

VOR

Kansas State Coordinator Report - July 2016-May 2017

HCBS Funding

A five percent increase for DD Home and Community Based Services has been proposed this legislative session. According to community service providers, this increase would be just enough to keep “community providers in business.” It will not be used to strengthen the anemic Direct Support Staff workforce, or begin to remedy the decades long Direct Support turnover crisis. Those concerns, and related quality of life issues, are allegedly being addressed by American Network of Community Options and Resources (ANCOR). *

*ANCOR Senior Director of Government Relations, Esme’ Grant, who is also an attorney, was the former Director of Public Policy for the National Association of DD Councils (NACDD)

Increases are often structured to give a flat increase across all employees in certain Kansas counties. In the county where I live, which happens to be the wealthiest county in the state, a CEO for a Community provider organization earning for example, \$100,000 annual salary (probably more like \$200,000) - would enjoy a \$105,000 annual salary next year with the five percent increase, while the Direct Support staff, previously earning \$10.00 per hour, will continue to receive a meager, disincentive wage of \$10.50 per hour.

Like many other states, Kansas has been challenged to vote in favor of Medicaid expansion, which would include coverage for lower income, able-bodied citizens. Often overlooked in the equation is the toll taken on the weakest members of society by including a larger pool of people. Limited resources are easily swayed away from the most at-risk individuals who have little or no voice. Legislators are expressing concerns how Kansas would *actually pay for such expansion* during a time of significant fiscal deficits. (Education already takes the largest percentage of Kansas taxes, (more than half) - and has one of the loudest, and sadly, often rude, disrespectful, and demanding voices in the advocacy arena.

DD Council activities

While serving on the DD Council, I was appointed Chair of the Abuse, Neglect and Exploitation (ANE) Committee. I listened to self-advocates and others expressing deep concern about abuse in community settings. While the committee worked hard on developing the ANE goals for the Council’s Five Year Plan, one of the State agency reps and myself met with opposition from the DD Council technical assistance arm, which provides training and support for DD Councils on a national level (ITACC). As Council members, we also requested clarification and assistance from the Administration on Community Living (ACL) to address troubling issues expressed by concerned families and a concerned state agency representative. In spite of detailing our concerns, asking

for assistance and answers to specific questions, ACL heavily sided with the DD Council's imbalance of power over family voices, and disregarded the undue influence from professionals overall.

Most disturbing DD Council activities:

- 1) Goals and Objectives finalized by Council staff did not accurately reflect the ANE Committee's work.
- 2) Undue influence was exerted by DD Council's National Association (NACDD), Council staff, and the Protection and Advocacy (P&A) representative.
- 3) The Council created Five year plan Goals and Objectives based on input *from less than one percent* of the 45,000 I/DD individuals living in the state of Kansas.
- 4) The Council held a Supported Decision-making conference last fall, strategically using certain speakers to cast doubt on the importance of Guardianship, and diminished the unique needs of I/DD subgroups who are non-verbal, medically complex, etc.

Marginalization of high risk individuals

Self-advocacy and the aging population often supersedes any acknowledgement of highest risk DD individuals in Kansas. Kansas Adult Protective Services is charged with protecting vulnerable adults including I/DD individuals, yet I do not recall anything but casual mention of the I/DD population in the quarterly Committee meetings which I attend. Focus is almost exclusively on self-neglect, and fiduciary abuse of the aging population.

Vulnerable adults

Kansas legislature is considering a bill this year which proposes the additional, inclusive language regarding the term "vulnerable" adults. P&A - Disability Rights Center, Kansas, opposed the inclusion of the word "vulnerable", stating before legislators that it was "term often reviled in the disability community."

ACL

The Administration on Community Living (ACL), which was created under the previous administration, has a current annual budget of 1.9 billion dollars. During my tenure as a member of the DD Council, I had filed a formal complaint with the Council Chair regarding the DD Council's erosion of transparency; but concerns were never addressed according Council policy. Three different Council members, including a concerned state agency representative, made separate appeals to the Administration on Community Living (ACL) for answers to ongoing DD Council transparency concerns. Not only were Council member requests ignored for several months, but ACL, when finally responding in a brief e-mail, aligned itself with the DD Council, deflecting response to troubling Council activities.

The National Association of DD Councils (NACDD) and ACL employees with whom we corresponded have worked in their capacities for several years at these respective agencies. Yet alarmingly, they downplayed their own previous remedial recommendations, when DD Council misconduct allegations surfaced back in 2011.

Several of us in VOR met with ACL officials in DC two years ago. We requested a “seat at the table” so to speak, and although we formally thanked ACL for our 30 minute meeting with them, to my knowledge, we have never heard back from anyone at ACL regarding our VOR request.

Conclusion

P&A's, DD Councils, ACL, ANCOR, NACDD and other entities have a long history of ignoring the needs of our loved ones and requests for consideration. ACL recently announced the award of a grant to Self Advocates Becoming Empowered (SABE), with a goal for SABE to lead the effort in partnership with several organizations as part of a \$2 million, five-year cooperative agreement, funded by ACL under the [Administration on Disabilities](#) as an AIDD [Project of National Significance](#). Currently, **SABE's number two goal is to close all institutions.**

Kansas is affected by well funded entities also, who exert undue influence, pressure and join in a collaborative effort to present one-sided information, marginalizing the most vulnerable citizens who are being put into harms way. Trust is earned - through actions of integrity, not given blindly, in hopes that an organization will suddenly act honorably towards DD individuals whose needs and outcomes have been ignored or misrepresented for too long.

Joan Kelley, VOR - Kansas State Coordinator

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