Kansas neurological institute at the beginning of each calendar quarter the amount of savings resulting from the transfer of individuals from the Kansas neurological institute to home and community based services that have been transferred during the preceding calendar quarter to the Kansas neurological institute community conversion conservation fund during the preceding quarter.

(c) If any provision of this section is repealed or becomes null and void and has no further force and effect, all moneys in the Kansas neurological institute community conversion conservation fund which were paid under the provisions of this section shall be returned to the

All proceeds resulting from a sale, lease, mortgage or any other transaction of Kansas neurological institute real or personal property shall be deposited in the state treasury in accordance with the provisions of K.S.A. 75-4215, and amendments thereto, and shall be credited to the Kansas neurological institute community conversion conservation fund.

credited to the Kansas neurological institute community conversion conservation

Proposed Amendments for HB 2296
BALLOON #1
For Committee on Aging and Long-Term Care
Prepared By: Katherine McBride
Office of Revisor of Statutes

HOUSE AGING & LTC
DATE: 2/22/11
ATTACHMENT # 1

1-8

(b) The joint committee shall consist of ~~nine~~ members as follows:

eleven

(1) One member of the house of representatives appointed by the speaker of the house of representatives;

(2) one member of the house of representatives appointed by the minority leader of the house of representatives;

(3) one member of the senate appointed by the president of the senate;

(4) one member of the senate appointed by the minority leader of the senate;

(5) one member of the house of representatives appointed by the chairperson of the house committee on appropriations;

(6) one member of the senate appointed by the chairperson of the senate committee on ways and means;

(7) one member of the house of representatives appointed by the ranking minority member of the house committee on appropriations;

(8) one member of the senate appointed by the ranking minority member of the senate committee on ways and means; ~~and~~

(9) one member of the house of representatives appointed by the majority leader of the house of representatives~~.~~

; and

(10) two members appointed by the governor, one of which shall be a former employee of the Kansas neurological institute and the other of which is a parent of a current resident of the Kansas neurological institute.

(c) Members shall be appointed for terms coinciding with the legislative terms for which such members are elected or appointed. All members appointed to fill vacancies in the membership of the joint committee and all members appointed to succeed members appointed to membership on the joint committee shall be appointed in the manner provided for the original appointment of the member succeeded. The first meeting of the joint committee shall be held before August 1, 2011.

(d) The members originally appointed as members of the joint committee shall meet upon the call of the member appointed by the speaker of the house of representatives, who shall be the first chairperson, within 30 days of the effective date of this act. The vice-chairperson of the joint committee shall be appointed by the president of the senate. Chairperson and vice-chairperson shall alternate annually between the members appointed by the speaker of the house of representatives and the president of the senate. The ranking minority member shall be from the same chamber as the chairperson. The joint committee shall meet at least four times each year at the call of the chairperson of the joint committee. Five members of the joint committee shall constitute a quorum.

(e) At the beginning of each regular session of the legislature, the committee shall submit to the president of the senate and the speaker of the house of representatives a written report on numbers of individuals transferred from the Kansas neurological institute to the home and community based services including the average daily census in the state

Proposed Amendments for HB 2296
BALLOON #2
For Committee on Aging and Long-Term Care
Prepared By: Katherine McBride
Office of Revisor of Statutes

DRC DISABILITY RIGHTS CENTER of KANSAS
EQUALITY ♦ LAW ♦ JUSTICE

House Committee on Aging and Long-Term Care
Testimony in Support of HB 2296

Good Morning Chairman Bethell 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 Home and Community Based Services (HCBS) Developmental Disability (DD) Waiver services. DRC stands to gain nothing from transferring any savings from closure to the HCBS DD Waiver.

I appear before you today in support of HB 2296. This bill is not about KNI hospital closure. This bill takes no position on KNI closure. This bill is about what happens *if* KNI closes. HB 2296 would effectively ensure that if KNI does close that all the savings resulting from closure would be tracked in a separate fund and would establish the precedent to ensure that those savings were dedicated toward the HCBS DD Waiver. Whether KNI closes is wrapped up in the Governor's Budget Recommendation. The budget is never final until the last Omnibus Appropriations bill is passed, which is typically one of the last bills to be dealt with. You can't afford to wait until the decision on whether KNI is closed is made in the budget. If you do, the gavel will be in the process of swinging down to adjourn the Legislature Sine Die. What you do with the savings from closure of KNI is an important public policy matter, and preferably, should be set in state law and discussed separate from the budget.

