Approved: March 10, 2009
Date

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 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.

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 polices 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.

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.

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.

HOUSE AGING AND LONG TERM CARE COMMITTEE

DATE: 3/5/09

NAME	REPRESENTING
Jeanetta Shrwe	TARC

PLEASE USE BLACK INK

Statewide Independent Living Council of Kansas **SILCK**

700 S.W. Jackson, Suite 212, Topeka, KS 66603 ☎ (785) 234-6990 voice / tdd ☎ (785) 234-6651 fax

Testimony to
Aging & Long Term Care Comm
HB 2094

My name is Shannon Jones. I am the executive director of the Statewide Independent Living Council of Kansas, (SILCK). During my many years of testifying in support of the waiver programs, the SILCK has always looked favorable on the possibility of long-term funding. Funding into the out years would be a great help for the Centers of Independent Living and especially, it would be helpful for the consumers who would like to be assured of continuous funding. We would like to know the basis of the budget figures used in HB 2094.

If we are going to have multi-year funding, then we need to know the base year from which projections are being made. What were the number of people needing and getting services in the base year and was there a waiting list. We would like to have that information for all of the waiver programs. What unit costs were used? What kind-of movement on and off programs was assumed?

We don't see any definition of community capacity expansion. What does that phrase mean? Who will be responsible for community capacity expansion in the local communities? What services and programs will be included as capacity expansion? What is the mechanism for accountability?

We are encouraged with the discussion which will take place around this bill. After 25 years of HCBS being an option in the array of services provided by the State, we urge that we take this as an opportunity to do more than simply spend money. We suggest the state gear the expenditure of funds to the formalizing of HCBS as an integral part of service delivery and maximizing the possibilities for economic self-sufficiency and independence.

We think a policy statement, prior to funding decisions, should lay out the positive value of persons living in the community and in their own homes. The statement should point in the direction of community living and not the creation of mini-institution in the community. The policy statement should illustrate how the expenditure of funds is being spent on an integrated basis and of the greatest benefit to the consumer.

For youth in the programs there should be an emphasis on education and training pointed to economic self-sufficiency. For young adults and adults there should be the opportunity for education and training and the learning of new skills

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and constantly pointed to jobs in the public and private sectors. There should be a comprehensive system of goal setting for each individual in the program. Reimbursement for services provided to consumers should be on the basis of goals stated and accomplished. The rates of reimbursement across all of the waivers should illustrate parity for similar services being delivered.

An important piece in relation to the formulation of the policies governing the waiver programs should be the recognition that HCBS is an integral part of Health Care Reform. If there is any chance of containing health care costs, an important part of that would be in showing HCBS programs as an alternative to institutional care. HCBS is half the cost of institutional care and is more humane and lends itself to giving people the opportunity for independence and less of a drain on the medical dollar.

Topeka Independent Living Resource Center

785-233-4572 V/TTY • FAX 785-233-1561 • TOLL FREE 1-800-443-2207
501 SW Jackson Street • Suite 100 • Topeka, KS 66603-3300

Testimony Presented to the House Long Term Care & Aging Committee
by Ami Hyten, Assistant Executive Director
March 03, 2009

For over 28 years, Topeka Independent Living Resource Center has worked in support of our mission to advocate for justice, equality and essential services for a fully integrated and accessible society for all people with disabilities. Throughout these 28 years, we have worked with people of all ages, with all types, natures, and severities of disabilities as we have offered support and resources for people who want to live, work and play in our communities. We appreciate the opportunity to present these comments on HB 2094 and associated efforts to create long term services and supports systems that support individuals in Kansas.

Our work and our mission are supported by the vision of the Americans with Disabilities Act and the Kansas Act against Discrimination and their recognition of and redress for the historical segregation and isolation from society experienced by people with disabilities. In their *Olmstead* decision, the United States Supreme Court deemed one of the most fundamental forms of isolation and segregation, the placement of people with disabilities in institutions instead of communities, to be discrimination prohibited by federal law.

Olmstead, the Americans with Disabilities Act, and our mission do not apply to some people and not to others. A person should not have less choice or less access because of her diagnosis, label or cause of disability. A person should not have to accept unwanted services or languish on a waiting list for essential services because of his type of disability. Our mission-based work promotes a fully integrated and accessible society for **all** people with disabilities.

We believe a system that maintains a waiting list for some people and some types of services is patently unjust. We believe a system that denies essential services based on how a person came to have a specific disability condition is patently unjust. We believe a system that unequally reimburses for similar services is patently unjust.

We also believe that, given the availability and support for systems change and critical analysis of service delivery systems, our state has an amazing opportunity to evaluate community capacity and long term care services in a meaningful way. We would encourage this Committee to use the ideas from HB 2094 to further analyze the status of our communities to meet all members' needs, not necessarily through funding more of the same services, but through creatively addressing the support needs of individuals in our communities. Creating parity in reimbursement may redress inequities among providers, but will not necessarily result in equality of service or development of essential services needed to support all people in our communities.

Thank you again for the opportunity to engage in a dialogue about the importance of building inclusive, integrated communities and service systems to support the freedom and independence of all people.

Advocacy and services provided by and for people wit

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Kansas Association of
KACIL
Centers for Independent Living

Jennifer Schwartz
Executive Director

Member Agencies:

Center for Independent Living for Southwest Kansas
Garden City, KS
620/276-1900 Voice

Coalition for Independence
Kansas City, KS
913/321-5140 Voice/TT

Independent Living Resource Center
Wichita, KS
316/942-6300 Voice/TT

Independence, Inc.
Lawrence, KS
785/841-0333 Voice
785/841-1046 TT

Independent Connection/ OCCK
Salina, KS
785/827-9383 Voice/TT

LINK, Inc.
Hays, KS
785/625-6942 Voice/TT

Prairie Independent Living Resource Center
Hutchinson, KS
620/663-3989 Voice

Resource Center for Independent Living, Inc.
Osage City, KS
785/528-3105 Voice

Southeast Kansas Independent Living, Inc.
Parsons, KS
620/421-5502 Voice
620/421-6551 TT

The Whole Person, Inc.
Kansas City, MO
816/561-0304 Voice
816/627-2201 TT

Three Rivers ILC
Wamego, KS
785/456-9915 Voice

House Aging and Long Term Care Committee
Representative Bob Bethell, Chair
Testimony on HB 2094
March 3, 2009

Thank you for the opportunity to submit testimony regarding HB 2094. I am Jennifer Schwartz, the Executive Director of the Kansas Association of Centers for Independent Living (KACIL). KACIL represents Centers for Independent Living (CILs) across Kansas. KACIL provides a framework so those member CILs excel in advocacy and services ensuring that all Kansans with disabilities have opportunities for independent living and enjoy their civil and human rights.

Centers for Independent Living provide services to people with any disability, of all ages. CILs provide information and assistance to businesses and other entities in the community to increase opportunities for people with disabilities to live, work and participate in all aspects of community life.

KACIL has spent many years working with legislators and state agencies to promote independent living, consumer control and community based services for individuals with disabilities and Kansas seniors. Our members have been involved in the creation and writing of the HCBS waivers, and in the development of many laws, policies and regulations in the state of Kansas.

HB 2094 provides a three year commitment to HCBS waivers in Kansas, and eliminates waiting lists. KACIL believes a commitment to community based services in Kansas is essential. We are very supportive of efforts to give people with disabilities, no matter their age or type of disability the choice of receiving long-term care services in the community. By providing adequate funding to eliminate waiting lists and raising reimbursement rates, quality services in the community are possible.

KACIL believes that there are two areas of the bill that need further discussion

We believe that further discussion is necessary to assure that funding amounts are adequate. The funding amounts don't appear to be what is needed for each waiver to eliminate the waiting lists. These funding amounts need to be reviewed to ensure that there won't be waiting lists.

We believe that community capacity expansion needs to be further defined to assure consistency and understanding throughout the four waivers. KACIL

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believes in the values of the independent living movement which are independence, consumer choice and control and full integration into the community. We would ask that these terms be defined, and ensure that with all community capacity expansion we continue to work toward individuals with disabilities achieving independence, and steering all away from any dependency model. The benefits of community capacity expansion must be focused on the individual receiving services.

KACIL has advocated for many years for rate parity among the waiver reimbursement rates, the same rate paid for the same service provided and not based on the disability of the person receiving services, we would request that rate parity across disability services continue to be a priority in establishing rates paid for services. We would ask that when rates are addressed for direct care worker that it is addressed across all waiver groups.

We would continue to challenge Kansas to move forward in balancing our long term care system of supports and services. Opportunities like HB 2094 show that Kansas Legislature is interested in making long term commitments to community based services, but we also need to ensure that the legislation provides adequate funding to the waivers which support the individual services that people with disabilities and Kansas Seniors need to achieve independence in their communities.

Thank you for your time.

TARC
Service. Support. Advocacy.

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Topeka KS 66611
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(785) 232 3770 Fax
www.tarcinc.org

March 3, 2009

TO: Members of the House Aging and Long Term Care Committee

FM: Jeanette Shwe, Direct Service Professional
TARC, Inc., Topeka, Kansas

RE: Support for HB 2094

Chairman Bethel and members of the committee, thank you for the opportunity to speak with you today.

I am Jeanette Shwe, a Direct Support Professional at TARC here in Topeka. This year TARC is celebrating 55 years of providing quality services and supports to persons with developmental disabilities in our community and I am proud to be a part of its long and successful history.

I started my association with TARC as a volunteer. I was so impressed with the organization, the staff and most importantly the wonderful persons they supported that I applied for a position and was hired.

I am honored to be one of the first nationally registered direct support professionals in the State of Kansas, and I am currently going through the process to become one of the first nationally certified direct support professionals in the nation. I have had the opportunity to further my education with the College of Direct Support. The curriculum has taught me new ways to best address and meet the needs of the people I serve. I am pleased to have the opportunity to learn new skills. I am now a true Direct Support Professional, Not a gatekeeper! I am not the expert, the person that I have been hired to support is the expert on their own needs. I've learned to listen.

My job at TARC is ever changing as the needs of the people that I serve change on almost a daily basis. I am highly trained in the medical field as well as specially trained in Alzheimer and Dementia. I am required to be certified in CPR, First Aid and the Mandt® System. I complete annual training on Abuse, Neglect, Exploitation and Human Rights. I must maintain a current CDL.

