MINUTES

JOINT COMMITTEE ON CHILDREN'S ISSUES

December 7-8, 2010
Room 546-S—Statehouse

Members Present

Senator Julia Lynn, Chairperson
Representative Mike Kiegerl, Vice-chairperson
Senator Oletha Faust-Goudeau
Senator David Haley
Senator Laura Kelly
Senator Susan Wagle
Representative Marti Crow
Representative Pete DeGraaf
Representative Bill Otto

Members Absent

Senator Roger Reitz
Representative Valdenia Winn

Staff Present

Martha Dorsey, Kansas Legislative Research Department
Iraida Orr, Kansas Legislative Research Department
Amy Deckard, Kansas Legislative Research Department
Leah Robinson, Kansas Legislative Research Department
Laura Younker, Kansas Legislative Research Department
Renae Jefferies, Office of the Revisor of Statutes
Nobuko Folmsbee, Office of the Revisor of Statutes
Florence Deeter, Committee Secretary

Conferees

Dr. Bill Craig, Chairman, Kansas Autism Task Force
Linda Heitzman-Powell, Ph.D., Director of Community Research Training
Lee Stickle, Director, Kansas Instructional Support Network
Mike Wasmer, DVM, Founder, Kansas Coalition for Autism Legislation
Lisa, Blake, and Loren Wendelburg, Parents and Son
Jeanie Zortman, Chairperson, Kansas Governor's Commission on Autism

Dee McKee, Financial Advisor, Governor's Commission on Autism
Matthew Reese, Ph.D., Director, Center for Child Health and Development, Kansas University Medical Center
Rocky Nichols, Executive Director, Disability Rights Center of Kansas
Ray Dalton, Deputy Secretary, Department of Social and Rehabilitation Services
Sean Swindler, Director of Community Program Development and Evaluation, Kansas Center for Autism Research and Training
Matt Fletcher, Associate Executive Director, InterHab, Inc.
Tom Laing, Executive Director, InterHab, Inc.
Jason and Angie Blakely, Parents
Edie Nichols, Parent
Mary Beth DeCock, Parent
Randi Swenson, Transition Specialist, Blue Valley School District
Colin McKenney, President/CEO, Multi Community Diversified Service, Inc., McPherson, Kansas
Leia Holley, Parent
Shirley Armentrout, Parent
Doug Bowman, Coordinator, Coordinating Council on Early Childhood Developmental Services
Samantha and Richard Teed, Parents
Deb Voth, President, Rainbows United, Inc., Wichita, Kansas
Chad Robinson, Parent
Maury Thompson, Executive Director, Johnson County Developmental Supports

Others Attending

See attached list.

Tuesday, December 7
Morning Session

Chairperson Lynn opened the meeting at 9:10 a.m., welcomed Committee members and conferees, and thanked legislative staff for their preparations. She expressed appreciation for the good bridges Kansas has built for the autism community for both children and adults. Acknowledging there is more to be accomplished, Senator Lynn indicated a need to provide pertinent information to the 2011 Legislature in order to bring an understanding of the evolving issues surrounding autism.

Representative Bill Otto announced that the Legislative Coordinating Council's reorganization plan has created a new standing Committee pertaining to Children's Issues.

Dr. Bill Craig, Chairman, Kansas Autism Task Force, submitted a report containing conclusions and recommendations of the Task Force, which concluded its work in 2008 on issues related to autism (Attachment 1). He noted that the number of reported autism cases has risen from 1 in 150 births in 2007 to 1 in 110 currently. Dr. Craig said that of the 3,000 persons on the waiting list for services through the Home and Community-Based Services Waiver for Individuals with Developmental Disabilities (HCBS/DD Waiver), 30 percent of them are diagnosed with autism spectrum disorder (ASD). Dr. Craig commented on the findings of the

Task Force and the many barriers individuals and families encounter. He briefly elaborated on the six recommendations of the Task Force (Attachment 2).

Answering questions from Committee members, Dr. Craig stated:

- There are genetic components that are a possible cause of ASD; environmental factors are being studied;
- Scholarship programs could be put in place for professionals who agree to serve in rural and underserved areas of Kansas;
- Regular in-service training for special education is greatly underfunded; and
- Autism impacts the educational development of individuals; the system needs to incorporate methods to ameliorate the situation.

Linda Heitzman-Powell, Ph.D., Director of Community Research Training, University of Kansas Medical Center, identified ASD as a pervasive neurological disorder that affects all areas of learning. She addressed the issue of the availability of services that use the current program of evidence-based practices (Attachment 3). She said that an "evidence-based" approach relies on the use of specific data to determine what is an appropriate and effective program for persons diagnosed with ASD. Dr. Heitzman-Powell included a list of nine best practices recommendations that are supported by the National Autism Center's National Standards Project (2009).

Dr. Heitzman-Powell provided a notebook copy of the Kansas Center for Autism Research and Training report on best practices, which is available in the Kansas Legislative Research Department for Committee members to peruse.

Dr. Heitzman-Powell commented on the Military Demonstration Program available to children whose parents are on active duty; the number of ASD individuals in the military arena is 1 in 88 persons, a much higher incidence than in the population at large. She noted that families are remaining on active duty in order to have services. An early autism waiver program through the Home and Community Based Services of the Kansas Medicaid Program is in place to serve other Kansas children from birth through age six. To date, only 45 are being served; 262 persons are on the waiting list.

The Committee viewed a video clip of individuals diagnosed with ASD showing the progress made when early intervention and best practices in comprehensive training are utilized.

In answer to questions, Dr. Heitzman-Powell stated the following:

- Personnel in mental health centers are not fully trained and often do not feel comfortable in suggesting ASD testing;
- Parental involvement is a critical component in implementing strategies and techniques; and
- Marital stress is reflected in a 75 percent divorce rate among ASD families.