Regardless of your views on KNI hospital closure, we hope that we can all agree that if KNI is closed, then all the savings from the closure must go to the HCBS DD Waiver to reduce the waiting list. If not, then there will be a net decrease in funding for the DD Waiver. KNI either will or won't close. This bill does not take a stand on that issue. If KNI is not closed, then this bill is effectively moot. However, you shouldn't wait until the waning moments of the Legislature to deal with this important policy issue of how the savings from KNI closure should be dedicated.

HB 2296 sets up the mechanism to try to follow the precedent set when Winfield State Hospital was closed in the mid-1990's. When Winfield was closed, all the savings from closure were tracked and went to the DD Waiver. This infusion of new dollars for the DD Waiting list created additional capacity in the community. This was the last time the DD Waiting Lists were for all intents and purposes eliminated. I have included a chart titled HCBS DD Waiting List

HOUSE AGING & LTC
DATE: 2/22/11
ATTACHMENT #2

(Unserved & Underserved) with my testimony that tracks the DD Waiting List over the past 10 years.

DD Hospital closure should not be about saving State General Fund (SGF) dollars. If a DD hospital is closed, we believe the savings needs to go to the HCBS DD Waiver to reduce the waiting list. You have a lot of people who have waited a long time for DD Waiver services. Passing HB 2296 can give you the tools to begin the process of fixing this injustice.

To understand how important this bill is you have to understand the extent of the HCBS Waiting List problem in Kansas.

3413 adults and children are on the on the HCBS Developmental Disabilities Waiting Lists (as of Dec. 1, 2010).

- ***If KNI is closed, SRS estimates it will save at least $15 million dollars of programmatic savings per year, which could be transferred to this fund and help dramatically reduce the waiting list. In addition, the facility is worth an untold amount of dollars. We support the balloon amendment which would clarify that both the programmatic savings and the savings from the sale of real estate and personal property at KNI should go to this fund.***

When we talk about the "DD Waiting List," we are talking about two different lists: 1) the "Unserved" Waiting List, where a service request has been made, but the person is forced to wait without receiving any services, and 2) the "Underserved" Waiting List, which is made up of people who have cleared the first "unserved" waiting list, start receiving *some* of the services they need, only to find out the cruel joke of the DD Waiting List Game ... which is that they are then put on a *second* waiting list for the rest of the services they need.

Average Wait Times for Waiting Lists (as of December 1, 2010)
"Unserved" Waiting List = Average wait time 31 months for adults and 29 months for children. "Underserved" Waiting List = 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 accurate estimate for children with DD on the Underserved Waiting List (as their service options are limited).

Unserved Waiting List Statewide Numbers = 2,400 Kansans (1440 children and 960 adults) are on the Unserved Waiting List. They receive no DD Waiver services.

- ***It's important to note that according to the Dec. 2010 SRS data, the person at the front of the line for the "Unserved" list 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!

U...served Waiting List Statewide Numbers = 1,013 adults. 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 "lucky" 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 <u>waiting for over 7.5 years</u> just to receive the services they need to accommodate their disabilities.**

Community Capacity Must Expand in Kansas; Kansas has the Lowest DD Waiver Spending in our Region - Kansas is <u>last</u> 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)
[NOTE: This is the latest national report that uses a uniform method by which to calculate the average to ensure that they can compare the states. The numbers from the Braddock report are slightly different from the numbers SRS will give you because of this uniform method to ensure comparability between the states.]

<u>Oklahoma spends nearly 50% MORE per person, per year on the DD Waiver than Kansas</u>.

<u>The savings must move to the community and the DD Waiting List in order to help Kansas reach goals of ending the waiting list and improving community capacity -</u>