My daily tasks include, but are not limited to: lifting and transferring the people I support; administering medications; de-escalating crisis situations; providing conflict resolution; educating; driving; and planning opportunities for community access. I must thoroughly document falls, seizures, injuries, improper clothing, challenging behavior, nutrition and just about anything else that affects the people we support. All the while I must promote an atmosphere of dignity and respect for all.

We support artists, authors, singers, cooks and so many remarkable, talented people through TARC Senior Services that I can't possibly tell you of the wonderful things that I have witnessed on a daily basis with the time I've been

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allowed. What I would like to say is that there are more than 3,800 people out there who have not had the opportunities that the 30 people I support have had because they are still on a waiting list for services. I wonder how many more authors, artists, singers and cooks are out there just waiting for that call to tell them that the funding has finally come through and that they can now choose the services that best meet their needs.

While I am fully committed to TARC and plan to work there until I can't work any longer, I've seen a horrible turnover in staff. In the past 4 years, in my small division within TARC we have had 16 well trained and devoted people leave and look for higher paying jobs. TARC's starting wage is $8.71 per hour. KNI is just 50 yards away and my counterparts that work for the State start at $12.05 per hour. As soon as a new employee hears this they leave. For those of us who decide to stay, we are forced to take 2nd and even 3rd jobs in order to make ends meet. We need equal pay for equal work.

I would like to thank you for giving me the chance to be heard. I know that you all have some very tough decisions to make and I wouldn't want to be in your shoes. I know that everybody is always asking for their piece of the pie – for the 3,800 plus on that waiting list all I'm asking for is a plate to put it on. Please vote in support of HB 2094.

Respectfully,
Jeanette Shwe
Direct Support Professional
TARC

MAKE A Difference

TESTIMONY BEFORE THE HOUSE AGING & LONG-TERM CARE COMMITTEE
March 5, 2009 - HB 2094

Mr. Chairman and members of the Committee, thank you for the opportunity to testify before you today. My name is Doug Bowman, and I am here as staff of the Interagency Coordination Council for Early Childhood Developmental Services. We are an advisory group based in both state and federal law, whose members are appointed by the Governor.

The Council would like to affirm its support of HB 2094. Specifically, I would like to address funding for Infant-Toddler Services (also known as Part C of IDEA) or *tiny-k*. The 36 local *tiny-k* networks identify children under the age of three with developmental delays or disabilities, create an individualized family service plan, and then implement it. Family members are an integral part of every team that determines who is eligible, what services are needed, where these interventions will be provided, and by whom.

There are no waiting lists. Federal law requires that every eligible child aged birth to three years be identified. Further, the law requires that all those supports and services deemed necessary by the team then be provided

The tiny-k system has historically been and continues to be under funded. Our local service programs continually need to pursue various funding sources to provide these vital early intervention services. These other funding streams are drying up in our current economy. This consumes time and energy that could more productively be used to serve children and families.

Years and years of insufficient funding cannot be made up in one year's time. But we more importantly risk losing local partners, because they are tired of subsidizing these vital services to our young families.

Through the work of these early intervention programs Kansas families are better supported and children are ultimately better prepared for entry into school and success in life. One in four children served by *tiny-k* needs no further special education services at age 3. We ask that you consider and provide funding to support our early intervention services to these vulnerable families. These investments would be paid back several times over.

Similar services provided by local school districts to many of these very same children after their third birthday are supported by state funding of one-half of the Base State Aid. Historically, we use this as our target for what we believe would be an adequate state appropriation. Take this amount times the number of children being served (up again this year to 3,425), and the result would be a state appropriation of $7.5 Million.

Thank you again, for your past support of this vitally important program.
I would be happy to stand for questions.

Coordinating Council on Early Chilhood Developmental Services
Curtis State Office Building, 1000 SW Jackson, Suite 220, Topek
TDD/TTY: (800) 332-6262 (796) 296-1294 E-Mail: dbowman@kdhe.st
Website: www.Kansasicc.org

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AID TO LOCAL tiny-k NETWORKS

Year	state/federal funds	total funds	Dec. 1st	PER CHILD Funding		
			# of children	State $	Fed $	Combined
FY 99	1,992,000 (SGF) 2,167,609 (fed)	4,159,609	1,649	1,208	1,314	2,522
FY 00	2,492,000 (SGF + CIF) 2,764,859 (fed)	5,256,859	1,884	1,322	1,468	2,790
FY 01	2,492,000 (SGF + CIF) 3,042,831 (fed)	5,534,831	2,187	1,139	1,391	2,530
FY 02	2,492,000 (SGF + CIF) 3,414,224 (fed)	5,906,224	2,485	1,003	1,374	2,377
FY 03	2,371,305 (SGF + CIF) 3,499,633 (fed)	5,870,938	2,738	866	1,278	2,144
FY 04	2,792,000 (SGF + CIF) 3,199,639 (fed)	5,991,639	2,828	987	1,131	2,118
FY 05	2,871,305 (SGF + CIF) 3,113,206 (fed)	5,984,511	2,749	1,045	1,132	2,177
FY 06	2,871,305 (SGF + CIF) 3,113,207 (fed)	5,984,512	2,947	974	1,056	2,030
FY 07	4,721,305 (SGF + CIF) 3,113,208 (fed)	7,834,513	2,985	1,582	1,043	2,625
FY 08	4,721,305 (SGF + CIF) 3,113,208 (fed)	7,834,513	3,117	1,515	999	2,514
FY 09	5,721,305 (CIF) 3,113,208 (fed)	8,834,514	3,210	1,782	970	2,753

FY 2009 Base State Aid was reduced to $4,400 divided by 2 - and taken times the 3,425 children = $7.5 M

March 5, 2009

TO: Representative Bob Bethell, Chair and members of the House Aging and Long Term Care Committee

Dave Herl Board President
FR: ~~Jerry Michaud~~, ~~President~~, Developmental Services of Northwest Kansas (DSNWK)

RE: HB 2094

Chairman Bethell and members of the Committee, thank you for the opportunity to share some thoughts on the state of the community developmental disability service system and the importance of HB 2094. DSNWK's service area covers the eighteen northwest counties of Kansas, a largely rural area covering more than 17,000 square miles. I am honored to have this opportunity to be one of the voices of the community Developmental Disability (DD) services system in Kansas and to speak to the urgent needs. DSNWK, for 42 years, has been providing community services and we are among many provider organizations across this State which have a long standing commitment to serving persons with developmental disabilities in their communities.

DSNWK emerged out of the grassroots effort of families who desired more for their sons and daughters. It was through this type of effort, in cooperation with the effort of other visionary leaders who recognized the inherent value of people with disabilities living in their communities, that our community system emerged. DSNWK has remained committed to its mission and has carried on this good work started by those early pioneers. In the 1980's, DSNWK was instrumental in assisting the State in the closure of Norton State Hospital. For families at the institution, a promise was made, by the State and its Community Partners. At DSNWK, our mission is to keep that promise. DSNWK today currently serves over 500 individuals throughout Northwest Kansas and employs nearly 500 staff members. DSNWK continues its work with each of the eighteen counties and every county contributes to the costs of services provided, totaling $890,000 annually. When state and federal funding levels are insufficient, our county commissions feel this burden-shift.

I am here this afternoon to share with you the challenges we have faced and report that our community service system, with all its strengths, continues to erode and is more weakened today than ever before. Negative economic implications and community market place costs have out-paced the funding levels provided to carry-on those needed services.

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Services in Northwest Kansas at DSNWK - Erosion:

Providers across the state, like DSNWK, continue to struggle with the level of funding received particularly when the challenges of attracting and retaining the workforce has become increasingly more difficult in the marketplace. The costs of carrying out services have also continued to rise. In each of our families, we have felt the pinch, and at DSNWK, with the 2% rate increase appropriated last session, these new dollars failed to cover the raising cost of our health insurance alone ($150,000 - revenue compared to $200,000 - expense). Health insurance for our staff and their families is an essential benefit with strong ties to retention, and a vitally important safety net for them and their families. Considering these two elements, a $50,000 deficit existed before any wage adjustment efforts were considered in our budgeting process. In implementing a limited wage increase for our direct support staff, as well as adjusting for the increased costs for fuel, food, etc., we knew we were approximately $377,000 in the red. Typical businesses increase the price on their goods and services to adjust for such cost changes. For organizations serving people with disabilities in the community, like DSNWK, this is not possible, as we are subject to the rates identified and paid through our contract with the State. The legislature, based on appropriation, sets this price, which determines the rates we receive. If the bill is not covered, providers are left with empty pockets and left-over expenses which are not paid. Being fiscally responsible facing this increasingly strained budget, the evaluation of our service locations commenced as elimination and consolidation of services as the only remaining option. Prior to the end of December 2008, DSNWK downsized and consolidated services, eliminated other services and closed its Wheatland Development Center in Colby. Many of these changes were effective in October 2008, and still others have been made since that time. The items noted below are the summary points of those changes made.

- Closure of Wheatland Developmental Center - Colby; 10 years in operation -- developed to meet a need locally in Thomas County: Service options are now only available with a commute to Atwood, 30 miles away. Increased transportation costs for persons/families -- least able to afford such a change.
- Downsizing services in Oakley: Physical plant reduced 2/3 and consolidation of management oversight;
- Closure of Ceramic shop in Atwood (employment opportunity) and staff reductions; Result is fewer local employment opportunities.
- Eliminated our Customer Connection Service and other administrative office staff positions.
- Vacated positions via retirement/attrition are not being filled. Consolidation of positions which equals less people doing more work at an inadequate wage. Approximately 20 positions have been eliminated (9 - Hays; 3 - Colby; 4 - Oakley; 2.5 - Atwood; 1 - Russell; 1 - Hill City)

A news release and recent news articles from the Hays Daily News tell the story of the

changes and challenges.
At the end of December, DSNWK was issued another financial blow when its Worker's Compensation insurance premium unexpectedly increased by $200,000. Providing direct supports often times involves lifting, transferring and/or physical interventions (to protect persons from harm during challenging behaviors); employees can and do get injured on the job. We experienced an increase in injuries during the last calendar year and this in turn created the higher insurance premiums. Such increases, with static funding, result in unbearable strain on organizations and the people associated with it.