Lee Stickle, Director, Kansas Instructional Support Network (KISN), stated that a diagnosis of ASD does not guarantee eligibility for special education services; an identified disability and an educational need must be evident (Attachment 4). She reported that the number of identified persons in Kansas is 1 in 261, and 90 percent of the population live in 10 percent of Kansas counties. Ms. Stickle said that the Kansas State Department of Education (KSDE) has increased the resources for in-service training of teachers and provides technical assistance. She noted that KISN includes on-site coaching to help improve skill levels for persons who are implementing services. Ms. Stickle reported that more than 3,000 people attended training and presentations in 2010. Concluding her remarks, she stated that now is the time to improve services for individuals with ASD, their families and communities across Kansas.

Mike Wasmer, The Kansas Coalition for Autism Legislation (KCAL), presented a graph showing the increase of autism since 1975 (Attachment 5). He noted that out-of-pocket expenses for families often exceed $50,000 per year. Mr. Wasmer reported that HB 2160, which is scheduled to take effect January 1, 2011, provides insurance for state employees only. Mr. Wasmer provided comparison data between Kansas and Missouri on the limitations of coverage and recommended the legislature adjust the insurance plan through implementation of SB 12 to include all Kansans.

Judith Ursitti, CPA, Regional Director, Autism Speaks, addressed the Committee both as a parent of two children with ASD and as a professional (Attachment 6). Ms. Ursitti said that in 2001 the legislature in the state of Indiana initiated medical care for persons diagnosed with ASD. By 2007, Texas became the first state to provide assistance through an insurance program and many other states have become involved in passing insurance reform to provide for those diagnosed with ASD. A federal law for free and public education for the disabled is now in place through the Individuals with Disabilities Educational Act (IDEA). She noted that the program provides payments for early intervention but does not contain any insurance coverage. Ms. Ursitti listed the names of self-insured companies who are providing benefits for persons with autism spectrum.

Ms. Ursitti said that Applied Behavior Analysis (ABA) is a therapy that provides one-on-one support with an emphasis on repetition of acceptable behavior in social and family settings. She noted that ASD is a neurological disorder that is treatable, but not curable. She indicated that health insurance coverage is critical for families faced with continuing health-care costs.

Lisa and Blake Wendelburg, parents of Loren, who was diagnosed with an ASD, spoke to Committee members of their experiences (Attachment 7). Loren was originally denied coverage for an assessment conducted at University of Kansas Medical Center when he was three years old. Loren has since received treatment through an ABA program; his attendants have provided treatment at a level of 20-40 hours per week. With methodical and consistent training he was able to enter a regular kindergarten classroom. He excels in reading, has performed in a community drama and functions well socially. Loren and his parents indicated he had been bullied and verbally abused by a teacher in Shawnee Mission schools. Ms. Wendelburg said no disciplinary action was put in place for the teacher, even though a Social and Rehabilitation Services (SRS) written evaluation indicated the allegations were true individually for Loren, yet unsubstantiated in the teacher's likelihood to abuse others. Ms. Wendelburg said the SRS reporting mechanism is very confusing. She reported that a teacher who is on the Kansas Child Abuse and Neglect Registry is allowed to hold a teaching license and be hired for classroom instruction, a variance which she finds reprehensible.

Afternoon Session

Jeanie Zortman, Dodge City, currently serves as Chairperson of the Governor's Commission on Autism (Attachment 8). She noted the increased number of children diagnosed with autism as determined by the Center for Disease Control; the average stands at 1 in every 110 children, the highest percentage being 1 in every 70 boys. Her testimony included data that shows 254 children are on the waiting list for the Kansas Autism Waiver. Ms. Zortman said the Governor's Commission has defined several goals and has initiated a comprehensive state plan that defines objectives for successful development of citizens with autism.

Dee McKee, Financial Advisor, Governor's Commission on Autism, reviewed the statistics regarding the funding for special education, which was reduced by a loss of $2,186,454 for the current school year (Attachment 9). If those funds are not replaced, the loss increases to $16,710,878 for the next year. Ms. McKee commented on Families Together, a Kansas organization that provides resources for parental support in following through with Independent Educational Planning for their child's training and education. She recommends that the "Can Be Healthy" program of insurance should be available to all, not just to employees of the state of Kansas. Ms. McKee said that when a child with autism reaches a point of needing catastrophic aid, the funds are to follow the child, and, specifically, the child's name should be put on the documents to ensure he/she receives catastrophic aid in all cases.

Matthew Reese, Ph.D., Director, Center for Child Health and Development, Kansas University Medical Center, stated that children with autism often do not improve without assistance from well-trained providers (Attachment 10). He said that the Kansas Instructional Support Network (KISN), and the Center for Child Health and Development (CCHD) collaborate to train teams throughout the state to screen, diagnose and use effective practices with children having ASD. Dr. Reese said that rural areas continue to lack sufficient personnel, many of whom leave the state for career opportunities. He indicated the need for ASD curricula in all community colleges to provide personnel training, and salary incentives for individuals receiving training in the field of autism. Dr. Reese reported that the Board of Regents has a proposed scholarship bill, which could allocate some funds for ASD-trained teachers.

Rocky Nichols, Executive Director, Disability Rights Center of Kansas, requested permission to introduce Amy Cohane, Gardner, Kansas, a parent of a child with autism who gave verbal testimony regarding her son, Ben. When visiting the school she noticed a "safe room" in her son's classroom. She tried to obtain her son's records; the special education teacher refused to let her have the records, which contained data on the number of times Ben had been confined in the "safe room." He had been secluded in the "safe room" 90 times within twenty days, sometimes for an hour at a time. Her son is non-verbal and began to vehemently refuse to go to school. Ms. Cohane said that, as a parent, she would be negligent in her child care if this seclusion had occurred in her home. She finds it difficult to understand how a school system can be involved in such procedures. She requests that schools be held accountable to the same degree a parent is accountable.