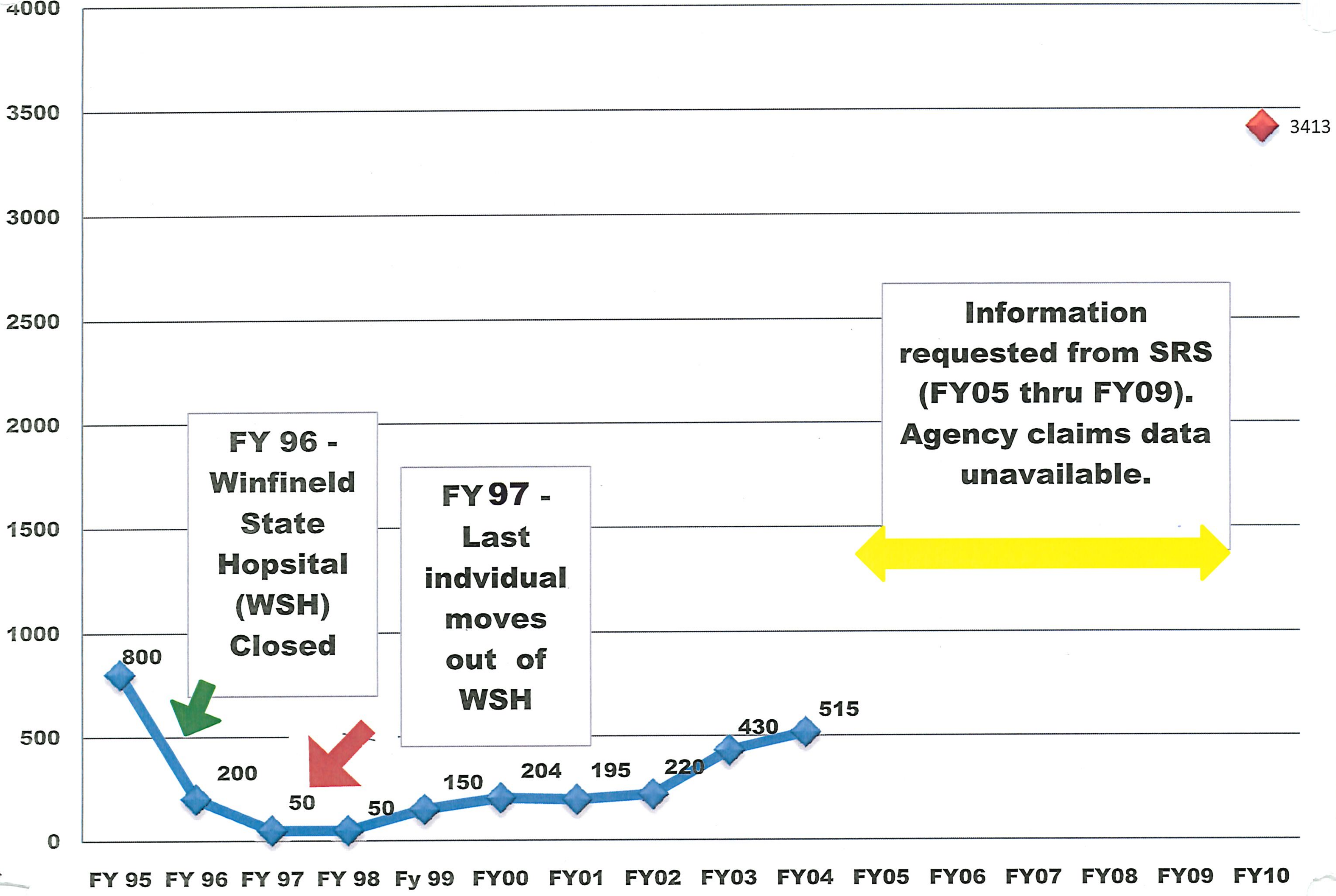
- **When Winfield was closed, all the savings transferred to the DD Waiver.**
- **The Facilities Realignment & Closure Commission recommended <u>all</u> the savings from KNI closure to go to the DD Waiver.**
- **Closure Creates Capacity (which we desperately need)**

- **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. 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.**
- **If, however, you want to close DD hospitals to save SGF dollars and help the budget crunch, then we frankly don't want any part of that.**

HCBS DD Waiver waiting Lists by Committee Member Counties

Member	Co.	Adult Unserved	Children Unserved	Adults Underserved	Children Underserved	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**

HCBS DD Waiting list (Unserved & Underserved)



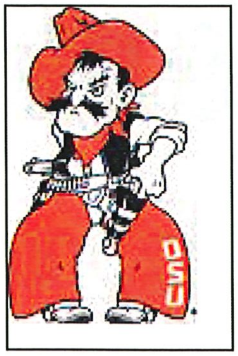
FY 96 - Winfineld State Hopsital (WSH) Closed

