

MINUTES OF THE HOUSE SOCIAL SERVICES BUDGET COMMITTEE

The meeting was called to order by Chairman Bob Bethell at 3:30 p.m. on March 12, 2008, in Room 514-S of the Capitol.

All members were present except Representatives Ballard and George who were excused.

Committee staff present:

Kimbra Caywood McCarthy, Kansas Legislative Research Department
Nobuko Folmsbee, Office of Revisor of Statutes
Judy Holliday, Committee Assistant

Conferees appearing before the committee:

Representative Nile Dillmore
Jane Rhys, Executive Director, Kansas Council on Developmental Disabilities
Ray Dalton, Deputy Secretary, Department of Social and Rehabilitative Services
Bill McDaniel, Commissioner of Programs and Nursing, Kansas Department on Aging
Kathy Lobb, Legislative Liaison, Self-Advocate Coalition of Kansas
Matt Fletcher, Associate Director, InterHab
Maury Thompson, Executive Director, Johnson County Developmental Supports, Johnson County
Ron Pasmore, Executive Director, KETCH, Wichita
Gary Daniels, Former Secretary, Department of Social and Rehabilitative Services
Patty Knauff, Director Human Resources, KETCH, Wichita
Donald Wilson, Hutchinson
Andrea McMurray, Direct Support Supervisor, Cottonwood, Lawrence
Coelet Galloway-Obu, Direct Support Professional, Cottonwood, Lawrence
Carolyn Hill, Executive Director, Starkey, Wichita
Reverend Michael and Mrs. Shelly Dunaway, Hiawatha
Wendy Parent, Associate Professor, University of Kansas
Bill Craig, Executive Director, Lakemary Center, Paola
Tom Laing, Executive Director, InterHab

Written testimony submitted:

Mike Oxford, Executive Director, Topeka Independent Living Resource Center
Lori Feldkamp, Executive Director, Big Lakes Developmental Services, Manhattan
Jennifer Schwartz on behalf of Statewide Independent Living Council of Kansas, Inc. (SILCK),
and Kansas Association of Centers for Independent Living (KACIL)
Angela Bauer, Parent Support Specialist, Families Together, Inc.

Others attending:

See attached list

Continued hearing on HB 2761--Home and community based services under DD, PD, FE and TBI medicaid waivers, waiting lists, service provider rates, multi-year appropriations.

Kathy Lobb, Legislative Liaison, Self-Advocate Coalition of Kansas, testified as a proponent of **HB 2761**. (Attachment 1) Ms. Lobb told the Committee about her opportunities to own her own home, pay taxes, receive services, and live independently. Empowering people to become more independent ultimately saves money for the state. She called attention to the people on the waiting list and the fact that as people go off the list, more go on. She appealed to the Committee to adjust the wages for direct care staff to enable them to earn a decent living wage.

Jane Rhys, Executive Director, Kansas Council on Developmental Disabilities, testified as a proponent of **HB 2761**. (Attachment 2) Ms. Rhys stated that her agency receives no state funds. The mission of the agency is to advocate for individuals with developmental disabilities to receive the supports they need to make choices about where they live, work, and learn. A developmental disability occurs before age 22 and results in major functional limitation in three or more areas of major life activity such as self-care, mobility, and economic self-sufficiency, and requires lifelong supports.

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In March 2008, of the 1413 adults and families with children waiting for services, none received Developmental Disabilities services. Kansas spends three to four times the amount for residents in a state hospital that they spend for individuals served in the community. An additional 2,032 persons from all areas of the state are waiting for additional services.

Representative Nile Dillmore testified as a proponent of **HB 2761**. ([Attachment 3](#)) Representative Dillmore told the Committee his testimony was a result of the many letters he received during the interim in support of **HB 2761**. He shared a letter from a staff member of KETCH, which provides services for the mentally retarded and developmentally disabled. The letter told of a patient in the facility and how her behaviors were influenced by the turnover in staff. This turnover would be eliminated if they received adequate pay.

Ray Dalton, Deputy Secretary, Department of Social and Rehabilitative Services, testified as a proponent of **HB 2761**. ([Attachment 4](#)) **HB 2761** provides funding over a three-year period for three of the Home and Community Based Services Waivers administered by SRS: the Mentally Retarded/Developmentally Disabled Waiver; the Physical Disabilities Waiver; and the Traumatic Brain Injury Waiver. These programs are funded through a combination of federal and state funding (60/40).

Mr. Dalton called the Committee's attention to charts at the back of his testimony regarding estimated waiver costs, average number of persons served, cost per person, and budget increases for each of the Waiver programs.

