

KNI Closure Proposal – 2011

Subject: My son Kevin

Dear Commission Members:

My son Kevin, age 40, has been a resident of KNI for over 32 years. He was born with a rare neurological disease called Tuberosus Sclerosis, causing profound mental retardation, seizures, behavioral issues (including extreme aggression) and brain tumors among many other debilitating effects. Despite having these significant problems and being given a life-expectancy of 16 years, he has lived many more years than we could have imagined. KNI gives round-the-clock care, provides highly trained professional staff, as well as the on-site medical facility, have all been life-saving for my son. Despite the emotional anguish and heartbreak this situation has brought to our family, we have felt nothing but gratitude for the care Kevin has received at KNI. However, now we are faced with the possibility that all of this might be taken away from him since the Governor issued an edict stating KNI must be closed, shuttered, dismantled. I understand deficits are a huge problem for the State of Kansas, however, KNI is a small part of a much larger fiscal problem and this closure surely isn't going to scratch the surface of the State's financial woes. Many strongly feel the unexpected exorbitant cost to the State for community group living, will in the long-run, be a disaster. Add to that, so many fragile lives being negatively impacted.

There are some within the halls of the Kansas Congress who have felt that the residents of KNI should be **de**-institutionalized. Question: How can you de-institutionalize a care facility when it isn't an institution of old? The stigma of old!!! KNI residents enjoy a home-like environment, in a familiar neighborhood and an existing community. The mindset for closure seems to be that moving these very fragile people into the community will give them freedom. The truth is they will be isolated and missing the activities they had at their KNI home. It is my opinion the residents and families are being lured into something that isn't real. If this process should take place and the State finds the escalating expenditures to be too great, then what? Or this population just can't succeed in a transition? I ask these questions when I had a recent one-on-one discussion with the Governor. His response, "we'll just send 'em to Parsons!!!" Well now, I thought the moral compass was directed to **de**-institutionalization when the truth is they will be RE-INSTITUTIONALIZED if Parsons is the alternative. These residents will be set back 20 years from the gains they've made at KNI. So this whole effort seems to me to be without compassion and to be potentially regressive and not progressive.

Unfortunately, there are some who may not understand what KNI truly is. I would like to explain what KNI means to those of us who have been fortunate enough to have our loved ones cared for these many years and how stabilizing and life saving it has been to my son since he was eight-years old. To ours and other families it is not simply a budget line on a piece of paper, it's our children's home, the place where our children grew up. They know nothing else.

I would define KNI as a home that offers a safety net protecting all the residents in a close knit community campus; a place with exceptional caregivers who provide on-site 24/7 medical care, behavioral intervention, emotional support for both residents and their families; help with daily routines

Appropriations Committee

Date March 9, 2011

Attachment 1

(imperative to people with severe neurological impairments) keeping feeding tubes sterile, dispensing vital medications, seizure recovery, etc.

I also want to point out, KNI takes care of people who look and behave in ways that are uncomfortable for most of us. Their severe cognitive and physical disabilities are evident. Many like, my son, function equal to a 12 or 18 month old in terms of cognition/language development. KNI employees are highly trained and specialized on how to work with this unique population. I fear a community home setting, where my son and other KNI residents would have more access to the world, and the world will have more access to them, would be problematic at best, dangerous/fatal at worst. I also worry that inexperienced staff dealing with this challenging population would be at greater risk of abusive behaviors. Statistically, people with developmental disabilities are 4 to 10 times more likely to be victims of crime than other people. (Sobsey, Wells, Lucardie and Mansell. 1995. Violence and Disability: An Annotated Bibliography. Baltimore, MD. Brooks Publishing.) In addition, approximately 67 percent of perpetrators who abused individuals with severe cognitive disabilities accessed them through their work in disability services. (Sobsey, D. and T. Doe. 1991. "Patterns of sexual abuse and assault." Journal of Sexuality and Disability, 9(3): 243259.) I fear less oversight and supervision in a community setting would allow more opportunities for abuse.

I also strongly believe that the cost to the state is actually higher by placing Tier 1 level residents and others like him, in a community home setting. Because of his behavioral problems and extreme medical issues there will be a consistent 911 response team required for emergency care and an added burden to SVH since the vital medical unit at KNI will be shuttered. Parsons' hospital equivalent to SVH is one hour away or Wichita 98 miles away. That's a disaster.

Only God should decide when my son shall pass from this life, not the Governor. Kevin should have the honor of leaving us while in his home of these many years and while receiving abundant care at KNI. It is not anyone's right to determine or expedite his passing by placing him in a place which offers sub-standard and inadequate medical care and no safety net. If he passed due to neglect elsewhere, there simply are no words to explain the anguish it would cause all of his family forever.

We love all our children, even those who are handicapped and live in the shadows of life and have no voice. They need your compassion, wisdom and understanding.

Thank you,


Judy Ford

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Attachment 1-2