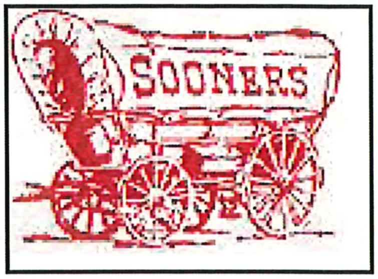
FY 97 - Last indvidual moves out of WSH

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

2-5

1. Oklahoma





2. Nebraska

3. Colorado

4. Missouri

5. Kansas

HCBS DD Waiver

1. Oklahoma $47,700 per person per year

2. Nebraska $44,500 per person per year

3. Colorado $40,200 per person per year

4. Missouri $36,700 per person per year

5. Kansas $32,500 per person per year

INDEPENDENCE
INCLUSION
INNOVATION

INTERHAB

February 22, 2011

TO: House Committee on Aging and Long Term Care

FR: Tom Laing, Executive Director, InterHab

RE: House Bill 2296: Regarding the establishment of a joint legislative committee for oversight of the closure of the Kansas Neurological Institute.

Thank you, Representative Bethell and members of the committee. We appreciate the introduction of House Bill 2296, and this hearing today. We appear in support of HB 2296 because we believe an organized legislative effort to oversee the reallocation of institutional resources is important. Additionally, this bill creates a statutory direction to the administration to assure that dollars saved from closure, if closure occurs, will be directed back into the DD system, to help provide needed financing for community services.

The long term interests of all persons with disabilities and all community service networks are better addressed when both the executive and legislative branches engage in intentional oversight. The bill proposes a means by which to do this, by addressing and materially evaluating the potential benefits that have been prospectively identified to be derived from institutional downsizing.

It is proper that the committee does not cross unnecessarily into regulatory and programmatic issues, the responsibility for which clearly rests with the administration and the community leadership. Nevertheless, we would urge the committee to consider adding a requirement in the bill that State and Community leadership make regular reports to the committee regarding the programmatic aspects of services for persons moving from institutional settings into the community.

In addition we have the following comments:

HOUSE AGING & LTC

DATE: 2/22/11

ATTACHMENT #3

1. Regarding the calculation of savings: (page one, lines 21-26)

We believe it is a more defensible measure of savings, if the comparison by which such savings are calculated is the comparison between the average daily institutional costs and the actual costs of each person who is served, or by the averages of all relocated persons by funding tier into which their disability profile places them. Furthermore, we would urge that the committee ask for a report which evaluates over time the changing nature, if any, of each such person's tier placement.

2. Regarding the reporting on the relocation of persons for services: (page two, lines 27-32)

The committee may wish to clarify the language as follows:

" .. and whether adequate progress is being made to transfer individuals from the Kansas Neurological Institute *into a different service setting, and whether adequate progress is being made to move persons* from the waiting list to receive home and community based services.

The clarifying language is to clarify as noted:

(a) there is no requirement that persons relocating from KNI in the event of its closure will enter into an HCBS program, and;

(b) the current language in the bill leaves open the impression that a person leaving KNI may go onto a waiting list, which will not occur.

3. Regarding the composition of the committee: Page 2, re composition

We would recommend the committee consider creating this oversight body with a similar philosophy as recent statutorily-created panels such as the 2010 Commission, in which a blend of legislators and non-legislators with specific expertise comprise the membership.

We support House Bill 2296, we encourage your thoughtful consideration of the changes proposed, and we thank you for your time and interest in the lives of persons with developmental disabilities.

Kansas Council on Developmental Disabilities

SAM BROWNBACK, Governor
KRISTIN FAIRBANK, Chairperson
JANE RHYS, Ph. D., Executive Director
jrhys@kcdd.org

Docking State Off. Bldg., Rm 141,
915 SW Harrison Topeka, KS 66612
785/296-2608, FAX 785/296-2861
htpp://kcdd.org

"To ensure the opportunity to make choices regarding participation in society and quality of life for individuals with developmental disabilities"

House Committee on Aging and Long Term Care Regarding H.B. 2296

February 22, 2011

Mr. Chairman, Members of the Committee, thank you for the opportunity of appearing before you today regarding House Bill 2296. I work for the Kansas Council on Developmental Disabilities, a federally mandated and funded entity under the federal Developmental Disabilities Assistance and Bill of Rights Act of 2000.

The Council was an active participant in the closure of Winfield State Hospital in the mid 1990's. In collaboration with the Legislative Coordinating Committee, we jointly funded a study of that closure and the outcomes for the Winfield residents who moved to the community. The results of that study and a recent (fall, 2010) update of the study, proved that persons with developmental disabilities have more inclusive lives and better health when they do not live in a large, congregate facility. I would also like to point out that the Kansas community service providers no longer have any large bed (17 residents or higher) facilities in Kansas. See attachment 1 from the Department of Social and Rehabilitation Developmental Disabilities Summary for the Month of January, 2011.