Requirements and Minimum Wage:

In July of this year, the federal minimum wage law takes its final of three steps, ending at $7.25 per/hour. In 2006, DSNWK was maintaining a margin over minimum wage by about $1.85 per hour for our direct support staff. We have been unable to adjust our base wage to keep this margin and subsequently, our base wage, without adjustment, will be just meeting the minimum wage law's requirements. This important and skilled work is not minimum wage work, nor should it remain such. Perhaps a clearer illustration of this is seen in the established starting wage by the state for its own direct support workers, $12.35 per/hour.

Legislative Leadership and Action can be delayed no longer:

Facing the challenges head on, most notably over these past six months, DSNWK has managed our rising costs through the eliminating of locations and positions. Doing so has been necessary to remain fiscally responsible, but it carries with it a compounding problem. Making such changes results in a reduction of an already overstretched staff and then shifting their workload onto the shoulders of the remaining staff. Community Service Providers encounter challenges in retaining good staff when competing wages in the community far surpass our reach under the current level of funding. Starting wages for fast food workers and for telephone support people are two such examples in the Hays area. Important as these jobs might be, they pale in comparison to the skill set and commitment needed to support persons with Developmental Disabilities in the community, yet the pay for community employees remains far short. Doing more, for less.

During this year, we provided wage increases to all our staff with the exception of our top management positions and myself, whose wages were frozen.

Are persons with disabilities and their community services invisible? The recent removal of proposed cuts to disability services in Kansas were halted in the rescission bill for FY 2009. This appeared to be the acknowledgment that community services can sustain no further damage. This was accomplished by the gracious efforts made by the House. In contract, on Friday, February 27, 2009, I received a notice that funding for this fiscal year, 2009, may be reduced in our fourth quarter payment, by nearly $40,000.

This reminds me of the biblical story of the good samaritan, only with a different ending.

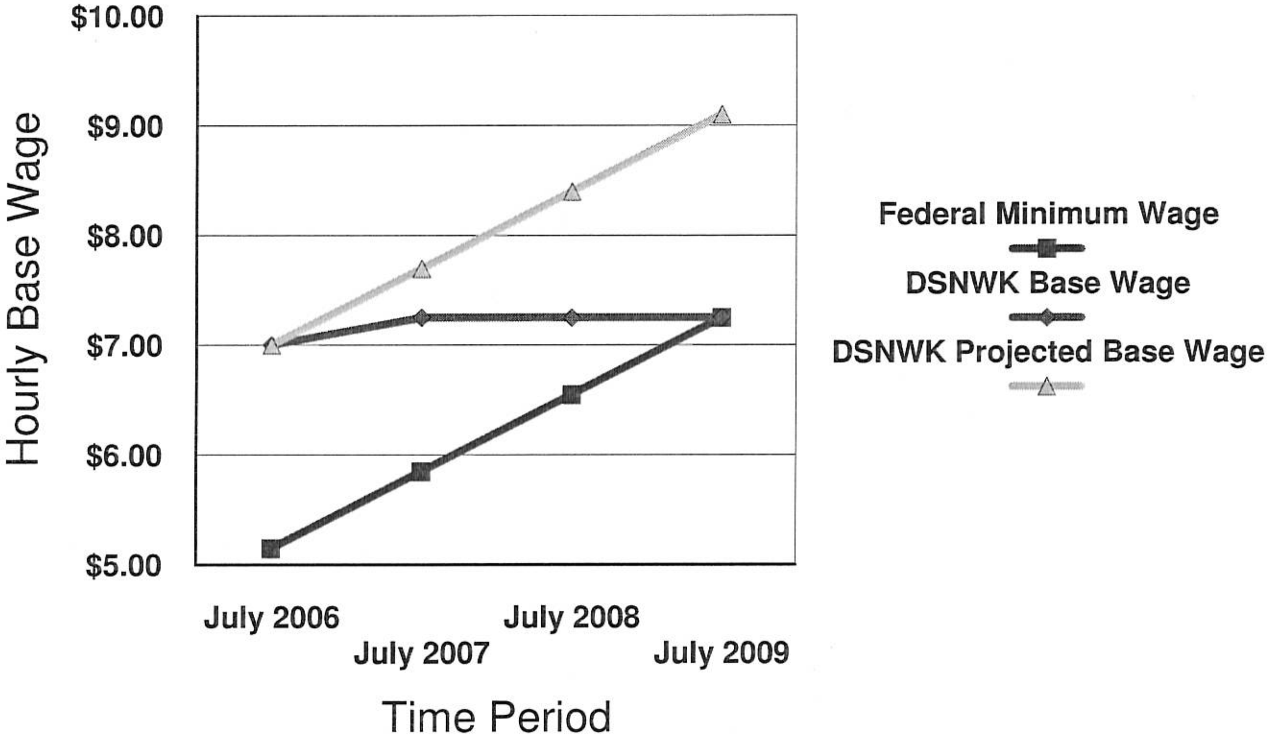
For the man who was left to die on the side of the road, many walked by ignoring or treating him as if he was invisible. In this case, it feels as if community services are that disabled and injured person, and instead of helping him, he just received another harmful blow.

Support passage of HB 2094

The damage that has been occurring in the community service system as a result of the funding shortfalls is real. Our network of community services and opportunities was created as a policy of our State, by the Kansas legislature, to finally address the needs of forgotten Kansans with developmental disabilities. This investment is at risk, and if the risk is not addressed, the ultimate victims will be our most vulnerable neighbors and their families. We as a state can no longer look past persons with disabilities as if they are invisible. In December of 2006, the Legislative Budget Committee recommended, for the first time, a long-term plan for addressing the issue in the Community Service System. It is now 2009, and those recommendations have gone without resolve. Our County Commissions are resolute in calling for action. The issues we face today are not the result of the current economic circumstances our Nation and State face; they are only exacerbated by them. This priority for Kansas can no longer be ignored. We urge the passage of HB 2094, with full funding, as a top priority. The federal stimulus plan provides the needed resources to pay for the implementation of HB 2094, a Bill to pay-the-bill which has been delinquent far too long.

DSNWK Hourly Wage Comparison

July 2006 to July 2009



DSNWK's base wage as of July 2006 was $1.85 per hour above minimum wage. As of July 2009, DSNWK's hourly base wage is projected to be exactly the same as minimum wage. In order to maintain the $1.85 hourly wage span, DSNWK's base wage as of July 2009 would need to be $9.10 per hour.

Time Period	Fed Min Wage	DSNWK Base Wage	Variance
July 2006	$5.15	$7.00	$1.85
July 2007	$5.85	$7.25	$1.40
July 2008	$6.55	$7.25	$0.70
July 2009	$7.25	$7.25	$0.00
Total Increase	$2.10	$0.25	($1.85)

County Commissions of the Eighteen Northwest Kansas

Resolution - February 9, 2009

WHEREAS: The County Commissions of the Eighteen Northwest Kansas (County Commissions) represents the interests of each of our respective county and our citizens including those with developmental disabilities and their families, and;

WHEREAS: It is the County Commissions that have the responsibility to manage the functions of County government, including budget management and specifically to collaborate with Developmental Services of Northwest Kansas, Inc. with regard to the provision of services for individuals in Northwest Kansas with Developmental Disabilities (ref. KSA 19 - 4004 et seq.), and;

WHEREAS: The County Commissions acknowledge that the Developmental Disability Reform Act in Kansas (Chapter 39, Article 18) calls for the Secretary of SRS for Kansas, in part, to establish "a system of adequate and reasonable funding or reimbursement for the delivery of community services", and;

WHEREAS: The County Commissions acknowledge that the Legislative Budget Committee in the fall of 2006 made recommendations to the Legislature for a multi-year funding plan to significantly increase the level of funding for community based services for persons with disabilities and thereby address community capacity concerns (rate increases for providers of services to attract and retain workforce) and eliminate the waiting list for persons with developmental disabilities, and;

WHEREAS: In the 2008 Legislative Session, House Substitute for Senate Bill 365, which encompassed House Bill 2761 - a bill built upon the recommendations of the Legislative Budget Committee from the fall of 2006 called for a multi-year funding approach to bolster the wages of community service provider employees and the elimination of the waiting list, was drafted with the intent to address the issues enumerated above, and

WHEREAS: In the 2008 Legislative Session, the failure of Legislature to pass the above referenced multi-year funded version of House Substitute for SB 365 out of the 2008 Kansas legislative session, has significantly impaired the ability of DSNWK and other similar providers to carry out their purpose and mission and ensure the integrity of community services to individuals with disabilities, and;

WHEREAS: The failure to adequately fund services according to the DDRA, shifts the cost burden of supports to the County level, and;

WHEREAS: It is the conviction of the County Commissions that the State of Kansas and its citizens have a vested interest in the success community based services embodied in the mission of DSNWK and its counterparts in other parts of the state, and;

WHEREAS: The success of community services depends on the ability of community service providers like DSNWK to attract and retain qualified employees, and;

WHEREAS: Employee recruitment and retention has been significantly hampered in recent years due to funding shortfalls related directly to inadequate state reimbursement rates, and;

WHEREAS: In the 2009 Legislative Session, House Bill 2094, a multi-year funding bill similar to those previous bills built upon the recommendations of the Legislative Budget Committee from the fall of 2006 to bolster the wages of community service provider employees and the elimination of the waiting list, has been introduced in the House along with its sister bill in the Senate, and;

THEREFORE BE IT RESOLVED: That the County Commissions do hereby express the urgency of this matter and request the Kansas Legislature to adequately fund community developmental disability services and implores the members of the Kansas Senate and House of Representatives, particularly those members who represent the districts in Northwest Kansas, to address fully and unequivocally, the funding shortfalls currently being experienced through the passage of HB 2094 and Sister bill in the Senate.