Bill McDaniel, Commissioner of Programs and Nursing, Kansas Department on Aging (KDOA), testified as neutral on **HB 2761**. ([Attachment 5](#)) His testimony dealt with the Home and Community Based Services-Frail Elderly (HCBS-FE). This waiver has allowed the State of Kansas to meet the needs of seniors aged 65 or older in their homes and communities. The HCBS-FE Waiver does not have a waiting list at this time. Seniors prefer to live in the community and the HCBS-FE services are a cost-effective alternative to nursing home care. The services provided focus on independence, productivity, and community living. Wages paid to community direct care staff through reimbursement rates to providers needs to be addressed.

Matt Fletcher, Associate Director, InterHab, testified as a proponent of **HB 2761**. ([Attachment 6](#)) Mr. Fletcher called the Committee's attention to Article Seven of our State Constitution, stating that the government was to provide for the welfare of persons with disabilities. Between 1880 and 1960, institutions for the developmentally disabled were opened (Winfield, Parsons, Norton, and KNI and Cappers in Topeka). Starkey in Wichita opened in 1930 to provide supports for persons in the community. Public perceptions changed about the developmentally disabled, first through education, then through community-based services as alternatives to institutional care.

Mr. Fletcher noted that reimbursement rates to providers since 1995 have increased only five times in thirteen years, and that if the Legislature gave the same yearly cost-of-living adjustments to this program there wouldn't be a need for **HB 2761**.

Mr. Fletcher discussed the wages and benefits for Direct Support Professionals which are the backbone of the service system. Although they provide constant support for persons with severe disabilities by cooking meals, bathing, etc., they are paid only \$8.83 per hour. The result is a high and costly staff turnover. If raising wages for State-employed Direct Service Providers helps curb rising turnover in state institutional positions, it will do the same in communities across Kansas.

Maury Thompson, Executive Director, Johnson County Developmental Supports, testified as a proponent of **HB 2761**. ([Attachment 7](#)) Mr. Thompson spoke to the changes experienced in the community developmental disability system the future of the community developmental disability system and the Legislature's role in that future; the waiting list and the underfinanced reimbursement rates for the Home and Community Based Services waiver.

Ron Pasmore, President and CEO, KETCH, Wichita, testified as a proponent of **HB 2761**. ([Attachment 8](#)) Mr. Pasmore told the Committee that early in his career at Winfield State Hospital, state institutions were the primary network of care for persons with developmental disabilities because there was no place for them in their community. They lived their entire lives in the institution setting. Now, through the network of the

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community service system, there are places in the community for persons with disabilities where they can live, work, and thrive. This is made possible by a dedicated staff, a responsive business community in which jobs are available, responsive state and community funding sources, and persons with disabilities who have the courage and desire to strive for greater self-sufficiency.

The most troubling problem is the inadequate workforce to meet all of needs of those served. The state institutions for the past served all who sought their services often without sufficient resources to meet the increase in demand. The community network is faced with much of the same challenge today.

Gary Daniels, Former Secretary, Department of Social and Rehabilitative Services, testified as a proponent of **HB 2761**. (Attachment 9) Mr. Daniels served as superintendent at Parsons State Hospital working with persons with disabilities. He called attention to the support of people with disabilities by the State Legislature since the formation of statehood and in the Kansas constitution.

The passing of the Developmental Disability Reform Act of 1996, and more recently the Five-year Strategic Plan presented to this group in 2005, outlined goals in setting public policy, community capacity building, service delivery, and financing. Mr. Daniels stated that Kansas has earned an enviable reputation as a leader in services and programs for the disabled.

Donald Wilson, Hutchinson, testified as a proponent of **HB 2761**. (Attachment 10) Mr. Wilson was a resident at Parson's State Hospital for seven years before moving to TECH at Hutchinson. Since then, he moved to his own apartment where he has lived for 15 years. He has trainers who help him budget his money and buy groceries. He has worked at Carlos O'Kelly's for almost 10 years. He enjoys fund-raising, bowling, and swimming, and is a certified scuba diver. His story wouldn't be possible without access to the community services available to him. He urged support of **HB 2761**.

Patty Knauff, Director Human Resources, KETCH, Wichita, testified as a proponent of **HB 2761**. (Attachment 11) Ms. Knauff told the Committee her job is to locate and hire staff to keep the agency running, and how the many barriers that are in place keep potential staff from being hired. Even when someone is hired, there is still high turnover due to the low wages offered and the opportunity for other employment. She stressed that rate increases to the direct care staff helps to not only retain that staff, but benefits those persons served.

Andrea McMurray, Direct Support Supervisor, Cottonwood, Inc., Lawrence, testified as a proponent of **HB 2761**. (Attachment 12) Ms. McMurray started at Cottonwood while in school fifteen years ago and still makes a wage classified by government standards as below poverty level. In fact, the direct service professionals working in the state's institutions start at \$12.05 per hour; she has worked 15 years at Cottonwood and still don't make that much. Direct service positions are considered entry level, but the many tasks she does—bookkeeping, medication monitoring, financial counseling, property management, emergency response, driving, etc.—if taken individually would all pay more. She receives ongoing education and is always improving her work skills. Yet, in spite of the high skill level required, the low wages paid makes for constant turnover, position openings and an inconsistent workforce. The effect this can have on the consumers is devastating, because they need staff who will be there, know their needs, treats them with dignity, build trust, security and self-worth. By passing **HB 2761**, good staff will stay and the people served will benefit.

