

MINUTES OF THE HOUSE AGING AND LONG TERM CARE COMMITTEE

The meeting was called to order by Chairman Bob Bethell at 3:30 p.m. on March 5, 2009, in Room 711 of the Docking State Office Building.

All members were present.

Committee staff present:

Doug Taylor, Office of the Revisor of Statutes  
Kelly Navinsky-Wenzl, Kansas Legislative Research Department  
Terri Weber, Kansas Legislative Research Department  
Judith Holliday, Committee Assistant

Conferees appearing before the Committee:

Shannon Jones, Executive Director, Statewide Independent Living Council of Kansas (SILCK)  
Ami Hyten, Assistant Executive Director, Topeka Independent Living  
Jennifer Schwartz, Director, Kansas Association of Centers for Independent Living (KACIL)  
Jeanette Schwe, Direct Care Professional, Topeka Association for Retired Citizens  
Doug Bowman, Coordinator, State Interagency Coordinating Council  
Dave Herl, Board President, Developmental Services of NW Kansas (DSNWK)  
Jane Rhys, Executive Director, Kansas Council on Developmental Disabilities  
Tom Laing, Executive Director, InterHab  
Patti Knauff, HR Director, Kansas Elks Training Center for the Handicapped (KETCH)  
Suzanne Wikle, Director of Health Policy, Kansas Action for Children  
Robyn Herzog, Recipient of Home and Community Based Services, Lawrence  
Andrea McMurray, Direct Care Worker, Cottonwood, Lawrence  
Amy Hayden, Mother of a child on waiting list, Johnson County

Written testimony only:

Lori Feldkamp, Executive Director, Big Lakes Development Center, Manhattan  
Barbara Bishop, Executive Director, The Arc of Douglas County  
Kathy Lobb, Legislative Liaison, Self-Advocate Coalition of Kansas

No written testimony:

Anne-Marie Hughey, Legislative and Policy Advocate, SKIL Resource Center

Others attending:

See attached list

Chairman Bethell called the meeting to order and reminded Committee members to sign in at [Americaonthemove.org](http://Americaonthemove.org) to participate in the fitness challenge with the Social Services Budget Committee. He told the Committee that they have accumulated 407 miles to date in their walking program. He will check with Representative Hawk on the program's end date, probably at first adjournment.

**Continuation of hearing on HB 2094 - Appropriations for FY 2010 through FY 2014, home and community based services under DD, PD, FE, TBI and autism medicaid waivers and tiny-k programs.**

Chairman Bethell opened the hearing on **HB 2094** and asked that the conferees give the executive summary of their testimony in the interest of time.

Shannon Jones, Executive Director, Statewide Independent Living Council of Kansas (SILCK) testified as neutral on **HB 2094**. (Attachment 1) Ms. Jones had a number of questions regarding how the projections for multi-year funding were made. She expressed concerns regarding community expansion, the services to be included, and the accountability for overseeing expansion.

Ms. Jones stated that a policy statement, prior to funding decisions, should present the positive value of persons living in the community and in their own homes. She told the Committee that home and community based services (HCBS) are a vital part of health care reform, and that in containing health care costs the HCBS programs are a viable alternative to institutional care at half the cost.

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Ami Hyten, Assistant Executive Director, Topeka Independent Living, testified as neutral on **HB 2094**. (Attachment 2) Ms. Hyten stated the mission of the Topeka Independent Living Resource Center is to promote a fully integrated and accessible society for all people with disabilities. She stated her agency's position that choices should not be limited due to a person's diagnosis, label or cause of disability. She encouraged the Committee to carefully analyze **HB 2094** and evaluate community capacity and long term care services in a meaningful way.

Jennifer Schwartz, Director, Kansas Association of Centers for Independent Living (KACIL) testified as a proponent of **HB 2094**. (Attachment 3) KACIL has worked with legislators and state agencies in the past to promote independent living, community based services for individuals with disabilities and Kansas seniors. The agency has been involved in the creation and writing of the HCBS waivers and policies in Kansas. Ms. Schwartz stated KACIL supports giving individuals choice of receiving HCBS services, regardless of age or type of disability, so these individuals can achieve independence in their communities.