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Commissioner, Chair

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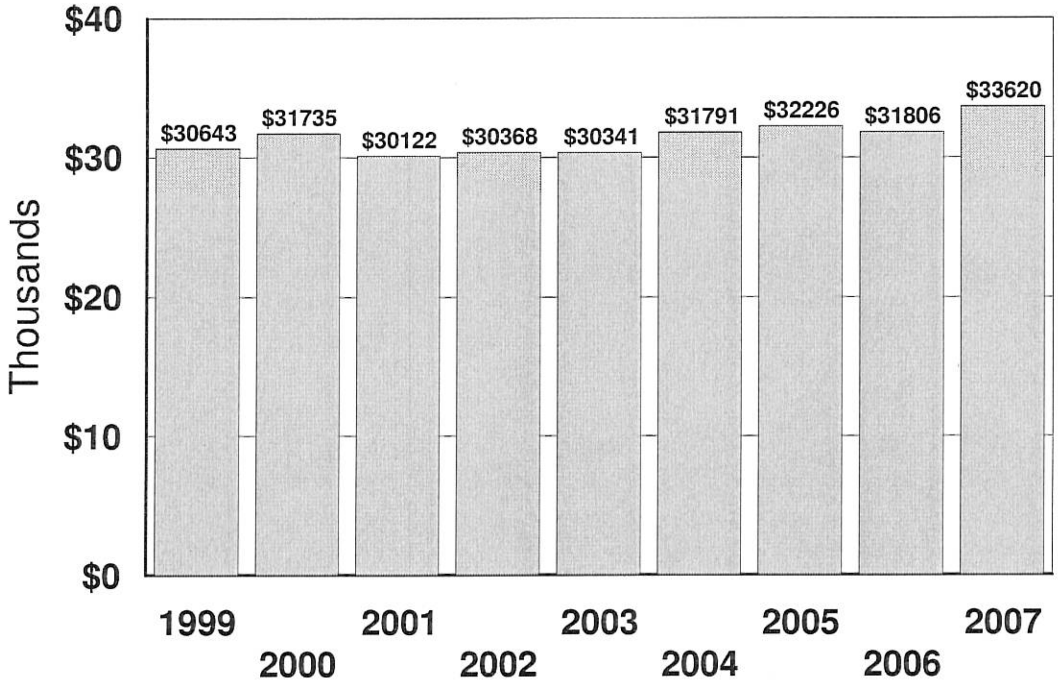
Commissioners

____
Commissioners

HCBS/DD Waiver Annual Funding Per Person
FY 1999 to FY 2007



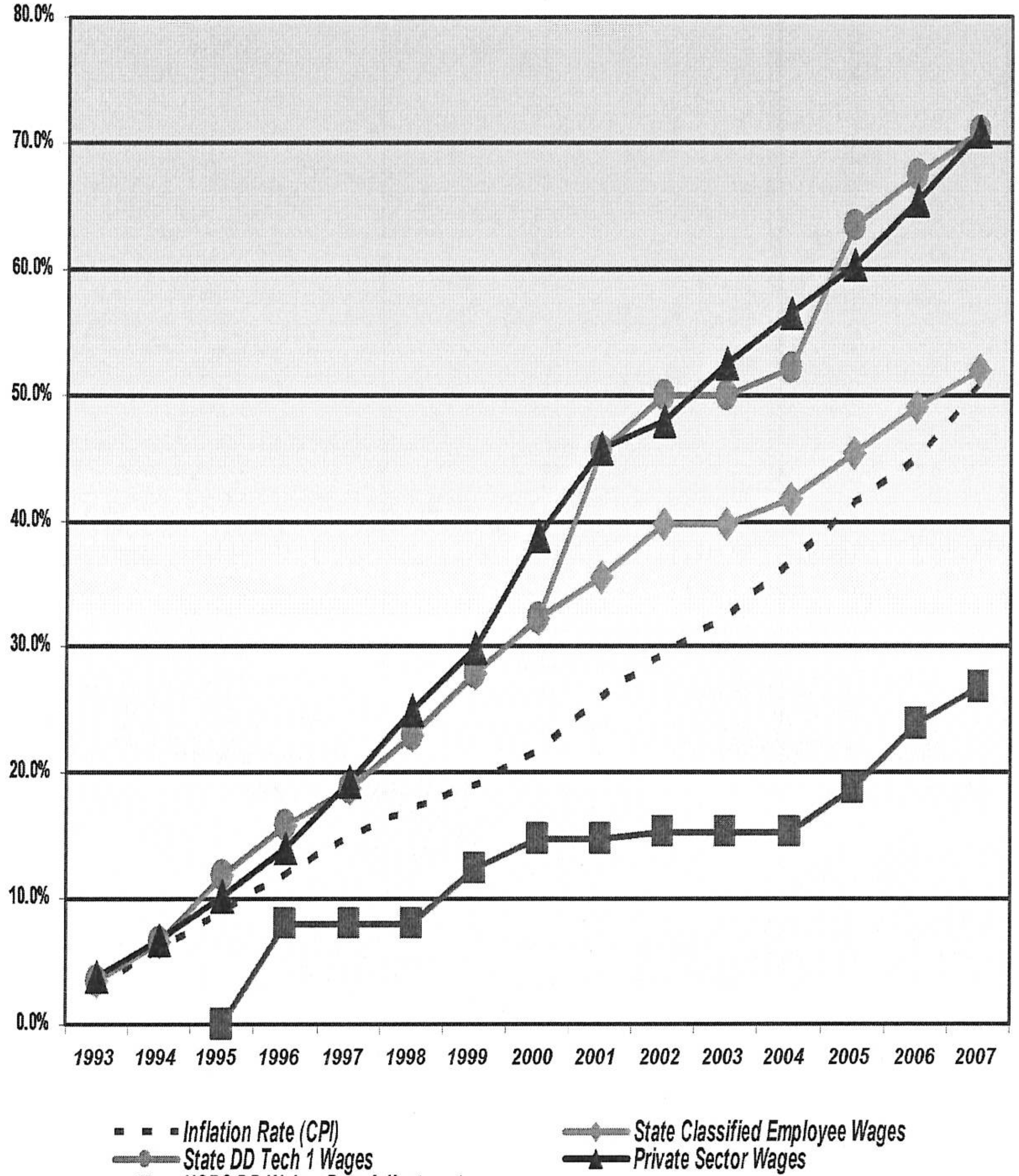
Fiscal Year	HCBS/DD Waiver Funds *	Percent of Increase in Waiver Funds from FY 1999	Number of HCBS/DD Funded Individuals **	Percent of Increase in Individuals from FY 1999	Avg Annual HCBS/DD Funding Per Individual	Percent of Increase in Per Person Waiver Funds from FY 1999	Percent of Increase in Per Person Waiver Funds Annually
1999	$156,893,188	---	5120	---	$30,643	---	---
2000	$170,350,998	8.6%	5368	4.8%	$31,735	3.6%	3.6%
2001	$175,759,758	12.0%	5835	14.0%	$30,122	-1.7%	-5.1%
2002	$189,467,567	20.8%	6239	21.9%	$30,368	-0.9%	0.8%
2003	$194,605,709	24.0%	6414	25.3%	$30,341	-1.0%	-0.1%
2004	$204,954,171	30.6%	6447	25.9%	$31,791	3.7%	4.8%
2005	$217,398,123	38.6%	6746	31.8%	$32,226	5.2%	1.4%
2006	$221,149,613	41.0%	6953	35.8%	$31,806	3.8%	-1.3%
2007	$248,145,859	58.2%	7381	44.2%	$33,620	9.7%	5.7%
2008	$274,809,894	75.2%	This information is unavailable at this time				

* HCBS/DD Waiver Funds information taken from a Home and Community Based Service Waivers (HCBS) FY 1999 to FY 2009 Legislative Approved report by the Kansas Legislative Research Department dated December 16, 2008.

** Number of HCBS/DD Funded Individuals (1999 - 2003) taken from the report titled Persons Served 1988 to Present - Community Based in the SRS Strategic Plan 2005 - 2010. The number of HCBS/DD Funded Individuals (2004 - 2007) taken from 372 Reports which are submitted annually by CSS/DBHS to CMS. The number for 2008 cannot be confirmed until the end of 2009 when the 372 Report is due.

HCBS MR/DD WAIVER RATE ADJUSTMENTS

Since 1993:



Information derived from "Increases in Salaries for State Classified Employees, Regents' Faculty and Classroom Teachers of School Districts, in Private Sector Wages, and in the Rate of Inflation" created by the KS Legislative Research Dept., October 2002 as well as from "Expenditures From All Funds and State General Fund" by Kansas Legislative Research Dept., October 2002. FY04 –FY07 CPI figures and private sector wage figures obtained from the Bureau of Labor Statistics. Additional figures derived from SRS legislative testimony.

Kansas Council on
Developmental Disabilities

KATHLEEN SEBELIUS, Governor
SCOTT SHEPHERD, Chairperson
JANE RHYS, Ph. D., Executive Director
jrhys@alltel.net

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"To ensure the opportunity to make choices regarding participation in society and quality of life for individuals with developmental disabilities"

HOUSE COMMITTEE ON AGING AND LONG TERM CARE

March 5, 2009

Testimony in Regard to House Bill 2094, an Act making and concerning appropriations for the fiscal years ending June 30, 2010, June 30, 2011, June 30, 2012, June 30, 2013 and June 30, 2014 for the department on aging, the Department on Social and Rehabilitation Services, and the Department on Health and Environment – Division of Health.

Mr. Chairman, Members of the Committee, I am providing this testimony on behalf of the Kansas Council on Developmental Disabilities regarding the proposed appropriations for the Kansas Developmental Disabilities Waiver.

The Kansas Council is federally mandated and funded under the Developmental Disabilities Assistance and Bill of Rights Act of 2000. Members are appointed by the Governor and include primary consumers, immediate family, and representatives of the major agencies who provide services for individuals with developmental disabilities. Our mission is to advocate for individuals with developmental disabilities to receive adequate supports to make choices about where they live, work, and learn. As a member of the Big Tent Coalition we support the 2009 Priorities developed by the Big Tent.

A Developmental Disability occurs before age 22, is lifelong, and results in major substantial functional limitation in three or more areas of major life activity such as self-care, mobility, and economic self-sufficiency. These disabilities require lifelong supports, they are not curable nor do persons get better as they get older.