The Council supported the closure of Winfield State Hospital (WSH) and supports the closure of Kansas Neurological Institute (KNI). House Bill 2296 would create a joint committee on oversight of the closure on KNI, similar to the oversight committee created for the Winfield closure. We see this as an opportunity to have Legislative oversight of a major event in Kansas.

In reviewing this bill we assume that page one, lines 23-26 refer to the "savings" resulting from the actual average costs to serve the KNI residents in the community and not the average cost of all persons with developmental disabilities who are served in the community. We recognize that

HOUSE AGING & LTC

DATE: 2/22/11

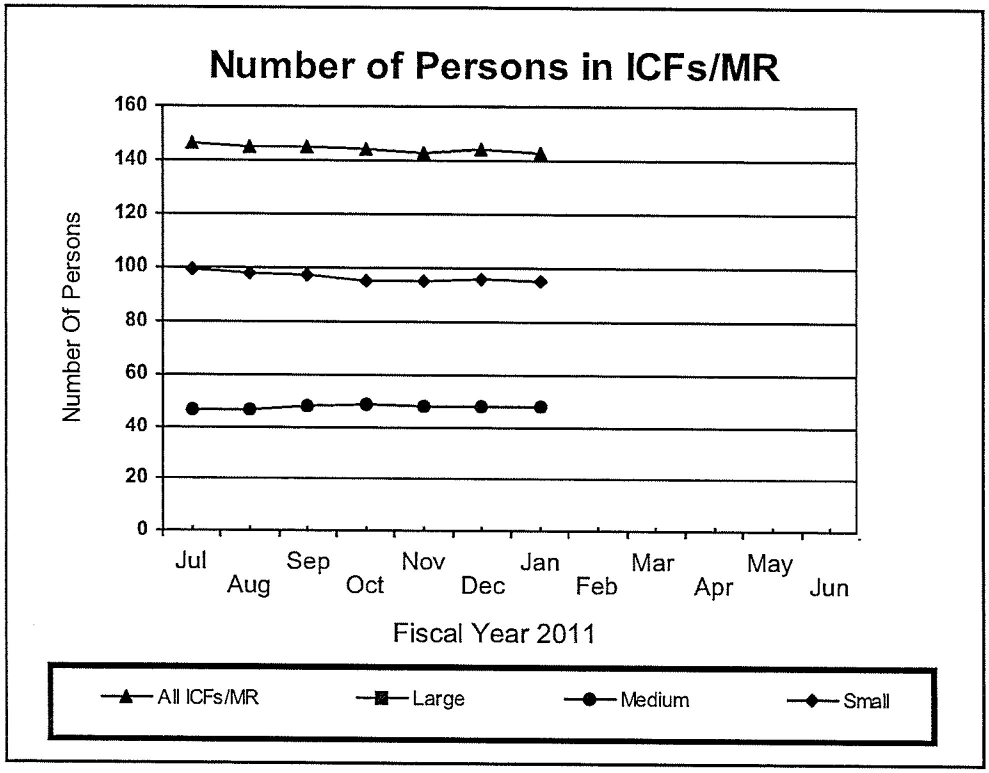
ATTACHMENT # 4

the costs of the current KNI residents will be higher than the total average costs of all persons served. However, even if the costs approach the costs of serving persons in a state hospital, we have documentation from previous studies on former Winfield residents that show they lead better lives and need fewer medical services than they did when residing at WSH. See attachment 2.

Again, we thank you for permitting us to testify and would be happy to answer any questions.

Jane Rhys, Ph.D., Executive Director
Kansas Council on Developmental Disabilities
Docking State Office Building, Room 141
915 SW Harrison
Topeka, KS 66612-1570
785 296-2608
jrhys@kcdd.org

Private ICF/MR Residents
Fiscal Year 2011
Date Of Report: February 04, 2011



Number of Persons	Jul	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	Jun	Net Change
Large (17+ Bed)	0	0	0	0	0	0	0						0
Medium (9-16 Bed)	47	47	48	49	48	48	48						1
Small (4-8 Bed)	99	98	97	95	95	96	95						-4
Total ICFs/MR Person	165	164	163	162	161	162	161						-4

Data submitted by CDDOs

SRS Division of Health Care Policy
Policy Evaluation, Research & Training
February 4, 2011

