

Testimony of
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I am the sister and guardian of a 60 year old man with cerebral palsy, chronic depression and bouts of paranoia. He is currently receiving very good residential and day program services here in Kansas through the HCSB waiver. Because of these services, my family is staying in Kansas rather than moving away in retirement. However, I believe the quality and continuity of these services is severely threatened under KanCare. I urge you to support HB 2457 and the removal of people on the MR/DD waiver from KanCare.

It is entirely inappropriate to put long term care for the developmentally disabled (DD) into a managed care system run by health insurance companies. These companies know nothing about the problems faced by people with DD. They know nothing about how to assess the need for staying in a known and friendly community, or what constitutes an appropriate day program for a particular individual, or payment for services involving quality of life -such as taking a client shopping - or payment for community excursions. These daily activities have nothing whatever to do with diabetes prevention or colonoscopies. Rather, having friends, going on excursions, finding meaningful things to do -these are the opportunities and freedoms that make a life worth living. They should not be regulated by a profit-seeking entity, which does not, and cannot, know anything about them. Only the client, or parents, or guardians, or, case managers who have known a client for years, are in a position to choose programs, providers, and activities that are meaningful and enjoyable to that client. These life-style choices should be made, as they now are, from the bottom up; not determined, as they will be under KanCare, from the top down.

My brother lives in a group home where finally, after almost eleven years in such a setting, he has a roommate whom he likes. Some of the staff at the home have known him for almost that long. The group home is near the church he has attended since moving to Wichita in 1998. Being near it, he is able to find transportation, and so is able to sing in the choir and fully participate in activities there. Needless to say, this is an important part of his life. It is the only time during the week that he is in a "normal" situation, with all "normal" people. It is the one activity that integrates him into the larger Wichita community. Besides church, my brother attends day programs at two different agencies, which gives some variety to his life during the week. Of the programs available in Wichita, these are the ones most suited to him: we know, we've investigated.

Before he started in the state system, he lived at home with our mother. I moved them to Wichita from Michigan in 1998 when it became apparent to me that her health was failing and that he was unable to call 911 in an emergency. She died two years later, at the age of 85, having cared for him for almost 49 years. In my mind, my mother was a saint. But alas, we are not all that way, and to expect there will be one in every family into which a child with developmental disabilities is born is simply to deny reality. Furthermore, it is still not clear to me that my mother, despite her loving intentions, chose the right path for my brother.

Perhaps she should have gotten him into state services in Michigan when he was younger. The rightness of that course would of course have depended on what was available in Michigan. In Kansas, there were good services available by the time he got here. And, ungrateful as it sounds, my brother has been happier with his group home and day programs than he was living at home. The reason is simple. At home, he was isolated and he had nothing to do. He had no friends. Like others with DD, he did not make friends. After he lost his job in Michigan, he became depressed, eventually spending most of his time in bed and contemplating suicide. He needed contact with people outside the home; he needed something to do. My mother tried: she took him out often, she always included him when friends of hers came to our home, and she hired people to come help with weekly chores. But that was not enough.

“Normal” people create their own social network; people with DD cannot. Nor, as it turns out, can a person’s family supply that social network for them. However, here is the miracle - a community can. A community of providers can supply programs, homes, and supports that enable people with DD to live “independent” lives, in a variety of living situations. This allows them to be as integrated as possible into the greater community and provides them with social groups to which they can belong.

By the time my mother and brother arrived in Wichita, he was so depressed, he was spending his days in bed and rarely getting dressed. When she died, his depression had somehow progressed to a kind of paranoia, making it impossible for me to care for him. For example, when I was trying to get him to a doctor, he locked himself in a bedroom and called the police on me. I eventually got him to Menningers Clinic in Topeka, where he spent nine months, and where the psychotropic medications he needed were finally given to him. From Menningers, he went into the state system here in Wichita. These two things turned his life around.

Not that it has been easy since then. We had to find the right group home, the right case manager, the right psychiatrist, the right day programs. It has taken eleven years to get him where he is today – a quiet, polite, helpful man, who feels himself to be somewhat independent, and who is as integrated into the wider Wichita community as it is possible for him to be.

Not only does my brother have good longterm care, he also has excellent health care. His primary care physician is a gerontologist, which is an excellent, background for working with my brother, who experiences the problems of old age sooner than other people. We have known this wonderful doctor for thirteen years; he also treated our mother, making him a kind of family doctor to us. My brother's psychiatrist took a while to find. She is outstandingly kind and attentive to him, and she understands his condition. Moreover, he trusts her, which, considering his bouts of paranoia, is extremely important. Similarly, he visits with a psychological counselor on a regular basis. He has known this man since coming to Wichita, and also trusts him. My brother needs him to talk through problems and to offer suggestion on how to deal with them. The counselor also alerts us -family and case-manager - when my brother is feeling exceptional stress or depression, and thus helps avert crises.

How likely is it that my brother will find an insurance company that has a drug formulary covering all his drugs (of which there are 17 including over the counter medications), and has contracted with all the independent providers that contribute to my brother's well-being - his group home, his two day programs, his psychiatrist, his primary care physician, his counselor, his case manager? If all companies will contract with everyone, then why have three companies? What happens if providers don't contract? What happens if they go out of business? Where will the people in group homes go if theirs closes? What happens if we lose the doctors whom we know and trust? How can the MCO manage care and have us still keep our case managers? It is obvious that important factors that have made my brother stable are going to change. KanCare will destroy the life that has been created for him since Mom's death.

Stability is what my brother needs desperately. He has it now, and, once gone, it will take years to recreate. The future I see for my brother under KanCare is full of disruptions with changes of service providers all down the line. This is bound to affect his mental health, which is fragile at best. Will he end up institutionalized? I fear for him, a person I love

Those with DD are people, too. They aren't interchangeable widgets that can be stuck here or there, manipulated and turned around to suit some model. Well, they can be, because they are helpless. And precisely because they are helpless, they are dependent on the morality of the rest of us to care for them, and to do it properly. The State is doing it properly, now, with its current system.

The DD community does not belong in KanCare, and those on the HCBS DD waiver should not be made part of the managed care experiment. Representative Jim Ward has submitted a bill, HB 2457, which would carve DD services out of KanCare. I beg you, please support this bill.