We have discussed this bill and the great need for funding of services for persons with Developmental Disabilities with many legislators. Attached is a salmon colored page that shows the number of persons served on the DD Waiver from 2006 – 2009 and the number on the DD Waiting Lists, both as of the end of January for each year. Also shown is the funding appropriated for each year. As of January of this year, there were 1,574 adults and families with children waiting for services. Ten years ago, in 1999,

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there were 307 adults and families with children waiting for services *(Developmental Disabilities Summary for the Month of January, 1999).* This is an increase of 1,267 persons or 80.5 per cent. In 1999 we served 5,119 on the Home and Community Based Services Waiver for Developmental Disabilities. In January of this year we served 7,433 for an increase of 2,314 or 31.3 per cent. To quote a good friend, "That is not right!" We have persons with Developmental Disabilities and families with children who have Developmental Disabilities who have been waiting for several years.

We firmly believe that money to fund H.B. 2094 could come from the federal Medicaid Stimulus dollars. That is the intent of these funds and we hope you will fulfill Congress' intent. Some of your colleagues have asked what will happen when these funds are gone? I do not have a crystal ball but I do have a proposal. Close one or both state Developmental Disabilities hospitals. All of the savings realized from closure must be used for DD community services. A second buff colored sheet shows Kansas DD state hospital costs proposed for 2010. The yearly average cost per client is $151,292.50 as compared to the $39,117 yearly cost for a person in the community. In addition, we have a federal Money Follows The Person grant that can be used to assist persons in transitioning to the community. If we begin closure now, the funds realized by closure should be available for use in the community in two years when the stimulus funds are gone. Other states are closing not one but several state DD hospitals - Massachusetts is closing **four**.

We know how to do closure, a study of the mid 1990's closure of Winfield State Hospital proves it. We can serve persons with serious medical needs and those with severe behavior problems in the community – we do it every day. This is a win-win solution to a serious problem that the DD community has faced for many years. We urge you to consider this as you review H.B. 2094 and that you pass this much needed bill.

I appreciate your time and patience and would be happy to answer any questions.

Jane Rhys, Ph.D., Executive Director
Kansas Council on Developmental Disabilities
Docking State Office Building, Room 141
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Topeka, KS 66612-1570
785 296-2608 jrhys@alltel.net

Kansas Developmental Disabilities Information

Persons With DD Served From SFY 2006 – 2009

Year	2006	2007	2008	2009	Average
No. Served - DD Waiver	6766	7004	7410	7433	7153
Per Cent Increase		2.47	5.8	.31	2.86
Waiting List Unserved	1288	1414	1389	1574	
Per Cent Increase		9.78	(1.77)	13.32	7.11

Costs

Year	2006	2007	2008	2009
All Funds	221,150,000	248,146,000	289,855,000	285,149,000
SGF	88,460,000	99,258,400	115,942,000	114,059,600
Medicaid	132,690,000	148,887,600	173,913,000	171,089,400

Estimate needed to eliminate Unserved Waiting List = **$61,567,403** All Funds (1,574 * $39,117)
SGY = **$24,629,961** (40% of the total)
Federal Funds = **$36,940,442** (60% of the total)

Current Waiting List = 1,574
Average Per Person = $39,117 ($289,855/7410 using 2008 data before cuts)

Direct Care Worker Salaries

Persons employed as Direct Care Workers in community based Developmental Disabilities (DD) settings have an average beginning hourly salary of **$8.83**. Those same workers would make and hourly beginning salary of **$12.35** at either DD State Hospitals, a difference of **$3.52.** This does not include Direct Care Workers whose salaries have been increased due to longevity, differences in community pay between providers and locations, benefits, etc.

Determining the exact amount of funding needed to bring Community Direct Care Workers salary to the same level is difficult because the number of community workers is not known due to fluctuation. However, H.B. 2094 would put additional funds for community capacity expansion as follows:

- $15,000,000 in the SGY 2010
- $10,000,000 in SFY 2011
- $10,000,000 for SFY 2012, and
- $10,000,000 for SFY 2013

TOTAL **$45,000,000**

The total of $45,000,000 over 4 years would significantly improve Direct Care Workers salaries. Not taken into consideration are fringe benefits (i.e. KPERS, health care, etc. Also not considered would be any possible state salary increases over the same time period. Because exact figures are not available, we believe that the above is a best estimate of funds needed to put community services at a competitive level with the state DD hospitals.

Developmental Disability Hospitals

For FY 2009, the estimated average daily census in the two state developmental disability hospitals will be 358. To serve these residents, the Governor recommends $53.2 million for the developmental disability hospitals. Shown below are the recommended operating expenditures, average daily census, and daily cost per client for each hospital in FY 2010. Operating expenditures are funded mainly from the State General Fund, fee funds, and federal Medicaid Title XIX funds. Additional federal funding is available for community programs.

Kansas Neurological Institute

For FY 2010, the Governor recommends $28.4 million for the Kansas Neurological Institute, of which $11.4 million is from the State General Fund. The amount recommended will support a staff of 570.20 FTE positions who will care for an average daily population of 160 residents at the Institute.

Parsons State Hospital & Training Center

The Governor's recommendation for Parsons State Hospital and Training Center totals $24.8 million and includes $10.4 million from the State General Fund for FY 2010. The Governor's budget funds 497.20 FTE positions. This level of funding will allow the Hospital to provide residential and medical services to an average population of 198.

Developmental Disabilities Hospitals

	Daily Census	Operating Budget	Daily $ per client	Yearly Cost per client
KNI	160	$28,379,109	486	$177,390
Parsons	198	$24,794,984	343	$125,195
Total	**358**	**$53,174,093**	**414.50 Av**	**$151,292.50 Av**

From *FY2010 GBR Volume 1*, page 88 (except for Yearly Costs at right)

40 YEARS
INTERHAB

WWW.INTERHAB.ORG

March 5, 2009

TO: Representative Bob Bethell, Chair, and

Members, House Committee on Aging and Long- Term Care

FR: Tom Laing, Executive Director

InterHab: The Resource Network for Kansans with Disabilities

RE: In support of "Invisible Kansans" legislation, House Bill 2094

Thank you for these hearings today, we have appreciated this chance to inform you about the urgent needs of Kansans with disabilities, and the funding plans needed to address our many unmet challenges.

This legislation is needed this year, to establish a funding plan that will reduce and eventually eliminate the waiting list and to maintain adequate and reasonable funding so that community service networks have the capacity to recruit and retain a quality workforce.

We have waited many years for a serious effort to make this long term commitment and strongly believe that, among the many important priorities of the State, this priority has languished too long and should be at the front of the line.

You have heard about the many issues we face in these hearings, and it is my goal today to highlight our needs in a way that may effectively summarize these hearings:

1. Persons served and their families face challenges most of us cannot imagine, even with assistance. Without assistance, their lives are often devastated. To tell these families, once again, to "wait until next year" would be a sad and cruel dismissal of their critical needs.

2. Your neighbors, working as direct care professionals in the community, are as worthy of your support as those who work in State institutions. We urge you to answer this: How do you explain budgets that provide a state worker a starting wage of almost $12..35 per hour when workers in your town average $8.78? Your budget decisions can eliminate this disparity.

3. Assistance into these programs will expand the communities' ability to provide job training and place more and more persons with disabilities into gainful employment. It should test the limits of your patience, as it does ours, to witness employment funding for persons with disabilities moving backwards this decade.

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4. <u>Legislators agree that early intervention is a favored activity for children, and yet ***tiny-k*** remains among the most underfunded programs in the disability arena</u>. This legislature must recognize how unfair it is to organizations that provide ***tiny-k*** services for infants and toddlers to have a Federal mandate, in which all eligible children must be served; but are funded each year as an afterthought, thereby pushing ***tiny-k*** organizations deeper into an ineffectiveness working with infants and toddlers who could make the greatest gains at this very important age.

5. <u>Remind your peers of the powerful impact of community services in your area –in terms of the families served, but also in economic terms for all of us</u> ... our organizations employ thousands of persons, and contribute hundreds of millions of dollars to your local economies. No program exceeds ours as a "good deal" for Kansas. Every dollar we spend brings an additional Federal boost to Kansas of $1.50 under the old law, and recent FMAP increases will bring in even more.

6. <u>Please stand up among your peers to fight for the principle that new FMAP funds should not be diverted to address other pet projects of programs.</u> Kansas families on the waiting lists and our underpaid community workers are counting on you to help in this regard.

Community service networks are an effective and efficient use of tax dollars. Persons with disabilities served are better served and remain connected to their families and communities, unlike the old institutional models that formerly were the State's only disability program offering. We save tax dollars, and help assure that taxes sent to Topeka are returned to every Kansas community. We help persons every day become less dependent, find work, and be active and productive in their communities.

We have met the assignments of government and in so doing have changed the world for the better for tens of thousands of Kansans and their families.

We ask you to reverse a decade of Statehouse indifference and say to your colleagues:

"Let's make a difference for Kansans with disabilities. They've been on our waiting list for too long already."

We have heard from a number of legislators that "We cannot address this bill this year" but we have heard from many more legislators who say "We wish we could help".

We have good news for you.

You <u>can</u> help address these issues <u>this</u> year, with a commitment to funding House Bill 2094.

<u>The need is clear, and the means are there with which to start. We urge passage of HB 2094.</u>

March 5, 2009

TO: Aging and Long-Term Care Committee
CHAIR: Representative Bob Bethell
FROM: Pattie Knauff, Vice President of Human Resources, KETCH
RE: Recruiting and Retention of Direct Care Staff from the Human Resources perspective

On behalf of the members of InterHab, thank you for allowing us this time today to testify.

I am the VP of HR at KETCH; I am not a social worker and I don't have a social work background. I have a degree in business, with emphasis in Human Resources. I am also an SPHR, or Senior Professional in Human Resources. I read the papers and listen to the news and I know that not everyone is sympathetic with maintaining or increasing funds for social services. Things are tough all over. But I'm here to tell you that for direct care workers, things have been tough for a long time and I would like to advocate for them.

