DISABILITY RIGHTS CENTER of KANSAS

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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.***

HOUSE CHILDREN AND FAMILIES
DATE: JANUARY 18, 2011
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

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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 Waiver

We have three answers to that question:

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

I will explain each answer below:

Upwards of 40 million dollars = As I will show in this testimony, Kansas is spending 40 million more 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 more 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.

Additional 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	