Mr. Nichols stated that schools are the last places where seclusion and restraint are not regulated (Attachment 11). He noted that Kansas hospitals, intermediate and long-term care facilities, and day care facilities are closely regulated. Mr. Nichols cited specific examples of seclusion and restraint in Kansas communities. He reported that there is a growing consensus nationally to limit seclusion and restraint, allowing it to be implemented only when an imminent risk of danger is present. Mr. Nichols requested having enforceable standards across the state to ensure protection for those with behavioral disabilities and ASD.

Senator Haley requested he be put on record in support of this issue and for the Legislature to call on KSDE to begin collecting data on restraint and seclusion, and that school district data specific to restraint and seclusion be released to individuals upon request.

Ray Dalton, Deputy Secretary of Disability and Behavioral Health Services, SRS, presented information regarding the autism waiver, which serves persons with ASD (Attachment 12). He reported that the autism waiver is the newest Home and Community Based Services (HCBS) waiver with approved funding implemented January 1, 2008. The waiver provides for services for consulting with autism specialists, individual and parent support and training, family counseling and respite care. Originally, 25 children were selected through a random process to receive services; others were placed on a waiting list. Currently 45 children are being served with 259 children on a waiting list. Mr. Dalton said additional funds are needed to eliminate the waiting list.

Mr. Dalton answered member's questions, stating:

- There are 1,420 persons aged 5-17 on the Developmental Disabilities waiting list and 259 on the ASD list;
- The spreadsheet submitted by Kansas Legislative Research Department does not contain a priority level for services provided through the waiver program; and
- The number of "frail elderly" on the list can be ascertained for the Committee.

The Chairperson thanked Mr. Dalton for his presentation and work for the disabled community.

Sean Swindler, Director of Community Program Development and Evaluation, Kansas Center for Autism Research and Training (K-CART), spoke of the need for support of the adult population with ASD who must wait for services as they transfer from the educational system to greater independence (Attachment 13). Mr. Swindler described the barriers and unique challenges for those with ASD who seek employment in the community. He indicated that K-CART is collaborating with Johnson County Community College (JCCC) to develop a support system for persons with ASD who are attending JCCC. He reported that the program involves peer mentors and has significantly impacted the lives of students with regard to social growth and self-confidence.

Mr. Swindler responded to the question of how to include persons with ASD in the community, stating that work force centers are underutilized and that a basic level of planning in advance of transition could secure further education or employment in the community. He suggested that the Centers for Independent Living (CIL) could be equipped with trained personnel to provide support for those with ASD.

Senator Tim Owens provided information on the insurance bill passed in the Kansas Legislature as being inadequate for providing coverage for persons with ASD. He referred to the action taken by the Missouri Legislature, which has a $40,000 cap on insurance for persons with ASD. He said that 24 other states have made improvements in insurance coverage and Kansas is two years behind in the system. Senator Owens intends to bring a bill that would have a greater impact than waiting on a two-year test track study, which does not begin until January 2011. He reported that residents of Kansas are considering moving to Missouri to have services and insurance. He requested the continued support of the Committee.

The Chairperson thanked Committee members, staff and conferees for participation in the meeting and recessed until 9:00 a.m., Wednesday, December 8, 2010.

Wednesday, December 8
Morning Session

Ray Dalton provided background information on the Medicaid waivers, which are federally approved requests to waive certain rules in order to draw down funds for persons with severe disabilities (Attachment 14). He reported that SRS fee funds have been used to fill gaps and those fee funds are now depleted. SRS requests an enhancement to replace the $11 million shortfall in the FY 2012 budget submission. He noted that because of federal regulations, options are limited and SRS would be constrained to control spending through rate reductions and limitation of services.

Mr. Dalton responded to members' questions stating that:

- Administrative costs have been reduced, management positions remain open, and some persons in management have been moved to direct-line positions;
- A supplemental request is in place for the frail elderly; there is no waiting list;
- Reduction of the waiting list for autism waivers will require $2 million from the State General Fund and $23.2 million for those on the Developmental Disabilities waiting list;
- Case load numbers have increased among the mental health and SSI disabled populations; when a person is in crisis, he/she can be moved up on the waiver list; and
- A report of the amount of money in fee funds can be provided.

Matt Fletcher, Associate Executive Director, InterHab, Inc., brought information regarding the funding of persons with DD and the issue of waiting lists (Attachment 15). He said that of the 4,000 on waiting lists there are two levels–the unserved and the underserved. Mr. Fletcher reminded members of the mandate passed in 1995 stating that a community network of supports is absolutely necessary for those with DD to be productive citizens. He included an outline with InterHab's approach to address the issues entitled, "Quality-Based Community Expansion" or "Q-Base." He said that InterHab recommends a multi-year funding plan covering a three-year time span to eliminate the waiting lists in Kansas.

Mr. Fletcher answered questions, stating:

- Direct care workers who are volunteers must be passionate people; there are some federal regulations which apply to volunteers;

- A base salary begins at $8.00 per hour; frequent turnover of care-givers is predominant;

- Dialogue has been in place with technical schools and community colleges to develop curriculum for training persons to enter the work place;

- SRS in conjunction with the College of Direct Supports in Minnesota has an on-line program for student certification in direct care management; and

- Since 2006, there have been minimal efforts in the area of finding ways to improve the system.

Tom Laing, Executive Director, InterHab, Inc., speaking on the issue of provider assessments for Home and Community Based Services personnel, said that it is advisable to retain the best professional personnel to care for persons with DD (Attachment 16). He explained that the proposed provider assessment is a method for utilizing current resources in the community and, if the proposal is put in place, it will benefit all who provide services at no additional cost to taxpayers.

Jason and Angie Blakely, parents of Connor Blakely, related the challenges and difficulties of caring for a child with DD and how the decreases in funding have impacted their lives (Attachment 17). Mr. and Mrs. Blakely want to care for Connor in their home; however, his aggressive behavior requires someone to be with him at all times. They are on a waiting list and have a need for respite care, among other services.

