



INDEPENDENCE
INCLUSION
INNOVATION

February 1, 2012

TO: Dave Crum, Chair, and
Members of the House Social Services Budget Committee

FR: Matt Fletcher, Associate Director, InterHab

RE: Kansas HCBS MR/DD Waiver Funding and HB 2475

Chairman Crum, and members of the Committee, thank you for the opportunity today to discuss the HCBS MR/DD Waiver and House Bill 2475.

The HCBS MR/DD Waiver:

The majority of funding in the community developmental disability service network comes from the federal government through the Home and Community Based Services (HCBS) MR/DD Waiver. This waiver serves individuals age 5 and over who meet the definition of mental retardation or developmental disability, or are eligible for care in an Intermediate Care Facility for people with Mental Retardation (ICF/MR). The HCBS MR/DD Waiver is funded through a roughly 60% Federal / 40% State match. The waiver's reimbursement rate pays towards the cost of many services, including:

- *Residential Services*
- *Day Services*
- *Medical Alert*
- *Wellness Monitoring*
- *Family/Individual Supports*
- *Environmental/Adaptive Equipment*

HCBS MR/DD Waiver dollars account for the vast majority of all community developmental disability funds. Much of this funding is utilized in maintaining a workforce which is required to meet the needs of those with developmental disabilities.

The Chronic Underfunding of the Kansas DD service system:

For almost 20 years, the Kansas community-based system of supports for persons with developmental disabilities has been underfunded. Reimbursement rate increases for the organizations that provide these services have topped out at 29% since 1993. In that same time, inflation increased by more than 54%, while the starting wages paid to direct-care workers who support persons with developmental disabilities in the State's two remaining institutions increased by more than 75%. The pool of funds for the HCBS MR/DD Waiver increased significantly during that time, but that growth can almost entirely be attributed to the increase in the number of individuals served by the HCBS Waiver.

The result of this chronic underfunding to providers has been an inability to attract and retain a consistent, high-quality direct care workforce.

Direct Support Professionals – The Core of the Kansas DD System:

No examination of the HCBS MR/DD Waiver's importance to Kansans with developmental disabilities can be complete without acknowledgement of the backbone of the system – the Kansas Direct Support Professional. The Direct Support Professional (or 'direct care worker' as the position is more commonly known) is an indispensable component of HCBS Waiver services to Kansans with developmental disabilities.

Direct Support Professionals are vital in ensuring that Kansans with developmental disabilities can thrive in the community of their choice. They provide support in day and residential settings, often without direct supervision, and must handle demanding tasks such as changing feeding tubes, as well as bathing and clothing persons who need their assistance. These professionals perform a difficult but necessary job, and deserve all the support we can give them.

In many organizations, Direct Support Professionals are also required to have up to and exceeding 30 hours of training, much of which has to occur within the first three months prior to the professional working independently with consumers. That training includes courses in types of developmental disabilities, working with families, maximizing community resources, counseling skills and more. Training is also required in abuse, neglect and exploitation, blood born pathogens, CPR, first aid and non-aggressive restraint techniques.

Kansas community service providers attempt to recruit the best candidates for these positions. Most organizations require that candidates have a high school diploma or equivalent and a good driving record, as well as passing a physical, drug test, adult and child abuse checks and a KBI criminal background check. Still, due to their inability to offer competitive wages, many providers have had to hire applicants with less 'soft' job skills such as a good work ethic, communication skills, the ability to read and write, and personal hygiene.

Take a moment to compare the importance of this position, in terms of its responsibility for the health and safety of a vulnerable person with the following:

\$8.78 per hour.

That's the average wage for Direct Support Professionals in Kansas, as reported in a 2009 national study of direct care wages in community DD service settings.

It's no wonder that community providers experience high turnover.

HB 2475:

It appears that the authors of HB 2475 are attempting to address the challenges I have laid out in my testimony. In fact, the bill specifically calls out that, on an annual basis beginning in FY 2014, a budget estimate be given to the Governor that contains adequate funding for the HCBS DD Waiver program. That this bill calls for 'adequate' funding to be recommended is a direct reflection of statutory language contained within the Kansas Developmental Disabilities Reform Act (KSA 39-1801-1811) that calls for "a system of adequate and reasonable funding or reimbursement for the delivery of community services".

The current mechanism contained within the KS DDRA to determine the level of appropriate funding for the DD system is a biennial independent study of reimbursement rates. Our membership has participated in each of the studies since the implementation of the KS DDRA in 1996, but have found each study to be incomplete and lacking in its analysis of the true costs of providing service to the DD population. Still, in spite of the flaws in these studies, they have occasionally provided glimpses into the depth of underfunding in the system. For example one study (2001) found that, on average, 29% of day service hours and 42% of residential service hours that were provided were completely unreimbursed via the State's reimbursement mechanisms.

While the intent of HB 2475 may be to increase funding, it lacks any capability of ensuring funding levels are actually increased for the DD system. We appreciate the intent of the authors of this bill, but are unsure how the bill will translate into any additional dollars actually being invested in this vital system.

If the Legislature were so inclined to want to fix underfunding in the DD system, we would encourage a contemporary review of work done by your peers in 2006.