Ms. Schwartz encouraged further discussion in two areas of the bill:

1. Funding amounts need to be adequate for each waiver to eliminate waiting lists; and
2. Definition of community capacity expansion to assure consistency and understanding throughout the four waivers.

Jeanette Schwe, Direct Care Professional, Topeka Association for Retarded Citizens (TARC), testified as a proponent of **HB 2094**. (Attachment 4) Ms. Schwe gave the Committee a brief overview of her involvement at TARC, first as a volunteer, then working to become one of the first nationally certified direct support professionals in the nation. She told the Committee she is not the expert, but the person that she is hired to support is the expert on their own needs; she just listens.

Ms. Schwe addressed the large turnover in staff at TARC due to the wage disparity. She stated that new workers are hired, then leave when they hear they can go to KNI just 50 yards away and make \$3.34 an hour more. There should be equal pay for equal work.

Doug Bowman, Coordinator, State Interagency Coordinating Council for Early Childhood Developmental Services, testified as a proponent of **HB 2094**, specifically, funding for the Infant-Toddler Services, or *tiny-k*. (Attachment 5) Mr. Bowman's agency is an advisory group based in both state and federal law, with members appointed by the Governor.

There are no waiting lists because federal law requires every eligible child age birth to three-years be identified and the needed supports and services be provided. These services have historically been underfunded and the funding sources are becoming depleted due to the economic situation.

Providing early intervention programs allows many children to become better prepared for entry into public schools, and one in four children served by *tiny-k* needs no further special education services after age three. In addition, the preschool assessments are used to evaluate a child's progress through early school years to determine if any other services may be needed.

Dave Herl, Board President, Developmental Services of Northwest Kansas (DSNWK), presented testimony as a proponent of **HB 2094**. (Attachment 6) DSNWK has provided community services for the developmentally disabled (DD) for 42 years in a service area covering the eighteen northwest counties of Kansas. Every county contributes to the costs of providing services to over 500 individuals, with nearly 500 staff members.

Mr. Herl testified regarding the challenge to attract and retain the workforce needed and addressing the rising costs of providing the necessary services. He told the Committee that the agency's only options were to evaluate the service locations and eliminate or consolidate services. Changes implemented included closure of Wheatland Developmental Center in Colby; downsizing services in Oakley; eliminating the Customer Connection Service and other administrative office staff positions; and eliminating positions through retirement or attrition. These changes have eliminated jobs, increased transportation costs to persons and families least able to afford it, and caused the workload to be shifted to fewer people for an inadequate wage.

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Mr. Herl stated that the federal stimulus bill will pay for the implementation of **HB 2094** to relieve the burden on agencies to provide services to its most vulnerable citizens.

Jane Rhys, Executive Director, Kansas Council on Developmental Disabilities, testified as a proponent of **HB 2094**. (Attachment 7) Ms. Rhys stated the number of persons on the DD Waiver and the number on the DD waiting list has increased dramatically in the past ten years and will continue. She told the Committee that the funding for **HB 2094** could come from the federal Medicaid stimulus dollars as intended by Congress. She proposed closing one or both of the DD hospitals when those funds are gone and the savings realized used for DD community services.

Ms. Rhys reminded the Committee that there is a Money-Follows-the-Person grant to assist persons in transitioning to the community, and if closure is begun now the funds realized by closure should be available in two years.

Tom Laing, Executive Director, InterHab, testified as a proponent of **HB 2094**. (Attachment 8) Mr. Laing told the Committee that this legislation is needed this year to establish a funding plan to reduce and eliminate waiting lists and maintain adequate funding so that community networks can recruit and retain a quality workforce.

Mr. Laing stated that community service networks are an effective and efficient use of tax dollars, and taxes sent to Topeka are returned to every Kansas community. He challenged each one on the Committee to be a champion for this bill.