Edie Nichols, parent of Kelli Nichols, was instrumental in founding the only support group for Kelli's diagnosed syndrome, Cri-du-Chat (Cry of the Cat), which at the present time includes 500 families in an international database (Attachment 18). Kelli functions at a 4- to 5-year-old level and is chronologically 26 years old. Ms. Nichols said that Kelli desperately needs to find a safe environment before a crisis arises within the family.

Mary Beth DeCock, parent and guardian of Steven DeCock, spoke about her son, saying that Steven is on the waiting list for day services. He does not qualify for work services and is developmentally unable to function much above a three-year old level (Attachment 19). She acknowledged the future need for residential care, even though that is not her desire for Steven.

Lurena Mead, Community Relations Manager, Johnson County Developmental Supports, read the testimony of Randi Swenson, Transition Specialist, Blue Valley School District, in which she expressed frustration with the wait time within the system. Ms. Swenson is an employee of the Blue Valley School District and has worked to help students with disabilities make a seamless transition from school to adult services (Attachment 20). However, she is concerned both for her daughter Emily and others who are waiting for five to seven years to receive services that will allow them to function successfully in community settings.

Maury Thompson, Executive Director, Johnson County Developmental Supports, spoke to clarify statements made by earlier conferees. He said that all entities must have exhausted their natural and community resources before they can have access to the waiver programs. Mr. Thompson reported there has been a significant increase in the faith-based response, primarily for those needing respite care. He noted that collaboration with Johnson County Community College has resulted in certification classes for those entering the profession to care for persons with DD. Mr. Thompson said that some agencies must operate on a very stringent budget since SGF funding has been eliminated. He said that about 750 of the 4,000 on the waiting list for services reside in Johnson County.

Colin McKenney, President and CEO, Multi Community Diversified Service, Inc., McPherson, Kansas, explained to Committee members the issue of limited options available through the Medicaid waiver for children (Attachment 21). He provided data from a survey taken by families of children with DD in Kansas. Many families indicated they would strongly consider a new waiver option to allow more flexibility in purchasing support services, equipment and supplies, giving them a standardized annual amount to be used and managed at their discretion. Mr. McKenney reported that studies done in 16 other states have found that often only half of the allotted $20,500 cap is being spent by parents who are choosing more wisely the services needed. He expressed the hope that this concept of funding could be fine-tuned with the Medicaid program and be available by 2013.

Mr. McKenney responded to questions, stating that:

- This would be an additional waiver and specific to flexible funding options;
- The model would have in place a fiscal intermediary to manage funds; and
- None of the funds would be used to pay the family to care for the child.

Leia Holley, parent of Sean Holley, addressed the Committee, saying that the challenge of finding personal care attendants for children with DD is extremely challenging (Attachment 22). She said that specialized Applied Behavioral Analysis and Behavioral Support therapies are not covered by the HCBS/DD Waiver, which for some children continues to limit their progress. Ms. Holley spoke in support of a more flexible waiver, which would give parents freedom to acquire relevant assistance.

Shirley Armentrout, Director of Academic Resource Center at Most Pure Heart of Mary Schools is a single parent of adopted twins, one of whom is blind and wheelchair bound. He received services from Community Development Disabilities Organization (CDDO) until recently when funds were cut. She said that during her six-month illness when she could not work, she began to question who would care for her son if she were not available.

Doug Bowman, Coordinator, Coordinating Council on Early Childhood Developmental Services, addressed the Committee regarding the Infant-Toddler Services Program, Part C of IDEA or the tiny-k organization (Attachment 23). He provided brochures which give information about tiny-k services and agencies in various communities across the state. He noted that there are no waiting lists in the tiny-k organization; by law, services are to be provided within 45 days. Mr. Bowman said that success of the program is continually measured and, in one out four children served, by a child's third birthday he/she is ready for the public school setting.

Mr. Bowman responded to questions, stating that:

- Federal grants, the Children's Initiative Fund, the Special Education Fund, SGF funds, Medicaid and private insurance are all providers of funds for the organization;
- A formula based on population and poverty levels is used to distribute federal dollars;

- KDHE uses a formula based on the number of children served and the birthrate in the state; and

- A state endowment fund has been available in the past for the organization.

Samantha and Richard Teed, parents of Hannah Teed, spoke to the Committee and provided a video to show how well the system has worked for them. Mr. Teed said that the TA Program, secondary insurance, TARC and the original nursing staff have all coordinated programs to benefit Hannah. Written testimony will be provided.

Deb Voth, President, Rainbows United, Inc., Wichita, Kansas, explained the necessity of providing adequate state funding for tiny-k in order to continue receiving federal monies (Attachment 24). She noted that in both Sedgwick and Butler Counties, services like speech, occupational and physical therapy, hearing and vision screening are provided within a family's home for children with special needs or disabilities who are under age three. Ms. Voth reported that in Sedgwick County funding was available for only 85 out of 250 families. She noted that in order to receive federal funds for Part C, Kansas must maintain good effort in allocating funds for the DD population.

Chad Robinson, parent of Colbie Clair Robinson, said their family has received adequate support through Rainbows United and the Pre-K programs in the Wichita School District (Attachment 25).

The Chairperson called for discussion of legislative initiatives to be included in the Committee report.

A motion was made by Representative Crow to provide insurance coverage for autism; seconded by Representative Otto. Following discussion Senator Wagle suggested supporting Senator Owens' legislation to change Kansas' autism insurance caps to be like those of Missouri. The motion carried.

Representative DeGraaf moved the House Appropriations and Senate Ways and Means be encouraged to fully fund an autism waiver of $2.1 million for the 2011 fiscal year with the stipulation of having appropriate subcommittee hearings to gather additional information from families whose stories are important. Representative Otto seconded. The motion passed.

Senator Wagle moved, and Representative Otto seconded, a motion to support Senator Owens' legislation to change Kansas' autism insurance caps to be like those of Missouri. The motion passed.

