

Some welcome closure of KNI



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From left, Russell, Tabatha and Eva Hall pose for a picture in their Topeka home. Tabatha used to live at the Kansas Neurological Institute, but now is cared for in her home.

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Russell Hall and his wife, Eva, are saving the state of Kansas money — about \$100,000 a year.

Hall removed his 30-year-old daughter, Tabatha, from Topeka's Kansas Neurological Institute in 1991, and he and his wife have been caring for her in their home with the help of funds from a Home and Community-Based Services waiver for those with developmental disabilities.

The annual cost for housing and services at KNI is \$148,526, while the average annual cost for a person on a HCBS waiver and living in the community is \$35,663, according to the Disability Rights Center of Kansas.

"We're saving taxpayers money, but we're not getting that money," Hall said.

Where those savings are being directed has become a point of contention as Gov. Mark Parkinson and lawmakers consider closing KNI and sending its residents into the community to live.

In late October, the Facilities Closure and Realignment Commission recommended KNI be closed and the institution's 158 residents be transferred to less-restrictive, community-based residential programs or to Parsons State Hospital.

KNI's closure is expected to free up about \$5 million annually from the state's budget that could be used elsewhere.

Parkinson has the option of rejecting the commission's recommendation to close KNI, or the Democratic governor could issue executive orders to begin the transfer of KNI residents to community-

based programs or Parsons State Hospital. Those orders could be blocked by one chamber of the Republican-controlled Legislature after it convenes Sunday.

The commission also recommended all savings from phasing out KNI — including money obtained from the sale of KNI property — be directed toward expanding in-home services to those with disabilities who are on waiting lists in Kansas.

About 4,000 Kansans with developmental disabilities are on the Department of Social and Rehabilitation's waiting list to receive home and community-based services provided through Medicaid waivers.

Some of the people on the list have been waiting for services since 2005. The commission recommended KNI residents being transferred into community-based programs be placed at the top of the roster.

Winfield's closure

Critics of the closure of KNI have expressed concern over moving people with profound disabilities into community-based housing programs. However, advocates say living in the community instead of in an institution increases opportunities and improves the quality of care for individuals.

For every person at KNI with the greatest severity of disability, there are 30 people living in the community with HCBS waivers with the same severity of disability, according to the Disability Rights Center of Kansas.

Sandra Love, of Wichita, said she made "the hardest decision of my life" when she placed her daughter, Suzanne Dale, in Winfield State Hospital 33 years ago.

Dale, now 38, has cerebral palsy and can't walk, talk or sit up by herself. She is unable to chew, so her food must be pureed.

"I knew her condition was permanent," her mother said, "and I couldn't care for her in the home."

When Winfield closed in the mid-1990s, Dale was transferred to a community-based group home in Wichita operated by KETCH. Three other people with disabilities live in the group home with her.

"They were at first apprehensive about taking Suzanne because she would have the most needs of any client they'd ever had," Love said. "She would also be the most expensive client and require the most care."

Love said KETCH modified the home to accommodate her daughter's needs: Lifts and a hospital bed with side rails were installed, and doors were widened for her wheelchair.

Because of the distance between Wichita and the state hospital, Love said she couldn't visit her daughter as often as she would have liked. Now, she visits Dale once a week, plus she has more frequent contact with the people taking care of her.

"I had a lot of apprehension about all of those changes, and it's worked out better," Love said.

Ron Pasmore, president and chief executive officer of KETCH, said the 241 residents at Winfield State Hospital had two options when the facility closed: Transfer to a community-based program, or transfer to KNI or Parsons State Hospital. Only 36 were transferred to other state hospitals.

KETCH received 20 to 30 residents from Winfield State Hospital, he said. Prior to their transfers, KETCH staff met with the individual, Winfield staff and family members to make the transition into the community as smooth as possible.

Pasmore said each former resident had a "startup fund" that could be used to pay for furniture, adaptive equipment and other items needed to set up a home.

"When a person lives in an institution, you don't have much," he said.

KETCH's programs at that time were focused on improving vocation skills, so the agency added social and recreation programs to meet the needs of the Winfield transferees.

At the time of Winfield's closing, about 800 Kansans with developmental disabilities were on a waiting list to receive community-based services. Because the money followed the residents into the community, Pasmore said the savings realized from closing Winfield not only provided housing and services to the former residents but also was enough to eliminate the waiting list.

"The people were on the waiting list, not because there wasn't enough capacity to house them in the community, but because there was not enough funding to serve them once they were placed in the community," he said.

Tom Laing, executive director of Interhab in Topeka, said the chances of KNI's closure eliminating the current waiting list is unlikely.

"KNI outcomes will be less dramatic than Winfield in terms of impact on the waiting list because the waiting list today is so much worse due to the lack of attention by this and the preceding administration," Laing said. "However, we can spend DD (developmental disability) resources more wisely by weaning ourselves from the institutional model."

Catch-22

The Halls — who are saving taxpayers' money by caring for their 30-year-old daughter, Tabatha, in their home — were notified a few weeks ago that the money Tabatha receives from the HCBS waiver would be pared by 10 percent due to the state's budget crisis.

The Halls had until Jan. 1 to decide what services their daughter could do without.

"We did it by cutting staff hours," he said, referring to two part-time workers who take Tabatha to the YMCA twice a week and supervise her so they can attend church.

They were also notified Tabatha would no longer have dental coverage through Medicaid.

"It's extremely difficult to do it on your own, but I'd rather have done this than kept her at KNI," Hall said. "She's doing a whole lot better now. The quality of care is the most important thing, but it comes with a price."

Pasmore said he is of "two minds" when it comes to the proposed closure of KNI.

"Living in the community is a better choice for the (individual) because it's more of a normal life and there are more opportunities in that setting," he said.

Closing KNI would mean about 500 workers would be displaced. But from a "practical standpoint," he said, the state needs to trim its budget to be economically sound.

Pasmore said the 10 percent cut to Medicaid's HCBS waivers, ironically, will affect former Winfield State Hospital and KNI residents who are now living in community-based programs that are saving the state money.

"The cuts affect staffing, which then affects quality of services," he said. "It affects the levels of pay to staff, which is already lower than in institutions, and contributes to greater turnover of staff. "

Professionals who provide direct services at institutions are paid \$12 to \$12.50 an hour, while state reimbursements pay \$8 to \$8.50 an hour to employees who do the similar work in community-based programs.

"We'll get to the point," Pasmore said, "where we can't serve people because we can't hire people."

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