2006 Legislative Budget Committee Recommendations:

In September of 2006, the Legislative Budget Committee held two days of hearings on the community DD system and received testimony from a wealth of experts both within the community and the State on the status of the system. The Committee took the information they received very seriously, and in January 2007 released recommendations for the community DD system that were unprecedented. The Legislative Budget Committee recommended a three-year funding plan to restore the DD system's ability to pay competitive wages to its workers and eliminate the State's shameful waiting lists (which now total more than 4,800 children and adults with developmental disabilities).

In reviewing the Legislative Budget Committee's report, you'll notice a recommendation for multi-year funding that would build needed capacity in the community to serve persons with developmental disabilities, and eliminate the State's waiting lists. What would such an influx of funding do for the community DD system?

- ***Increases in reimbursement rates would allow providers to offer wages for Direct Support Professionals that are comparable with what the State pays its own direct care workers.***
The starting wage for direct care workers at the State's two DD institutions is \$12.35 per hour. Compare that with the average community wage for direct care workers - \$8.78 per hour (as reported by the American Network of Community Options and Resources in 2009). The multi-year plan developed by the Legislative Budget Committee in 2006 called for bridging this parity gap by bringing community direct care wages up to the level of what the State pays its own employees for the same work.

- ***The State's two waiting lists could be eliminated.*** According to the December, 2011 SRS monthly summary of DD services, 3,246 adults and children wait to receive service in Kansas. Another 1,636 adults and children receive some basic support, but need additional services. The Legislative Budget Committee recommendations could effectively end the DD waiting lists in Kansas – a first for the State in sixteen years. However, without a significant effort to first fortify current service capacity in Kansas communities, as well as build expanded capacity to meet the needs of individuals who may have additional significant behavioral, medical and mental health challenges, the community service system would face severe strain in eliminating these waiting lists. The Legislative Budget Committee acknowledged this by staggering the recommended funding increases – ‘frontloading’ the funds meant for capacity building and ‘backloading’ the waiting list funds.

The Legislative Budget Committee has provided you with a thoughtful plan for building a quality future for Kansans with developmental disabilities. They have created a multi-year approach that will fill in current funding gaps as well as address the expanding needs of the DD system.

We Respectfully Urge Your Support of HB 2475 as Well as Reconsideration of the 2006 Legislative Budget Committee's Findings:

The community DD system and the professionals who do this demanding work need the assistance of State policymakers in ensuring that community care for Kansans with developmental disabilities is *quality* care. That begins with ensuring that the community has the resources needed to attract and retain quality staff.

We appreciate the thoughtful consideration of this Committee to the challenges that face the Kansas DD service system, and we stand ready to work with you in addressing those challenges. Thank you for the opportunity to appear before the Committee today. I would be happy to try and answer any questions the Committee might have.

Legislative Budget Committee

PUBLIC DEVELOPMENTAL DISABILITIES SYSTEM

CONCLUSIONS AND RECOMMENDATIONS

The Legislative Budget Committee recommends that the Legislature establish a phased-in effort to accomplish the programmatically linked goals of community capacity expansion and the elimination of the waiting list for services from Home and Community Based Services waiver for persons with Developmental Disabilities (HCBS DD). This effort would consist of the following:

- Expand community capacity through rate adjustments to achieve rates which would more closely reflect a parity between community wages and state institutional wages by adding \$15 million SGF in FY 2008 and \$10 million SGF in FY 2009 and FY 2010; and
- Eliminate the waiting lists for developmental disability (DD) services by adding \$10 million from the State General Fund in both FY 2008 and FY 2009, and \$15 million in FY 2010.

Additionally, the Committee recommends that the Senate Ways and Means and House Appropriations Committees request information during the 2007 Legislative Session on items including but not limited to the following:

- To assure that all programs are designed to meet the intent of the DD Reform Act for greater emphasis on independence, inclusion, integration and productivity;
- To examine, and replicate if appropriate, models in other states which are better designed to assist families of dependent children, rather than relying solely on the current HCBS DD waiver;
- To establish minimum standards for all persons and entities who provide services to persons with DD;
- To assess current capacity planning at the Department of Social and Rehabilitation Services to upgrade the State's ability to provide monitoring and oversight for the expanded numbers of community service providers; and
- To propose ways by which to upgrade employment related services for persons with DD, including providing the Legislature with a fiscal estimate on unbundling supported employment services so as to allow providers of such services to build employment service capacity in the community, and therefore be able to reduce reliance on facility-based employment services.

Proposed Legislation: None.

BACKGROUND

The Legislative Coordinating Council directed the Legislative Budget Committee to study the state's system for serving individuals with developmental disabilities. Specifically, the Committee was directed to review the updated Department of Social and Rehabilitation Services' (SRS) strategic plan and quality assurance and enhancement activities. In addition, the Committee was to examine current and proposed models to meet the demand for community based services.

COMMITTEE ACTIVITIES

At the September meeting the Committee heard full-day testimony from nearly 20 conferees regarding the developmental disabilities system. Conferees included representatives of state agencies, consumer organizations, Community Developmental Disability Organizations (CDDOs), Community Service Providers (CSPs), provider associations, and other advocacy organizations.