Representative DeGraaf moved parents be informed of the measures taken when restraint/discipline of their child has been administered. Representative Otto seconded. The motion passed. Representative Otto suggested that the State Board of Education be encouraged to look into procedures and policies of school districts.

Representative DeGraaf moved that the State Board of Education look into licensure of teachers who are involved in abuse of children as reported to SRS. Senator Wagle seconded. The motion passed.

Chairperson Lynn called for discussion on the provider assessment, which would offset the cuts made in the past year. She noted a rate increase would help finance the continuing rise in caseloads. Representative Otto recommended House Appropriations and Ways and Means consider the issue. Consensus was unanimous.

Chairperson Lynn led discussion on flexible funding and recommended the 2011 Legislature be encouraged to look in depth at this issue.

The Kansas Legislative Research Department submitted a document of revised estimates on human services caseload expenditures for FY 2011 (Attachment 26).

The Chairperson thanked members and conferees for their participation and closed the meeting at 4:00 p.m.

Prepared by Florence Deeter
Edited by Martha Dorsey

Approved by the Committee on:

March 25, 2011
(Date)

JOINT COMMITTEE ON CHILDREN'S ISSUES

GUEST LIST

DATE: Dec. 7, 2010

NAME	REPRESENTING
Steve Solomon	TFI Family Services
Jessica Clatterbuck	TFI Family Services (Intern)
[illegible] Case	GBA
Rob Mealy	Kearney & Assoc.
[illegible] Snell	KCAL
Lu Stickle	KISN KSDE
[illegible]	KUMC
Dr. Dee McKee	Ks Autism Committee Member
Michele Butler	Cap. Strategies
[illegible]	TFKC
Katy Belot	SRS
Doug Bowman	CCECDS
Nan Perrone	CLO
Jennifer Crow	Children's Alliance
Shannon Bell	LGR
[illegible]	United Health Group
Mike [illegible]	Dir. of SPED/Wamego
David Couch	Supt. - Russell County USD 407
[illegible]	KVC Health Systems
Michelle Blasdel	Children Forces
[illegible] Clements	Public Solutions, Youthville, DCCCA
Rocky Nichols	DISABILITY RIGHTS CENTER
Nick Wood	DISABILITY RIGHTS CENTER
Ray Dalton	SRS

JOINT COMMITTEE ON CHILDREN'S ISSUES

GUEST LIST

DATE: 12-7-10

NAME	REPRESENTING
JEANIE ZORTMAN	KS GOVERNOR'S Comm on AUTISM
Judith Ursitti	Autism Speaks

JOINT COMMITTEE ON CHILDREN'S ISSUES

GUEST LIST

DATE: 12-8-10

NAME	REPRESENTING
Elizabeth Reimer	OJA
Ray Dalton	SRS
Jessica Clatterbuck	TFI Family Services (Intern)
[illegible] Coley	GBA
SEAN MILLER	CAPITOL STRATEGIES
Steve Solomon	TFI Family Services
Gina MeierHummel	KAC
NICK WOOD	DISABILITY RIGHTS CENTER
Robin Clements	DCCCA & Youthville
Sue Storm	
Tom Laing	InterHab
Maury Thompson	Johnson County Developmental Sup.
Doug Bowman	CCECDS
Michelle Blasdel	Advocate
Valarie	citizen
David Klepper	KC STAR
Shirley Armentrout	Advocate
Chad Robinson	Citizen/Parent
Deb Voth	RAINBOWS United

Report of the Kansas Autism Task Force to the 2009 Kansas Legislature

CHAIRPERSON: Bill Craig

LEGISLATIVE MEMBERS: Senators Donald Betts and Julia Lynn; and Representatives Melody McCray-Miller and Judy Morrison

NON-LEGISLATIVE MEMBERS: Sarah Bommarito, Kathy Ellerbeck, Jarrod Forbes, Denise Grasso, Louise Heinz, Linda Heitzman-Powell, Yeyette Houfek, Donald Jordan, Linda Kenney, Tracy Lee, Jim Leiker, Martin Maldonado, Dee McKee, Nan Perrin, Matt Reese, Colleen Riley, Michael Wasmer, Jane Wegner, and Jeanie Zortman

STUDY TOPIC

The Kansas Autism Task Force is directed statutorily to study and conduct hearings on the issues related to the needs of and services available for persons with autism. State law requires that the Task Force submit reports to the Legislative Educational Planning Committee (KSA 46-1208d).

December 2008

Attachment # 1
JCCI
12-7-10

Kansas Autism Task Force

FINAL REPORT

CONCLUSIONS AND RECOMMENDATIONS

As a result of its findings, the Kansas Autism Task Force recommends that agencies which serve as support systems for families and children with autism (Kansas Department of Health and Environment (KDHE), Department of Education, and the Department of Social and Rehabilitation Services (SRS)) should incorporate the guidance of the "Best Practices in Autism Intervention for Kansas" handbook (attached) produced by this Task Force into their administrative guidelines.

As a result of its findings in other areas, the Kansas Autism Task Force recommends the Legislature consider and adopt legislation as follows:

- Create a specific mechanism in the KDHE *tiny-k* funding formula to support local *tiny-k* providers who must provide high cost, intensive services when they are required by a child's Individualized Family Service Plan (IFSP).
- Expand funding of the Autism Medicaid Waiver to fully serve the current waiting list and transfer the future funding of this program to the consensus estimating process, where anticipated need will be the basis for funding. A waiting list is not an acceptable option.
- Pass legislation which requires that health insurance policies cover the diagnosis and appropriate treatment of individuals with autism.
- Pass legislation which creates and funds a scholarship program to support the education of professionals in the field of autism who agree to serve in underserved areas of the State.
- Pass legislation to fully fund the Mental Retardation/Developmental Disabilities Home and Community Based Waiver (HCBS) waiting list and create adequate rates for the Developmental Disability system.
- To complete the objectives set for it by the Legislature, the Kansas Autism Task Force must have its term extended for an additional year. The necessary legislative authorization to accomplish this should be made retroactive to January 2009. (Please see the "Task Force Activities" section, page 4, for the complete rationale for this extension.)