Coelet Galloway-Obu, Direct Support Professional, Cottonwood, Inc., Lawrence, testified as a proponent of **HB 2761**. (Attachment 13) Ms. Galloway-Obu stated that direct care professionals greatly impact people with disabilities, and she loves her job. However, her wage is \$8.83 compared to \$12.05 earned by state direct care workers for the same work. Ms. Galloway-Obu told the Committee that if the low wages continue, it will be impossible to keep qualified, trained direct support professionals employed at Cottonwood.

Carolyn Hill, Executive Director, Starkey, Inc., Wichita, testified as a proponent of **HB 2761**. (Attachment 14) Ms. Hill reminded the Committee that one year ago she shared with them examples of the challenges Starkey and others face in supporting people with the dual diagnosis of an intellectual disability and a mental illness. She stated this situation has worsened and a tragedy that would result in immediate changes to our state system is seconds away.

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Ms. Hill related the story of a patient who because of dual diagnosis is at times violent and requires restraints, often resulting in injury to staff members. Starkey has tried with limited success to gain access to mental health facilities or state hospitals. She posed the question, If community hospitals will not treat individuals with dual diagnosis, if mental health facilities refuse admission because these individuals are considered too violent, and if there are no beds for them at state hospitals, who do they turn to for consultation and support? She stated that the Social and Rehabilitative Services regulations have not been updated for more than a decade, and they do not support Starkey in meeting the needs they are trying to address today.

Ms. Hill stated that the risk they are confronting is enormous—to the individual, to the other people they serve, to the staff, and to the organization. It only takes one incident to cause permanent injury, disability or death, one allegation of suspected abuse or neglect, to devastate an organization.

Mrs. Shelly Dunaway provided testimony as a proponent of **HB 2761**. (Attachment 15) Mrs. Dunaway told the Committee her son, Corey, is a 19-year old with Down Syndrome. She and her family chose to reside in Hiawatha partially because of the services they understood would be available to Corey from Brown County Developmental Services upon graduation from high school in 2008. They recently found out that he is 1,926 on the statewide waiting list for services, which means he won't graduate for two more years.

Mrs. Dunaway told the Committee that being forced to spend time on a 'waiting list' stifles the children's enthusiasm and momentum, and frustrates their desire for independence as they wait to become a productive member of society.

Wendy Parent, Associate Professor, University of Kansas, testified as a proponent of **HB 2761**. (Attachment 16). Ms. Parent provided statistics on the number of disabled workers in the United States, and the number of those who are employed. She reported that statistics show there are more jobs than people to fill them, and that the labor force needs these workers. Employers have reported that their employees with disabilities perform as well or better than the nondisabled coworkers, are as dependable and productive, and costs for accommodations were minimal and worth the expense. She stated that individuals who work in competitive jobs become tax-paying citizens contributing to our economy, rather than receiving government subsidies.

Bill Craig, Executive Director, Lakemary Center, Paola, testified as a proponent of **HB 2761**. (Attachment 17)

Mr. Craig told the Committee his personal story of being a parent to a son with significant disabilities that will require lifelong care. He stated that investing taxpayer funds for 18 years in persons with disabilities and watching them languish while on the state's waiting list is frustrating to the client and the families. The skills learned, as well as their enthusiasm, are quickly lost as they sit and wait.

Tom Laing, Executive Director, InterHab, testified as a proponent of **HB 2761**. (Attachment 18) Mr. Laing told the Committee that **HB 2761** was a legislative effort to address the challenges facing the statewide network and by eliminating the waiting lists, to ensure quality based community expansion of services. He provided the Committee with pictures of "Madison," a Down Syndrome child with significant medical challenges. He told the Committee that the next chapter of the story of Madison's future is one that they will write.

Written testimony only on **HB 2761** from:

Mike Oxford, Executive Director, Topeka Independent Living Resource Center (Attachment 19)

Lori Feldkamp, Executive Director, Big Lakes Developmental Services, Manhattan (Attachment 20)

Jennifer Schwartz on behalf of Statewide Independent Living Council of Kansas, Inc. (SILCK), and Kansas Association of Centers for Independent Living (KACIL) (Attachment 21)

Angela Bauer, Parent Support Specialist, Families Together, Inc. (Attachment 22)

The hearing was closed on **HB 2761**.

The meeting adjourned at 5:50 p.m. The next meeting will be on Thursday, March 13.