Staff presented an overview of the developmental disabilities system to orient the Committee and lay the foundation for testimony. Following the staff presentation, SRS briefed the Committee on the number of persons served, or waiting for services, and the impact the additional funding approved by the 2006 Legislature is having on waiting lists. In addition, the agency presented information on the Developmental Disabilities (DD) Strategic Plan, quality assurance activities, targeted case management services, and the Federal Deficit Reduction Act.

Although, many comments and suggestions were made by conferees, testimony centered on the following primary themes:

- Closure of remaining state hospitals and private large bed facilities;

- Reduction of the waiting list for Medicaid Home and Community Based Services (HCBS) waiver services and expansion of community based services;
- Increased wages for direct care professionals;
- Improved quality assurance and monitoring;
- Focus on the vision set out in the Developmental Disabilities (DD) Reform Act; and
- Service requirements for individuals with severe, and sometimes violent, behaviors.

The expansion of community based services and the elimination of the waiting list for HCBS waiver services are underlying themes in nearly all of the testimony. However, cautions were expressed regarding the need for capacity expansion, quality oversight, funding and other measures to ensure the expansion is successful. Conferees commented that a quality system of services requires both access for individuals needing services and service providers reimbursed at levels sufficient to recruit and retain employees with the right skills and abilities.

A number of conferees addressed issues with having adequate direct care professionals in the community. The most common comment was regarding the salary of direct care professionals, especially in relation to what staff at the state hospitals are paid. According to testimony, the current state-wide average wage for direct care staff in the community is \$8.83 per hour while the beginning wage for a similar position at a state hospital is \$11.81 per hour. According to testimony, the estimated cost to increase community based staff wages to \$11.81 per hour is \$35 million from the State General Fund. Several conferees commented on the amount of work required

from direct care staff and the difficulty in hiring, training and retaining qualified staff to provide around-the-clock services.

The closure of the remaining two state hospitals and private facilities was discussed by two conferees representing advocacy organizations. According to conferees, institutional services are not the most economical way to serve persons with developmental disabilities. Additionally, federal pressure is building to re-balance funding in favor of community based services. Conferees recommended that all savings generated from closing institutions be directed into the community to fully fund services. The suggestion also was made to set a binding date for closure to facilitate the process. Finally, one conferee suggested the Committee review the report on the closure of Winfield State Hospital and Training Center which reported that individuals moved into the community had better outcomes than when they were in the hospital.

Improving the system for quality assurance and monitoring was cited as a principal of providing quality community services. Conferees indicated that the current system has not kept up with the expanding community system resulting in a concern about whether people are receiving the appropriate services and if state dollars are being spent effectively. Conferees cited the lack of new funding for quality monitoring, both at the state and local level, despite increases in the numbers of consumers, providers and service models. In addition, one conferee commented on the reduction in day-to-day contact that SRS staff have to monitor the provision of services due to staffing reductions and reorganization. Conferees asked for additional resources dedicated to the development of outcome measurements and the establishment of minimum standards for all providers.

A refocusing on the vision of the DD Reform Act, particularly with respect to

adult independence, was a key in a number of presentations. Multiple conferees commented on the need for timely transition of services when youth graduate from high school and move into adult services. According to conferees, these services are critical to moving people into the community and out of the family home where their adult independence may be hampered by overly paternalistic families. Integral to this process and to the provision of better services during school age years, is better communication between SRS and the Department of Education about program requirements and service coordination. Another challenge to adult independence noted by conferees was payments made to families to provide care. According to the testimony, paying family members to provide service may provide a disincentive to those families to move the child out of the home for fear of losing a source of income. The result is a lack of independence for the now adult child to gain independence and integrate into the community.

Another piece of the adult independence theme was testimony about the importance of Supported Employment and Supported Living programs. Testimony was presented that stressed the importance of these two types of services to ensuring adults were integrated into the community. Conferees requested additional support for these programs.

Challenges with dealing with developmentally disabled persons who have severe behavioral issues in the community were addressed by two service providers. According to the testimony, service providers have very little ability to reject clients whose behaviors pose dangers to staff or exceed the providers ability to serve the individual. The providers commented that, particularly in light of the relatively low wages, direct care staff were being put in harms way without sufficient recourse. It was suggested that the state needed to look

at alternatives to deal with persons who exhibit criminal, predatory, violent or other aggressive behaviors.

Other topics presented to the Committee included the value of consumer self-advocacy; gaps in services for children; and the need for Ombudsman services. With regard to consumer self-advocacy, the following three steps were given to ensure consumer rights: consumer participation in quality assurance; increased opportunities for choice and control of services; and increased education and awareness of service delivery options. In addition, more financial support for statewide self-advocacy training was requested. Gaps in services for young children were identified that results from a system designed to serve adults. These gaps include: the lack of HCBS waiver services for persons under age five; in-home supports not designed to meet families' needs; lack of billing system for mental health services; inflexible systems that do not support community collaboration and limited discretionary funds. Finally, one conferee noted the need for Ombudsman services to support and educate persons with developmental disabilities.

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