In addition, the Department of Education should strive to ease the access to Catastrophic Aid funds for school districts who serve high-cost students, such as those with autism.

It is incumbent on the three state agencies primarily responsible for services to individuals with autism (KDHE, Department of Education, and SRS) to collaboratively maintain a dynamic mapping website of the availability of services and supports across the state with current contact information. This site should be readily available and usable by parents seeking information and service.

Proposed Legislation: The Kansas Autism Task Force has no authority to introduce legislation.

BACKGROUND

The Kansas Autism Task Force was established by 2007 SB 138 to study and conduct hearings into issues including but not limited to:

- The realignment of state agencies that provide services for children with autism;
- The availability or accessibility of services for the screening, diagnosis and treatment of children with autism and the availability or accessibility of services for the parents or guardians of children with autism;
- The need to increase the number of qualified professionals and paraprofessionals who are able to provide evidence-based intervention and other services to children with autism and incentives which may be offered to meet that need;
- The benefits currently available for services provided to children with autism;
- The study and discussion of an autism registry which would (a) provide accurate numbers of children with autism, (b) improve the understanding of the spectrum of autism disorders and (c) allow for more complete epidemiologic surveys of autism spectrum disorders;
- The creation and design of a financial assistance program for children with autism;
- The establishment of a hotline that the parents or guardians of children with autism may use to locate services for children with autism;
- Additional funding sources to support programs that provide evidence-based intervention or treatment of autism, including funding for the development of regional centers of excellence for the diagnosis and treatment of autism; and
- Develop recommendations for the best practices for early evidence-based intervention for children with autism.

TASK FORCE ACTIVITIES

The Task Force and its subcommittees met frequently in 2008. For a detailed description of the activities of the Task Force, refer to the minutes of meetings dated March 5, April 14, June 12, July 16, August 22, September 17, and November 12, 2008.

The Task Force decided to make a request to the 2009 Legislature to extend the term of its activity for an additional year for the following purposes:

- A final edition of the "Best Practices in Autism Treatment in Kansas" handbook must await the incorporation of the soon-to-be released national standards manual. Subsequently, a readily accessible version of this document will be made available to all interested families, providers, and others.
- The Task Force believes it must be available as a resource to the 2009 Legislature during the Session as it deliberates the recommendations of the Task Force.
- At the conclusion of the extension year the Task Force will make a recommendation to the Legislature for a mechanism to provide ongoing advice and oversight for the concerns of Kansans with autism.

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CONCLUSIONS AND RECOMMENDATIONS

Our Findings

- Autism spectrum disorders (ASDs) are biologically based, neurodevelopmental disabilities with a strong genetic component that are characterized by impairments in communication, social interaction and sensory processing. With varying degrees of severity, ASDs interfere with an affected individual's ability to learn and to establish meaningful relationships with others.

- The prevalence of ASDs in Kansas (and nationwide) is increasing in epidemic proportions. (The Centers for Disease Control currently report the prevalence of ASDs as 1 in 150 births. Ten years ago, this estimate was 1 in 2,500.)

- There is no proven "cure" for autism and the effects of this disability are typically lifelong. However, effectiveness of early, intensive intervention in reducing the effects of this disorder is supported by a growing body of scientific research. The costs of this intervention for at least three years during the crucial developmental age (1 through 7) may exceed $150,000.

- Half of the individuals who receive this level of intervention do not require subsequent special education services and 80 percent show measurable reduction in symptoms. The cost of supporting an individual with autism who does not receive such intervention through age 55 is estimated to average $4,400,000.

Current Barriers

The current barriers to individuals with autism and their families in Kansas include:

- Long wait times for thorough diagnostic assessments by properly certified professionals.

- The *tiny-k* network which provides the front line for early identification and intervention in Kansas is not adequately funded and provides no allowance for the high cost of early intervention.

- There is a dramatic shortage of qualified personnel to implement early intervention.

- The qualified personnel who are available are concentrated in the urban areas and not accessible to vast portions of rural Kansas.

- Current funding for the newly created Autism Waiver is limited to fewer than 50 children. The current waiting list contains more than three times the current number served.

- The only source local school districts have for covering the expense of these high cost services is Catastrophic Aid funding through the Kansas Department of Education.

- Currently, the Kansas Insurance Department has no authority to require non-discriminatory coverage for Kansans with autism.

- Most Kansas families of individuals with autism eventually will need to look to the public Developmental Disability system for services. The current waiting list for needed service (2,233 individuals waiting for HCBS services and an additional 1,279 awaiting other services, for a total of 3,512) is growing each year as appropriations have failed to keep pace with the need. In addition, the inadequacy of reimbursement rates to cover the cost to recruit and retain direct support workers of acceptable quality has further rendered this system a broken resource.

Vision Statement

The Task Force expresses the following Vision Statement for autism supports and services to which Kansas should aspire.

> **All children in Kansas will receive screening for a developmental delay within the first year of life and for an autism spectrum disorder (ASD) within the second year. Children with a positive ASD screen will be referred for evidence-based intensive intervention immediately while undergoing a thorough diagnostic assessment within six months. Evidence-based intervention services (defined as at least 25 hours a week of systematic intervention for a period of three years for a child under the age of 8) will be readily available for all Kansas children with an ASD.**
>
> **High quality supports will be readily available to persons with autism who require them throughout the life span.**
>
> **Families, public schools, state and federal programs, service providers, and private health insurance carriers must each be fully participating partners in the achievement of this vision.**

LEGISLATIVE RECOMMENDATIONS

As a result of its findings, the Kansas Autism Task Force recommends that agencies which serve as support systems for families and children with autism (KDHE, Department of Education, SRS) should incorporate the guidance of the "Best Practices in Autism Intervention for Kansas" handbook produced by this Task Force into their administrative guidelines.