There are many barriers before bringing one new employee in the door. The person must be **18 years of age**. They need to have a **stable work history**. We request their **KBI record**; they can't be on the **Abuse, Neglect or Exploitation registries.** They have to pass a **drug screen**, and they can have **no drug convictions** because they'll be handling other people's medications. They have to be in **fairly good physical condition** if they're lifting, positioning, or moving individuals who are in wheelchairs, or possibly physically restraining people. They have to have a **valid driver's license** and a **good driving record**, and they also have to **have a vehicle that they are willing to use** in the course of employment because they'll be driving our folks to the grocery store and on outings. By the way, they will need to provide **proof of insurance** on that vehicle. All this for wages starting somewhere between $7.50 and $9.75 per hour.

As I write this testimony, I can see that we have over forty openings in Community Living alone. Because so many of the staff members work in the home of the person served without a supervisor present, we need people who are **independent thinkers** and can **make good decisions in a crisis**. They need to be **honest** and **dependable**. They teach our clients how to **cook**, **clean**, **balance a checkbook**, **plan a menu** and go **grocery shopping**. Therefore, we need staff members who know how to do those things themselves. We have found ourselves in a position of offering classes such as Basic Meal Planning to our staff. In other words, the process of getting and keeping good employees doesn't stop once they're in the door.

We recently had an opening in our development department at our agency. We received over fifty applications for this one position. We were fortunate to hire

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one. **For direct care staff, one employment advertisement typically brings in thirty to forty applications, less if you advertise too often**. Of those, we would be lucky to hire five.

I am co-chair of the InterHab Human Resources network. This network brings together Human Resources staff from agencies like KETCH located all over the state. I can assure you we are all experiencing the same frustrations recruiting staff. **When there is an excess of qualified workers in an area willing to work for lower pay, an employer might be able to *lag* the market, or pay lower than the point where demand meets supply. At the point we are advertising on the back of bathroom doors, it's clear we don't have an adequate number of people willing to work for the wages offered.**

On the subject of turnover, labor economics tells us to look at our pay rates when we see an increase in the number of people leaving for "other employment." **This single cause of turnover – "other employment" has gone up more than five and six-fold over the last few years, and yet our staff count has less than doubled.** This trend continues into 2009.

Another increasing trend that I see in my position is the number of employees who have no concern about being terminated for cause (fired). January of '09 has already seen two, and one of those was a staff member who we learned spent over $400 buying gift cards for her friends at Christmas with client grocery money. This was discovered after complaints that there was no food in the house. In recent years I have terminated staff for coaching clients to say profanities, bringing a gun to work, and forgetting to unload two persons served before parking the KETCH vehicle for the morning. Another new reason for termination that was unheard of in the past is missing work due to being incarcerated. We are getting at least one of those a year now. **Being 'terminated for cause' is second only to 'other employment' as to why we have turnover, and the types of infractions are increasingly placing persons served at risk.**

I would also like to assure you that rate increases do benefit direct care staff, and ultimately persons served. KETCH was able to provide 3% merit raises in the last year and we have known years that this was not possible. In addition, as you know the cost of doing business increases each year. Our health insurance costs increased by 18%, and KETCH absorbed much of that increase. **We are doing as much as we can with the resources available.** Our resources will be further stretched as we are seeing staff whose spouses have been recently laid off come in to take out our health insurance. It's painful for them and it's painful for us. It makes it all the more important for them to receive a fair wage to help prop up their families, even though it won't make them whole.

According to my Personnel/Human Resources textbook, fifth edition, written by Robert L. Mathis and John H. Jackson, **"When people work, they expect to**

receive fair value (equity) for their labor. This perception of fair value is at the heart of equity theory and has a significant impact on the satisfaction and performance of employees. By exchanging their labor and talents for rewards, employees are induced to continue contributing to the organization." Thank you for your interest in our issues and for your time. We sincerely appreciate any effort you can make to improve this situation.

KANSAS
ACTION FOR
CHILDREN

Making a difference for Kansas children.

Kansas Action for Children Inc.
720 SW Jackson | Suite 201
Topeka, KS 66603

P 785-232-0550 | **F** 785-232-0699
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Celebrating 25 years
of child advocacy

Date: March 5, 2009
To: House Aging and Long Term Care Committee
From: Suzanne Wikle, Kansas Action for Children

Good afternoon Chairman Bethell and members of the committee. My name is Suzanne Wikle and I am the director of health policy at Kansas Action for Children. I stand before you today in support of the appropriations in HB 2094 to provide an additional 100 children with early intervention services through the Autism Waiver during FY 2010.

Early intervention is critical

Autism is a neurological disorder that becomes evident during early childhood. Evidence suggests that as many as 1 out of every 150 children have a form of autism, and the evidence is clear that a child who receives early intervention and treatment will fare better than a child that does not. The Autism Waiver is specifically designed to target children ages two through five because these are the years when intervention and treatment have the greatest impact. By the age of five, 85% of a child's brain is already developed, making early intervention essential for long-term success.

Long-term savings for Kansas

Providing early intervention creates long-term savings for the state through reduced special education funding. In fact, research demonstrates that 50% of children with autism that receive early intervention do not require special education services once they enter the public school system.

Increased federal resources

Kansas is currently faced with a unique opportunity to serve children through the Autism Waiver at a reduced cost to the state. The recent increase in our Medicaid matching rate means that the federal government will provide at least two thirds of the cost to serve additional children. Because the autism waiver is limited to children under age six, the children we are able to serve in FY 2010 with the enhanced federal match would otherwise "age out" from the waiting list and never receive these services.

In FY 2010, Kansas can reduce the waiting list for the Autism Waiver by combining enhanced federal dollars with $937,000 SGF to provide 100 additional children with services. Kansas Action for Children asks the committee to appropriate the funds needed to serve 100 additional children.

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Key facts about autism and the Autism Waiver

WHAT IS AUTISM?

Autism is a neurological disorder that becomes evident during infancy or early childhood. Autism is characterized by impaired social interaction, impaired communication skills, limited interests and repetitive behavior. National studies indicate that 1 in every 150 U.S. children have an autism spectrum disorder.

WHAT IS THE AUTISM WAIVER?

The Kansas Autism Waiver provides children who have been diagnosed with an autism spectrum disorder with access to early intervention services not already covered by their health care plan.

WHO IS ELIGIBLE FOR THE AUTISM WAIVER?

The Autism Waiver covers children from the age of diagnosis through age 5. After the age of 5, children access services through the school system and other waiver programs. Right now, the Kansas Autism Waiver is limited to 45 children. Another 200 children remain on a waiting list.

WHAT DOES THE WAIVER COVER?

The Autism Waiver covers clinical services, therapeutic services, intensive individual support, respite for families, parent support and parent training. Services not related to autism, such as preventive care, medical check-ups and immunizations, continue to be covered by the family's health care plan.

A Kansas success story

As we learn more about science and brain development, new opportunities arise that allow us to be innovative and effective in managing our state's future. The Kansas Legislature took the latest research into account when it created the Autism Waiver. The Waiver provides Kansas children with the early intervention services they need to keep some of the obstacles associated with autism from becoming more challenging and costly concerns for Kansas families, our schools and our state.

> *Research shows that 50% of children with autism will not require special education services if they receive intervention services before they enter Kindergarten.*

THE WAIVER IS WORKING IN KANSAS

Today, the Autism Waiver is a Kansas success story. The children being served by the Waiver are able to access quality intervention services in a timely manner. And, when it comes to autism, timeliness is critical. Scientists tell us that children diagnosed with autism have the best outcomes if they are diagnosed early and begin receiving services right away. Early intervention results in increased functional skills, improved communication skills, and fewer behavior problems.

EARLY INTERVENTION MEANS REDUCED COSTS FOR KANSAS SCHOOLS

When children with autism have access to early intervention, they benefit from better outcomes in school. With more children receiving early intervention, we stand to reduce the special education costs being absorbed by our school system. In fact, research shows that 50% of children with autism will not require special education services if they receive intervention before they enter Kindergarten.

EARLY INTERVENTION IS BOTH EFFECTIVE AND COST-EFFECTIVE

We can build upon the success of the Autism Waiver and take steps toward reducing our state's special education costs by allowing more Kansas children to access services through the Waiver. Expanding the Autism Waiver is both effective and cost-effective. The Waiver covers comprehensive services that are proven to be effective in treating autism. And, it's a cost-effective approach to addressing the needs of the autism community because of the federal resources available.

WITH FEDERAL RESOURCES ON THE TABLE WE CAN DO MORE

Federal resources typically cover 60% of the costs associated with the Kansas Autism Waiver. With provisions in the stimulus package, the federal match will increase to at least 66%, making now the most cost-effective time to expand the Autism Waiver. In 2010, Kansas can reduce the waiting list for the Autism Waiver by combining enhanced federal dollars with $937,000 SGF. This would allow another 100 Kansas children to receive essential early intervention services.

KANSAS ACTION FOR CHILDREN

Founded in 1979, Kansas Action for Children is a nonprofit, nonpartisan organization dedicated to shaping policy that improves the lives of Kansas children and their families.

Hello, my name is Robyn Herzog and I currently receive services from Cottonwood in Lawrence.

I live in my own apartment and have a good job in the community. I pay taxes and I vote. I got a computer recently and I like to e-mail my friends and family. I love my life and where I am right now. I am happy which makes me want to help others and participate in activities.

BUT... I did not get here on my own. I have a whole team of staff and a good family that help me. What I like about my team is that they help me and teach me so I can lean and do things for myself. I want to be independent not DE-PENDANT.

The only reason I am now able to live on my own in supported living is because I had staff to help me find an apartment that was in my budget. That sounds easy but there were applications to fill out and forms to submit... and I would not have been able to do that on my own. My mom helped me move. Staff helped me get set up and get to know my neighborhood and the rules of the apartment complex. I sat down with staff to make a routine for shopping for groceries and stuff like that. They taught me how to use the bus to get around and let me know about opportunities for things to do in the community. They help me with my budget so I know how much I can spend and how much I need to save if I want to go on a trip or buy something big like my computer. Basically they teach me about living and chores and activities.

I also have a job couch who helped me look for a job, fill out applications, and prepare for interviews. Once I was hired, my job couch stayed with me to teach me until I could do it myself. I really like my job and it makes me feel good about myself.

I do not even want to think about what my life would be like if I didn't have a team of good staff working for me- they are awesome!