Patti Knauff, Director of Human Resources, Kansas Elks Training Center for the Handicapped (KETCH) testified as a proponent of **HB 2094** and as an advocate for the direct care workers. (Attachment 9) She stated there are many barriers in place when bringing a new employee in the door. Ms. Knauff told the Committee that when there are openings, they are lucky to find five who qualify out of thirty to forty applicants. There is not an adequate number of people willing to work for the wages offered, and if they are hired they leave for 'other employment' or are 'terminated for cause' due to infractions that put patients at risk.

Suzanne Wikle, Director of Health Policy, Kansas Action for Children, testified as a proponent of **HB 2094** to provide an additional 100 children with early intervention services through the Autism Waiver. (Attachment 10) Ms. Wikle stated that providing early intervention creates savings for the state through reduced special education funding, and that 50 percent of children with autism that receive early intervention do not require special education services once they enter the public school system.

Robyn Herzog, Recipient of HCBS Services, Lawrence, testified as a proponent of **HB 2094**. (Attachment 11) Ms. Herzog works as a dietary aide, has her own apartment, pays taxes, votes and enjoys her life. She stated she would not be able to participate in many activities without the staff that supports her while allowing her to be independent, rather than dependent.

Ms. Herzog told the Committee that her staff members move to other jobs because they need more money, and that leaving makes it very stressful for her because she must become accustomed to someone new taking care of her. She stated that a job that important should pay more.

Andrea McMurray, Direct Care Worker, Cottonwood, Lawrence, testified as a proponent of **HB 2094**. (Attachment 12) Ms. McMurray told the Committee about the duties she performs in a regular day and the complexity and intensity of the work, yet direct support positions are considered entry level or temporary work, and that they deserve better.

Ms. McMurray addressed the high staff turnover, which is degrading to the person receiving services and damaging to self esteem. Staff consistency builds trust, security and self worth, and good staff will stay and the people served will have a conducive environment to reach their true potential.

Amy Hayden testified as a proponent of **HB 2094**. (Attachment 13) Mrs. Hayden is the mother of Ty, a 7-year old with Autism, Cerebral Palsy and Epilepsy. Ty has been on the DD waiting list since July 2006, and in December they were told they would remain on the waiting list until 2012 when Ty is 11 years old.

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Mrs. Hayden testified that Ty receives various therapies at home each week, for which they pay all costs out of pocket. Ty now attends elementary school in an Autism Classroom. Mrs. Hayden told the Committee that the DD funding would help them pay for the necessary services Ty needs. She stated that if she becomes unemployed they could no longer afford these services, which in turn would put an end to his growth toward independence.

Chairman Bethell asked if anyone else would like to testify on **HB 2094**. Anne-Marie Hughey, Legislative and Policy Advocate, SKIL Resource Center, came forward to offer comments on the bill. (No written testimony) Ms. Hughey reported that SKIL is neutral on the bill but also has many questions. She reiterated their position that there should be full funding for all HCBS waivers.

Proponents submitting written testimony of **HB 2094** were:

Lori Feldkamp, Executive Director, Big Lakes Development Center, Manhattan (Attachment 14);  
Barbara Bishop, Executive Director, The Arc of Douglas County (Attachment 15); and  
Kathy Lobb, Legislative Liaison, Self-Advocate Coalition of Kansas (Attachment 16).

Chairman Bethell asked for approval of the minutes of the February 17 meeting, the February 18 meeting at the Rail, and the March 3 meeting. **Representative O'Brien made a motion, seconded by Representative Furtado, to approve the minutes. The motion carried.**

There was discussion regarding the direction of **HB 2094** after the hearings and whether it would go to another committee. Chairman Bethell stated that more discussion is needed on the bill regarding the availability of funding, and that **HB 2094** will stay with the Aging and Long Term Care Committee.

The meeting was adjourned at 5:10 p.m.

The next meeting is scheduled for March 10, 2009.