As a result of its findings in other areas, the Kansas Autism Task Force recommends the Legislature consider and adopt legislation as follows:

- Create a specific mechanism in the KDHE *tiny-k* funding formula to support local providers who must support high cost, intensive services identified in a child's Individualized Family Service Plan (IFSP).
- Expand funding of the Autism Medicaid Waiver to fully serve the current waiting list and transfer the future funding of this program to the consensus estimating process, where anticipated need will be the basis for funding and a waiting list is not an option.
- Pass legislation which requires that health insurance policies cover the diagnosis and appropriate treatment of individuals with autism.
- Pass legislation which creates and funds a scholarship program to support the education of professionals in the field of autism who agree to serve in underserved areas of the state.
- Pass legislation to fully fund the Mental Retardation/Developmental Disabilities HCBS waiting list and create adequate rates for the Developmental Disability system.
- To complete the objectives set for it by the Legislature, the Kansas Autism Task Force must have its term extended for an additional year. The necessary legislative authorization to accomplish this should be made retroactive to January 2009. (Please see the "Task Force Activities" section, page 4, for the complete rationale for this extension.)

In addition, the Department of Education should strive to ease the access to Catastrophic

Aid funds for school districts who serve high-cost students, such as those with autism.

It is incumbent on the three state agencies primarily responsible for services to individuals with autism (KDHE, Department of Education, and SRS) to collaboratively maintain a dynamic mapping website of the availability of services and supports across the state with current contact information. This site should be readily available and usable by parents seeking information and service.

Attachment: Executive summary of the "Best Practices in Autism Intervention for Kansas" handbook.

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Attachment

Executive Summary

Best Practices for Autism Treatment in Kansas

Best Practices Subcommittee of the
Kansas Legislative Task Force on Autism

Subcommittee members
Linda S. Heitzman-Powell, Ph.D., Convener
Adjunct Faculty, University of Kansas
Nanette Perrin, M.A.
Board Certified Behavior Analyst
Louise Heinz
Parent Representative
Jane Wegner, Ph.D.
Speech-Language-Hearing
Tracy Lee, M.S.
Special Education
Martin Maldonado, M.D.
Psychiatrist

Guest Members
Significant Contributors
Phoebe Rinkel, M.S.
University of Kansas Life Span Institute
Representing Kansas State Department of Education

Peggy Miksch, M.S., IMH-E™ (IV)
University of Kansas Life Span Institute
Representing Kansas Department of Health and Environment

Other Contributors
Nathan Yaffe, Student
Sarah Hoffmeier, MSW
Family Service and Training Coordinator
Diane Bannerman Juracek, Ph.D., BCBA
Senior Administrator
Community Living Opportunities, Inc.

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EXECUTIVE SUMMARY
Best Practices Subcommittee

The purpose of this report is to (1) synthesize the evidence regarding effective evidence-based interventions that guide best practices for the treatment of individuals affected by ASD; and (2) based on the findings, make recommendations on best practices for children with autism. This report was generated from the ideology that our process and recommendations are based on the most current science.

Synthesis of Evidence-based Practices

The Best Practices subcommittee agreed to review: 1) other state documents; 2) other comprehensive reviews that have been completed; 3) discipline-specific comprehensive reviews that were submitted to the subcommittee by members of the committee or guest members, and 5) key reports or scientific documents that have been generated in the last 5 years. The subcommittee agreed with Horner and colleagues' (2005) definition of evidence-based practice:

> "[evidence-based] Practice refers to a curriculum, behavior intervention, systems change, or education approach designed for use by families, educators, or students with the express expectation that implementation will result in measurable educational, social, behavioral, or physical benefit (pg. 175)."

The Best Practices subcommittee also defined criteria for strong, moderate, emerging, minimal and no evidence of interventions, and these criteria were used to make recommendations. These criteria were developed based on published criteria for reviewing evidenced based practices by prominent researchers and national scientific reviews including the National Standards Project (National Autism Center – http://www.nationalautismcenter.org/), the National Research Council, the American Speech-Language-Hearing Association's National Center for Evidence-Based Practice, and the Council for Exceptional Children. The agreed upon criteria were:

- Strongest evidence: more than six studies with more than 20 participants, with beneficial effects and no conflicting results or harmful effects, using Randomized Control Trials or single subject designs, and conducted by 3 researchers in 3 geographic regions.
- Moderate evidence: more than nine studies and the same criteria as used for 'strongest evidence, however one study showing conflicting results.
- Emerging evidence: four to five studies with more than 10 participants, the same benefits and scientific design as for strongest evidence but no criteria for the number or location of research.
- Minimal evidence: one to two studies, with four participants and the same benefits and scientific design as for strongest evidence but no criteria for the number or location of research.
- No evidence: no methodological criterion and no experimental control

Once these sources were identified, the recommendations cited as evidence-based were then synthesized. Interventions and program recommendations that adhered to the committee's criteria for "evidence" were then included in this report. Due to time and resources constraints, the Best Practices subcommittee procedures DID NOT include: 1) a comprehensive, first hand search and review of the scientific literature; 2) a review of all disciplines that could provide services for individuals with an ASD; and 3) a review of alternative medicines or techniques.

<u>Findings and Recommendations to the Autism Task Force</u>

Recommendations in this report are made with the understanding that each individual on the spectrum is unique. Given early diagnosis and intervention, outcomes will vary for individuals with an Autism Spectrum Disorder (ASD) just as outcomes for any child will vary based on individual characteristics. Individualized programs are recommended based on child needs and best available evidence of effective practices.

