



Topeka Independent Living Resource Center

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Testimony on PD Waiver Waiting List Issues
to the
Joint Committee on Legislative Budget

Presented by:
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The Topeka Independent Living Resource Center (TILRC) is a civil and human rights organization whose mission is to advocate for justice, equality and essential services for a fully integrated and accessible society for all people with disabilities. TILRC is a federally funded and acknowledged Center for Independent Living (CIL) and is staffed, managed and controlled by people with a variety of significant disabilities. TILRC provides direct services, including Home and Community Based Services (HCBS), as well as individual and policy advocacy services. TILRC is cross-age; cross-disability. We have provided services and advocacy without regard to age or type of disability for over thirty years.

Through the years, our agency has talked to this body about the role of the United States Supreme Court's *Olmstead* decision as it relates to the support of home and community based programs as an alternative to institutionalization for people with disabilities. The United States Supreme Court's holding in *Olmstead* said, in essence, that making services available to people with disabilities only if those people lived somewhere with other people with disabilities, was discrimination.

The State of Kansas has demonstrated tremendous leadership in addressing and ameliorating this type of discrimination through the development of an extensive home and community based services system, supported by a statutory mandate in Kansas law that provides, "*priority recipients of attendant care services shall be those individuals in need of in-home care who are at the greatest risk of being placed in an institutional setting.*" (KSA §39-7,100(b)(1)).

Our agency and disability advocates in the State have long expressed concern about waiting lists for home and community based services. To be clear: waiting lists are not *per se* a concern. There is nothing in the language from the *Olmstead* decision that says States cannot have waiting lists for services. To the extent States have waiting lists, however, those waiting lists must move with reasonable speed and States must have "safety valves" to allow people in crises, at threat of institutionalization, or with health, safety or well-being at risk, to access community based services. Consistent with Kansas State law, the people who are eligible for long term services and supports should be prioritized by those who are at the greatest risk of institutionalization.

Joint Legislative Budget Committee
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Attachment: 8

Advocacy and services provided by and for people with disabilities.

As a Targeted Case Management provider on the PD Waiver, our agency provides initial eligibility screening for people who need community-based long term services and supports, and submit those people's information to the State for inclusion on the PD Waiver waiting list.

Through the years, providers have received differing instructions on the expectations for re-screening and "following along" with the folks who have been placed on the waiting list. By memorandum of January 1, 2010, providers were told that no follow-up for people who had been placed on the waiting list was necessary until services were being started. More recently, questions about the process for continued monitoring of people on the waiting list have been raised, with the new expectation that consumers placed on the waiting list should be re-screened at least annually, and possibly that consumers on the waiting list should receive monthly contact. Providers have had no clear or consistent direction on what the State's expectations have been, or how the State would propose to reimburse providers for multiple screenings or monthly contacts with consumers who are not technically HCBS Waiver consumers.

From the outset, our agency waiting list process has been that waiting list consumers go through our unified intake procedure so that all consumers are screened for eligibility by the same person, all consumers are given access to the same information, and all consumers are given the choice of using independent living services to help identify community resources or provide the consumer with training and assistance for self-care or house keeping skills. Independent living advocates are also well-trained and well-positioned to help people who are at imminent risk of institutionalization with exercising their *Olmstead* rights using formal complaint processes. These are core independent living services, which agencies like ours are uniquely positioned to provide, because of our mission and the availability of resources through our federal grant.

The other benefits of using a unified, independent living-focused process are that the advocate helps determine if a consumer meets a crises exception criteria, helps secure the necessary documentation to support a crises exception and prepares a crises exception memorandum to submit to KDADS. The advocate discusses other options such as the W.O.R.K. program and works to identify other programs to meet the consumer's needs. Having a single point of entry also helps consumers remember who they talked to at the time of intake, and feel comfortable re-connecting if their situation changes in the future.

We received the waiting list review letter from the State around two weeks ago with a list of 177 names. I personally took over the list and began the requested process of contacting the consumers on the list. We tried to make initial phone contact, and have followed up with a short letter asking consumers to contact us to discuss the services. Our past experience tells us that people change phone numbers and addresses routinely. We have made direct contact with about half of the people on the list.

We have had around a dozen people decline services when offered at this time, including people who were no longer eligible because they had obtained services through another program, had moved out of state, or who had passed away. The majority of people with whom we have connected give a resounding "yes" when asked if they still need the in-home services and supports. Some of these people have been waiting for services since April 2009.

Thank you for the opportunity to appear before you today to provide our agency's perspective on the waiting list issue for the PD Waiver in Kansas. We would also like to thank this body for your leadership in providing funding to begin to address the waiting list, and look forward to working with Secretary Sullivan and his staff as we work collectively to offer services and supports that will keep Kansans with disabilities living safely and with dignity in their own homes.