

To: The Bob Bethel Home and Community Based Services and KanCare Oversight Committee

From: Joan Kelley, Stakeholder and Legal Guardian

Re: Challenges and Outcomes for our most vulnerable

August 12, 2014

Good afternoon, Chairman David Crum and members of the Committee,

Thank you for the opportunity to give presentation today, and I want to commend this Committee for your ongoing work and service.

As a stakeholder who believes in community, my husband and I utilized an array of community-based services for our profoundly disabled grandson in the State of Kansas beginning 1998. Our loved one currently lives at KNI, the Kansas Neurological Institute, residing there since the fall of 2008. He was placed there after exhausting every community option, and although we have sought reintegration, our search continues, as unfortunately, a number of community providers have refused to serve him.

Currently, I represent concerned families as Vice-President of the KNI Parent Guardian Group.

## **Systemic Deficiencies**

### **Quality of Care**

The Community Direct Support Staff wage has not changed significantly for over a decade. I can tell you first hand that even with professional supports in place, my husband and I were unable to retain staff at \$8.00 an hour back in the year 2000.

I would respectfully like to ask the Committee: What caliber of people do you think currently retain employment in \$8.00-10.00 dollar an hour range, working in a group home, caring for the most vulnerable, behaviorally difficult, and those with the complex medical needs, when they could work at a department store or Mc Donald's for similar pay - without having the weighty responsibilities of caring for these most challenging individuals? Current HCBS Direct staff turnover rates are approximately 60%.

The 2011 KNI Legislative Post Audit clarified that "The State Doesn't Track Certain Safety Outcomes For Developmentally Disabled Adults."

<http://kslpa.org/docs/reports/r-11-015.pdf> - pages 43-44

Recently this was confirmed by the State's Protection and Advocacy Organization (Disability Rights Center), when friends of ours requested a way to ascertain troubled community homes. They were shocked, since their nonverbal son is unable to tell anyone if acts of abuse are being committed against him. As we look at oversight of scattered homes across our state, surely this is of great concern to all of us well. Current systems are inadequate to address safety issues of those living in community, who cannot speak or defend themselves.

## **Abuse**

I submit documentation of nation-wide community abuse, since in recent years, popular down-sizing and facility closure policies have been implemented without resolving community deficiencies, or creating adequate solutions of true capacity building.

<http://www.vor.net/images/AbuseandNeglect.pdf>

## **Costs**

The discharge of less difficult-to-serve residents leaves the highest need individuals remaining in State facilities. These individuals often require the highest levels of support, and if community services are to be even relatively comparable to those who remain in facilities like KNI, they will necessarily be expensive.

During the Legislative Post Audit mentioned above, three Community Disability Organizations (CDDO's) reviewed five KNI transition candidates. They estimated that little or no savings would be realized by the transfer of these individuals, and in the case of my grandson, these organizations (CDDO's) estimated their costs would actually be higher! Perhaps this in part explains why HCBS providers have been reluctant to serve him.

<http://kslpa.org/docs/reports/r-11-015.pdf> - **Appendices D,E; pages 61-65**

It was recently stated before this Committee that HCBS savings are realized only after a transition, and a "bed is closed." When a bed is closed, it serves to prevent families in crisis from adequate assistance because we have not built capacity and HCBS providers offer no feasible solution.

I shall refrain from speaking further, but have included US Senator Chris Murphy's call for a Federal probe into the alarming number of preventable deaths of our most vulnerable living in community settings.

Thank you, and I am happy to answer any questions from the Committee.

Respectfully,

Joan Kelley

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Attached: US Senator (CT) Chris Murphy letter to the Office of Inspector General

cc Kansas Senator Julia Lynn  
US Congressman Kevin Yoder  
US Senator Jerry Moran