I wouldn't be able to have a job so I couldn't afford my apartment and live the way I want to. I would be very depressed. I feel sorry for all those people on the waiting list who have to wait to get services. It must feel like their life is on hold. Imagine having to wait to start your life- most people don't even like to wait in line at the movies.. but this is LIFE we are taking about! THE WAITING LIST IS NOT FAIR! All people with disabilities deserve to get a job and a place to live just like people without disabilities do.

I also want to tell you about my staff. They are great and helpful but they have to move on to other jobs because they need to make more money. When a staff leaves it is very stressful. I get worried and overwhelmed. I have to have substitute staff a lot and I have to go over again and again with each new person what I need. It seems like a waste of time. I miss them when they leave because we get close. If my staff could make enough money and stay with me I wouldn't have to waste time or miss them. it is hard for me to understand why a job that important doesn't get paid more. This is my LIFE we are talking about and it IS important.

Please, Please do not cut funds for these programs and staff. Without them I would not be such a happy productive person in my community.

Thank you.

Good afternoon, my name is Andrea McMurray and I work in the residential department of Cottonwood Incorporated in Lawrence.

I honestly started in the field just because it fit into my school schedule. I had very little experience with people with disabilities, but it turns out that I really have a knack for it and I enjoy it.

NOT that it was easy------

I will NEVER forget that first weekend shift. It started Friday at 4pm and ended Monday morning at 8:30. It went well, I learned a lot. But once home, I remember finding myself just sitting the couch stunned by the whole experience. The responsibilities were enormous! .... It is EVERYTHING- and it is around the clock. Most people think of the job as merely personal care attending (showering and wiping) - and that IS a part of it, but that is just such a small part of the job! The list of roles you need to be able to fill are endless- and I don't mean the list is long...it is literally endless! I help people with their personal finances, inform them of community activities, teach health and hygiene, handle disputes, help take care of their pets, their homes, and drive them to church. I help them keep up with relationships and participate in things that are important to them. I might be brushing someone's teeth one minute and trying to fix a Walkman the next. I'm helping someone clean a fish tank... and later, while checking out at Target, find myself having to explain what an interest rate is, and why the credit card that the checkout clerk is offering (with a 29% interest rate) is NOT a good deal. Like I said... everything! It is truly overwhelming. BUT, after some experience, extensive training and certification including first aid, CPR, safety, ethics and integrity, medication administration, how to handle aggressive behaviors, respectful interactions, psychotropic medication monitoring, data taking - you name it. .....I am NOW A HIGHLY EDUCATED and SKILLED DIRECT SUPPORT PROFESSIONAL. I stress professional because you cannot just walk into this job, nor can you expect to coast through the work. You might not know this but the education we receive is amazing and in-depth. It is on-going and always improving. And as science makes advances learning about diseases and disabilities like Alzheimer's and autism, our staff training is state-of-the-art and can be geared to each consumer's individual needs--- NOW THAT IS HIGH QUALITY SERVICE! At this job we help people achieve their highest level of independence so they can live in the least restrictive environment possible. You know it is easy to just come in and do someone's laundry for them, but we are trained to have the patience to teach them how to do it themselves.

Now that you have a clearer picture of the complexity and intensity of the work ... ya wanna know how much we get paid? The average pay for a direct support positions in the community is $8.82/hour! That's average! I think my pay rate when I started was $4.35/hour! You can make more scooping ice cream! And even though ice cream is very important I am sure scooping it has none of the challenges and responsibilities of a DSP position.

Due to the low pay, direct support positions are considered entry level, or even temporary. It CANNOT continue to be that way. The people we serve deserve better than that! Consistency is imperative to the success of the people I serve. When someone has a staff that stays with them, a staff who knows what that person needs and how they like things done, they can move on to more important things. It makes me think of this gentleman I know who only needs help getting in and out of bed and the shower for him to get on with his life, get to his bus stop, and get to his job where he is a prized member of the staff and a

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contributor to society- he is also a taxpayer and he votes! But he has a really hard time getting and retaining staff due to the low pay and the consequences of that are devastating.

I want people to know that I am NOT an adult babysitter. I WANT to consider this my career. I want to be able and stay, improve and pass down wisdom- possibly until I retire. But how can I, how can anyone, when my wages are classified even by GOVERNMENT STANDARDS as below poverty level. I want this to be a career and not just "one of my four jobs". When I was reviewing in my head the list of everything I do at Cottonwood -I'm sorry if I'm beating this point, but seriously... bookkeeping, grocery shopping, medication monitoring, nutritional counseling, time management. I am a therapist, a life coach, a grief councilor, an emergency responder, a chauffeur, a beard trimmer, etc. -----I realized that any one of those jobs taken individually pay more than my job- and I do ALL of them! Sometimes all at once!

O.K , so what does that give us? Difficult positions requiring high skill level plus low wages equals understandably high turnover, constant position openings, and an inconsistent work force. What are the consequences of this situation? We all know that training is expensive and money wasted if the employee leaves -but that's not my department. What I see is the effect it has on our lives. It can be truly devastating. Imagine forming connections that are constantly broken- it is painful. I've seen it trigger long depressions and causes people to withdrawal. They stop trusting anyone. Constant turnover is degrading. When the person served has to spend all their time spinning their wheels, re-teaching new staff what they need and basically be reminded of their weaknesses and what they can't do over and over again it is hard on self esteem. They become defined by the disability.

Just a couple of mornings ago I was filling in at a group home (with a perpetually open position) and I asked the women over breakfast if having different staff often bothered them- without hesitation one woman snapped, "How would you like different strangers there when you needed help in the bathroom or something? Another woman added that it bothered her not knowing who would be driving her home from to work - or if they were a good driver. A reasonable concern. It all just leads to a "one-step-forward-two-steps-back" kind of situation for people's lives.

I also see what consistency CAN do. No matter what level of care a person needs, when they can depend on staff to be there, who appreciates their individuality, a staff who already knows their needs and treats them with dignity, who is vested in them - it is amazing what that person can accomplish. Staff consistency builds trust, security, and self worth – a winning combination for anyone.

So if you provide direct support professionals with a better wage the impact will be on many levels. Not only will it show respect for the services I provide, but ultimately show higher a respect for the people I serve- AND THAT THEIR QUALITY OF LIFE IS IMPORTANT TO YOU. I want you to realize that I am not asking for this rate increase so I can buy more stuff- it is so I can afford to stay at this job. IT WILL MATTER. Good staff will be able to stay and people served will have a conducive environment to reach their true potential - and everyone benefits from that.

I have two last points to make..

My DSP position is in group homes, known as community based services. A DSP who works in an institution has a starting wage of $12.35. That is STARTING wage. Check this out.. I have worked at Cottonwood for over 15 years now and I do not make that much yet!! I am

SURE you can see this discrepancy NEEDS to be corrected.

Lastly, I just want to draw attention to the fact that if you believe in this bill and pass it- for every dollar Kansas puts in - the federal government will put in a $1.50!
-WHAT A DEAL!

So I want you NOT ONLY to be thinking about what we will ALL gain from this bill but I also want you to think about what we will LOOSE if it doesn't!!

Thank you.

Testimony to House Aging and Long Term Care Committee
By Amy Hayden
Mom of a child with Developmental Disabilities
March 5, 2009

Committee members, I appreciate the opportunity to speak to you today about the Developmental Disabilities waiting list. I am the Mom of Ty Hayden. Ty is 7 years old and has Autism, Cerebral Palsy and Epilepsy.

Ty has been on the DD waiting list since July 21, 2006. We would have applied sooner had we known that we would be spending as much money as we do annually. We thought, "He is our son and we will provide all that he needs." We were proud parents that did not want a hand out. We also thought that he would get better and we would not need as much therapy as the years went on. In my head 7 was the magical year. I thought by the time he was 7 he would be potty trained, would be able to communicate with a few more words than he has now and would be able to follow a few one step directions. By no means did I think he would be cured but I did not know the severity would be still so great. In 2006 we realized this was bigger than we could handle and we swallowed our pride and asked for help. We knew there was a waiting list and were told it would be 3 to 4 years before we would receive funding. Each year the expenses have increased and the hope that we would be called to start receiving funding would come. In December 2008 we got the devastating news that we would now have to wait until 2012. Ty will be 11 by then.

Ty has many challenges he faces every day. He is almost completely non-verbal, still in diapers, is on a Gluten-Casein free diet, can walk but not with control and needs one on one support at all times. With Ty's limited communication it makes it very tough for him at home, school and out in the community. With prompting, he is now able to approximate the sounds of Eat, Drink, More and can say "Hello" and "Bye" when prompted. It is Dave and I‘s dream for him to say "Mom" and "Dad"!! I can't imagine how wonderful those two small words will sound and the joy we will get on that day. He is just learning to use a communication device in school and therapy and will eventually progress to using it at home. He is unable to ask for a drink, a snack, use the restroom, tell us if his stomach hurts, if he feels pain, etc. It makes our lives very difficult. Ty will cry and we will not always know why. There are different cries for different things. When he is having stomach problems he will generally cry really hard, when he is frustrated or when he gets tired of working he becomes fussy. If he is hungry he will sometimes take our hand and take us to the kitchen but that is very rare.

Ty started receiving services from Johnson County Infant Toddlers in May 2002. He had Speech, Occupational Therapy and Play Therapy 1 hour of each therapy per week. At the time I thought the therapists would come for a couple months and we would be done. To Dave and me we still did not see the delays the doctors and therapists saw in Ty. Ty is our first child so when he didn't start to babble we didn't think anything of it. We had

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therapists in our home 3 hours every week until he was three. When he turned three he went to preschool at Arbor Creek Elementary. We were so excited to have him in school. He was in an Early Childhood Disability classroom that had six kids with disabilities and 6 peer models. At the time we thought it was a great program and were happy to finally have our house back with just our family, no therapists. He started attending a gymnastics class for kids with Autism and we met a terrific family who we are still very close to. After being with this family for weeks they asked why Ty was not in an Autism classroom. We did not know anything about such a program. Eight weeks before his preschool's summer break we toured the Autism Preschool Classroom at Mahaffie Elementary. This is when we learned about early intervention and the importance of one on one teaching. We hired an Autism Specialist and 2 paras for the summer. We had to pay for this therapy out of pocket, no help from the school, insurance or the state. From that summer on, Ty has had in home therapy five to six days a week 1-2 hours a day. He also attends Prairie Center Elementary during the day in an Autism Classroom. In order to provide Ty with the same education during the summer as he receives during the school year, we are forced to pay out of pocket for more in home therapy each summer. Without these extra services, Ty wouldn't have made the progress he has. I often consider how fortunate we are to be able to provide these extra's, knowing that many Kansans with children on the DD waiting list can't even afford the minimal necessities for their children. I often feel guilty that my younger son sometimes has to go without things that he wants, in order for us to pay for these necessary services for Ty. We are not extravagant people and try our best to do everything we can, but waiting list dollars would help our family, as well as thousands of families provide needed medical, behavioral, and educational opportunities for our children.