Attachment 2

Are People Better Off?
Outcomes of the Closure of Winfield State Hospital 13 Years Later

A Follow Up to the Final Report (Number 6) of the Hospital Closure Project
Issued by Dr. James Conroy in December, 1998

Submitted to:
The Kansas Council on Developmental Disabilities

Submitted by:
Della Moore
Director of Quality Assurance
Creative Community Living, Inc.
1500 E 8th Avenue
Suite 208
Winfield, KS 67156
620-221-9431, FAX 620-221-9336, email della@cclccl.org

October, 2010

4-4

In December of 1998 Dr. James Conroy submitted his final report on the closure of Winfield State Hospital. He referred to the people moving from the hospital as Movers. His report was extensive using a multitude of measures. At that time he stated, "Movers are believed to be better off." (Conroy, p.33)

The logical question is how well Movers are doing today, 13 years later. While we have neither the time nor the resources to replicate Dr. Conroy's work, we believe the 14 quality of life dimensions used by Dr. Conroy offer a strong basis for comparison (Conroy, p. 33). We further believe the parents/guardians of the Movers offer the most reliable information as the Movers do not communicate verbally well or at all. With that in mind we were able to contact 40 parents/guardians of the Movers from 1997. We contacted the parents/guardians via telephone and used the following script to administer the survey.

Script for phone interview:

My name is ______________________________ and I work for Creative Community Living. We are collecting information to share in summary form with the Kansas Council on Developmental Disabilities. This information will most likely be used in testimony before legislators as they examine closure of another state hospital. This short survey should only take 5 – 10 minutes of your time. May I proceed? (If answer is "no", ask if there is a more convenient time you can call. If the answer is still "no", thank them and hang up.)

Every parent/guardian we were able to reach participated in the survey.

We anticipated there would be a slight increase in the level of satisfaction with community-based services. We did not anticipate the degree of increase in all dimensions.

Category	**State Hospital**	**Year 1**	**Year 13**
Health	2.6	2.7	4.3
Running his/her own life - making choices	2.2	3.0	4.0
Family Relationships	2.1	2.3	3.9
Seeing friends, socializing	2.3	2.8	4.2
Getting out and getting around	2.3	3.1	4.3
What he/she does all day	2.5	3.1	4.1
Food	2.6	3.5	4.2
Happiness	2.8	3.3	4.3
Comfort	2.9	3.4	4.5
Safety	3.1	3.5	4.3
Treatment by staff	3.4	3.8	4.4
Dental care	2.9	2.4	4.2
Privacy	3.2	3.7	4.3
Overall quality of life	3.0	3.5	4.4

The comments offered by many parents/guardians also supported the increase in degree of satisfaction. Below is a sampling of the positive comments:

- Can tell you in every aspect of their lives things are much better now than at State Hospital.
- As far as her life now is concerned, I really couldn't ask for it to be better.
- I think families are much more comfortable visiting in the community than they were at State Hospital. I've seen a lot of change in my life and that was one of the most positive.
- Life improved dramatically as has health.
- At first I was opposed to closure of State Hospital but I feel she would not have had the opportunities she does now.
- I feel he gets much better care now and has better Quality of Life than when at State Hospital.
- Safety is much better now, more one-to-one care.
- There wasn't as much preventative medical treatment, more reactive. I was one of the last to think this was possible.
- Think whole transition has gone well – better for everyone.

Obviously, there was some dissent although very minimal. Approximately 99% related to staff turnover, but there was consistent praise of the job done by staff today. As one parent phrased it, "There is always someone who cares."

Family relationships showed the least level of increase. The comments relating to those scores referred to declining health and death of family members rather than discontent with community settings. As the comment section shows, many family members found it more convenient and/or comfortable to visit in the community.

Dr. Conroy wrote in 1998, "The Kansas experience of the closure of Winfield has been far more successful than this consulting team predicted." (Conroy, Executive Summary) Thirteen years after the closure the success seems to have kept building.

References

Conroy, James W. (1998). Are People Better Off? Outcomes of the Closure of Winfield State Hospital, Final Report (Number 6) of the Hospital Closure Project. *Required by Substitute House Bill 3047.*

END
THE
WAIT

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

HOUSE AGING & LTC
DATE: 2/22/11
ATTACHMENT #5

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 boyscouts.........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 autistism, 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 Unserved	Children Unserved	Adults Underserved	Children Underserved	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**