Dave and I both have to work to provide the money to pay for all of Ty's needs. It is physically and emotionally demanding to work and raise Ty. We are constantly at the school for conferences, observation visits and IEP meetings. Managing Ty's school, therapy, doctor's appointments, and activities is a full time job on top of my 8-5 job with Sprint. Working for Sprint I do not have job security at any given time. If I were to lose my job, the therapy would have to stop. This is not fair to Ty, but without money coming in from my job this would have to be cut. The DD funding would help us pay for all the necessities that Ty has. Putting an end to those services, is putting an end to his growth towards independence.

This is what we pay for out of pocket for Ty.
Therapy $ 550/month during school year and $2500 during summer (Average)
Diapers $455/year
Food for GFCF diet $2600/per year
Car Seats $600 this year alone
Stroller $1300
Specialist in Texas $125/phone consult consults every 8 weeks
Van $18,000-We had to purchase a new vehicle this year because I am no longer able to lift him up into the vehicle I had since he is not able to get in and out on his own.
Medication/Supplements $100 month after co pays
Communication Device $80

Again, we appreciate this opportunity to share with the committee members Ty's story. We also want to thank you for your dedication to all of the families with disabilities. The hardships placed on individuals due to the DD waiting list is a real thing. There are many Kansans with loved ones who feel the pain of knowing that they are unable to financial provide all that is needed. My hope is that this committee steps up to the plate and advocates for approving a plan to eliminate the developmental disability waiting list and embrace SB 2094. I don't understand how anyone can look at Ty's sweet face and say that children with disabilities are not a priority.

Thank you-

Amy Hayden

TO: House Aging & Long Term Care Committee

FROM: Lori B. Feldkamp, President & CEO
Big Lakes Developmental Center, Inc.

DATE: March 3, 2009

RE: HB 2094 – InvisibleKansans Bill

My name is Lori Feldkamp and I am the President & CEO of Big Lakes Developmental Center in Manhattan. I am writing this to express my support for House Bill 2094, the InvisibleKansans Bill. This bill is necessary to provide critical funding for services over the next four years for individuals with developmentally disabilities (DD), as well as other disabilities. This bill provides funding to address the growing statewide waiting list for DD services but also attends to community capacity needs and the ability of providers to hire and retain qualified staff.

Waiting Lists

Many people with developmental disabilities across the state are waiting for services because of a lack of funding. This situation has been going on for YEARS and continues to get worse as funding has not been made available in sufficient quantities. In FY09, only 35 persons with developmental disabilities were provided funding and removed from the STATEWIDE waiting list. According to SRS's numbers, there are close to 4,000 people waiting for funded services statewide. Each year, approximately 300 new persons are added to the list.

Many Kansans, young and old, are waiting for needed services. For example, young Kansans graduating through the special education system have nowhere to go after graduating except their parent's couch. Vital skills learned in the school system are lost while they remain on a waiting list for years. Many of them cannot be left at home alone and parents are faced with challenge of quitting their jobs and having to stay home or finding care they cannot pay for. In these difficult economic times, the pressure can be too much for a family to bear.

Community Capacity

The ability of community service providers to be competitive in the marketplace to attract and retain staff is directly tied to the resources the organization. Community providers are dependent on the State as their sole customer AND determiner of rate of payment. As with most providers in the state, funds we receive to provide services make up over 80% of our total budget. Over 80% of our expenses are for wages and benefits.

The ability to develop a competitive wage and benefit structure is directly dependent upon the funding, you as a legislative body, see fit to provide. Since 1993, the HCBS DD Waiver rate adjustments have averaged 1.81% per year. For many of those years, there were NO adjustments to the rates, at all. There are no automatic cost of living increases or assurances that rates will be increased annually to assist organizations with the increasing costs of doing business. Other community businesses simply increase their prices to offset rising costs, we do not have that ability.

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Big Lakes' starting wage is $9.00 per hour, which is higher than the state average and the wage built into the reimbursement rate structure. However, the higher wage comes at a price, as we have to create more part-time than full-time positions and are unable to provide part-time benefits. Our full-time benefits have been reduced over the years as those costs have increased significantly. The turnover rate for direct support professionals is terrible and the quality of applicants for those open positions is not good. In 2008, Big Lakes' turnover rate was 51% as we hired 139 employees; we have a total of 245 positions, the majority of which are part-time. Training costs are huge for us as initial training averages 45 hours with each new hire. Persons served receive inconsistent care as there is a "revolving door" of staff in their life and they learn they cannot count on any one person to assist them for any length of time.

The American Network of Community Options and Resources (ANCOR) recently released their 2008 Direct Support Professional (DSP) Wage Study. In the study, they point out that many states, including Kansas, have a wide discrepancy in the wages paid to DSPs by state-run providers (hospitals) and to DSPs performing the SAME WORK functions by private providers. DSPs are healthcare professionals who provide "hands on" daily supports, training and habilitative services to persons with developmental and physical disabilities. This workforce is responsible for the health, safety and emotional support of the individuals being served. DSPs ensure compliance with state regulatory requirements for the delivery of these critical supports, as well as provider policies and procedures.

According to ANCOR's report, the DSP average "entry" wage in Kansas is $8.00 per hour while state hospitals starting wage is $12.35; I'm sure most of those positions also receive full-time benefits. The average DSP wage in Kansas is $8.78 per hour while state hospitals average wage is $14.68. That is a 67% difference, in just wages, for the SAME WORK!

Economic Impact

HB2094 provides $120 million over a four year period in direct economic stimulus for the state of Kansas. Funds will go to pay wages and benefits to people providing vital services for persons with disabilities AND will add money to local economies in Kansas. Addressing the statewide waiting list will send money to every corner of the state. Serving individuals that are on the waiting list will CREATE jobs that cannot be "outsourced"!

Summary

The challenge of staff recruitment and retention is expected to only worsen as baby boomers retire and the number of available workers decreases over the years. With the closure of institutions in the 1990s, the state has shifted the responsibility of serving our most vulnerable citizens to community service providers. While in the past, this process has been successful, it does not negate the government's responsibility to insure adequate funding is provided to ensure quality services in the future. House Bill 2094 is an important first step in assisting community service providers in recruitment and retention of employees for the next four years and addressing the growing waiting list for services statewide. Failure to address community capacity will only set up providers and individuals receiving services for failure.

I respectfully request the committee vote YES on HB2094.

The Arc
of Douglas County
Building a community
of acceptance.

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3/3/2009

Dear Chairperson Bethell and members of the committee:

A good education for your child, a job, a place to live – these are some of the basic goals of every Kansan. Kansans with disabilities share those dreams; they just need some supports to help them achieve those goals. Yet for years many Kansans with disabilities have been told to wait. Parents who know that with the correct interventions and supports during childhood their son or daughter would be a more independent and productive adult watch that precious time dwindle away. Students who graduate from high school sit in their parent's living room as their skills diminish and their confidence and independence erode. Parents grow older worrying about how their adult child will live when they can no longer provide care.

The Arc of Douglas County, its members and the people it supports strongly support the passage of the Invisible Kansans bill. HB 2094 is the opportunity for Kansas to take the steps necessary to make those goals a reality. It provides needed funds to meet the basic support needs of the most vulnerable members of her population. This bill would eliminate the waiting lists for Medicaid waivers allowing families to move forward with their lives; it would assure that children with autism receive the specialized intensive intervention that can significantly change the course of their lives. It provides supports and services for young children with disabilities that will reduce their dependency on adult services and funds the supports that adults need to be independent productive members of their community.

Now is the time to act on the waiting list crisis. As the state reviews the use of the enhanced Medicaid funding in the federal economic stimulus package, it is imperative that the legislature take a strong stand in assuring that the funds are used for the people who need them most. These funds are restricted to qualifying Medicaid services and may not be used to reduce the budget deficit or build our state reserves. Clearly the people who will be supported through HB 2094 are the very ones for which this additional money was designated.

We know that these are difficult economic times but the needs of Kansas citizens with disabilities are the same whatever the 'times' may be. We strongly urge you to take the bold step, the right step, in supporting The Invisible Kansans bill (HB2094) and the people whose lives it effects.

Sincerely,

Barbara Bishop

Barbara Bishop
Executive Director

The Arc
A chapter
of The Arc
of the
United States

United Way
A United
Way Agency

HOUSE AGING & LONG TERM CARE
DATE: 3/5/09
ATTACHMENT: 15

Self-Advocate
Coalition
of Kansas

Promoting empowerment and Independence.

My name is Kathy Lobb, and I serve as the Legislative Liaison for the Self Advocate Coalition of Kansas. I am a self advocate that believes HB2094 should pass because we don't want to see people on the waiting list for the next four years.

People on the waiting list could be served throughout the state no matter where they live in Kansas; this means that families would not have the person waiting at home when they could get the help and support they need.

I receive services from a non profit in Lawrence, Kansas where I live and work. If this bill doesn't pass, people with disabilities on the waiting list will not any way to live on their own without help. I would like to see that change this year.

I know that there's very little money in the budget, but I wanted to let you know that waiting for services is not an option. I know what it is like to wait for services. Now I am someone who lives in the community and pays taxes, thanks to the supports I receive.

I would like to thank Jerry Henry and Bob Bethel for their support and hard work on developmental disability issues. Both have received an award from the Council on Developmental Disabilities. This bill will help families across the state; passing it is the right thing to do. Other consumers have the right to receive the type of services that I do; they have the right to live, work and play in the community. They have a right to a high quality of life.

Sincerely,
Kathy Lobb

Kathy Lobb

Legislative Liaison for the Self Advocate Coalition of Kansas

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