Recommendations are based on common elements of reported "best practices" and evidenced based programs: data collection and data-based decision making, structured and well-defined teaching procedures, use of procedures to increase desirable behaviors, function-based treatment of problem behaviors, and use of developmentally appropriate and well-rounded curriculum including peers when appropriate. Examples of evidence-based practices included: <u>Applied</u> Behavioral Analysis and Discrete Trial Teaching (e.g., University of California at Los Angeles, and replication sites); and 2 other intervention programs cited in a meta-analysis conducted by Simpson and colleagues (2005) Pivotal Response Training (PRT; University of California at Santa Barbara), and Learning Experiences: An Alternative for Preschoolers and Parents (LEAP). Examples of emerging or probably evidence-based (needing more research) included: Treatment and Education of Autistic and Communication Handicapped Children (TEACCH; University of North Carolina); and individual interventions such as assistive technology, augmentative alternative communication (AAC), incidental and naturalistic teaching, joint action routines, peer mediation intervention strategy, social stories intervention strategy, developmental play/assessment teaching, Picture Exchange Communication System (PECS), and video modeling.

Recommendations are also inclusive of general characteristics of quality programs based on syntheses provided of *Model Early Childhood Programs for Children with ASD* (see Boulware, et al. 2006; Dawson & Osterling, 1997; the National Research Council, 2001). Programs considered high quality by the reviewers (i.e., using evidenced-based practices, favorable reviews by multiple professional organizations) found a range of 15-40 hours per week of service, with average of 25 hours week. They found that the characteristics necessary for an effective program are: use of a comprehensive curriculum sensitive to developmental sequence, use of supportive, empirically validated teaching strategies, involvement of parents, gradual transition to more naturalistic environments, highly trained staff, and a systematic supervisory and review mechanism.

Finally, a large project sponsored by the National Autism Center, recently completed the National Standards Project, as an effort to use scientific merit to identify evidence-based guidelines for treatments of individuals with ASD younger than 22 years of age. The focus of the project was limited to "interventions that can reasonably be implemented with integrity in most school or behavioral treatment programs. A review of the biomedical literature for ASD will be left to another body of qualified individuals." (Wilczynski, et al., 2008, p. 39). A panel of multidisciplinary autism researchers applied a rigorous scoring system to evaluate the quality and usefulness of interventions for individuals with ASD described in nearly 1,000 studies. Results of the project are expected before the end of 2008 (http://www. nationalautismcenter.org). A recent publication by those involved in the *National Standards Project* includes recommendations of the best practices listed above (e.g., discrete trial training). The report also recommends four key behavior support interventions including: antecedent (preventive) intervention, positive reinforcement to decrease challenging behavior, behavior-contingent (restrictive) intervention as a function-based approach, and family support.

The following recommendations are the results of the Best Practices subcommittee work for the Legislative Task Force on Autism.

Best Practice Recommendations based on a Synthesis of Sources

1. Use of a model based on the science of human behavior such as that found in an Applied Behavior Analysis model of intervention. Applied Behavior Analysis has been referenced throughout the literature as having the most scientific evidence to support the use of techniques found in intensive behavioral programs.
2. Entry into intervention as soon as an ASD diagnosis is seriously considered rather than deferring until a definitive diagnosis is made.
3. Intensive early intervention is recommended. Intensive intervention has been defined throughout the review as active engagement of the child at least 25 hours per week, 12 months per year, in systematically planned, developmentally appropriate community, home, and educational-based interventions designed to address identified objectives.
4. Instructional programs and curriculum address all areas of delay and specifically address core deficits of ASD (e.g., social, communication, and repetitive/stereotypic behaviors).
5. Ongoing measurement and documentation of the individual child's progress toward identified objectives are recommended.
6. Promotion of opportunities for interaction with typically developing peers.
7. Problem or interfering behaviors are targets for reduction and/or replacement by using empirically supported strategies to teach socially valid replacement behaviors.
8. The staff members delivering the intervention have received specialized training in ASD that includes an experiential component.
9. Inclusion of a family component (including parent training as indicated); must involve family participation in development of goals, priorities and treatment plans and provide on-going parent support, training and consultation.

This report offers a synthesis of evidence-based practices and program characteristics for young children with ASD. Examples of quality programs are referenced, and characteristics described. Single intervention strategies with evidence supporting their effectiveness are also described. Recommendations to the Autism Task Force are provided as guidelines for practitioners to

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improve outcomes for children with ASD, and support for their families across the state of Kansas. Guidelines are based on current research and our review process of the research as described (review of state documents, reports from professional organizations, literature syntheses, and meta-analyses reports). A final recommendation is to provide periodic updates and supplements to the report as new research and treatment are developed.

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LAKEMARY

JOINT COMMITTEE ON CHILDREN'S ISSUES
DECEMBER 7, 2010

The 2007 Kansas Legislature created the Kansas Autism Task Force for the purpose of studying the issues related to the needs of persons with autism in Kansas and making recommendations to address those needs.

At that time it was noted that the prevalence of Autism Spectrum Disorders in Kansas, and nationwide, appeared to be increasing in epidemic proportions. The Centers for Disease Control reported the prevalence of these disorders as 1 in 150 births. Most recently that number has been revised to 1 in 110. While greater awareness and early identification certainly plays a part in these numbers it by no means accounts for the astounding increase.

In day two of your hearings you will be focusing on the more than 3,000 individuals waiting for developmental disability services in the State. A recent snapshot of the individuals on that waiting list indicates that as many as 30% of them carry an Autism Spectrum diagnosis. So the magnitude of the problem and the obligation that it carries forward for this State is increasing at alarming proportions.

The Autism Task Force completed its work in December of 2008 and provided a report to the 2009 Kansas legislature. Among its findings, the following are key: Autism Spectrum Disorders are biologically based neural developmental disabilities with a strong genetic component. Their prevalence is increasing in epidemic proportions. There is no proven cure for autism; however, the effectiveness of early, intensive intervention is proven to reduce the effects of this disorder. As many as half of the individuals who receive this level of intervention may not require subsequent special education and support services.

I will briefly describe its recommendations and the status of those recommendations at this time. Subsequent testimony today will provide much greater detail about their status.

First Recommendation: Create a mechanism in the KDHE Tiny-K funding formula to support providers who must provide high-cost, intensive services for children with autism. The thinking of this proposal was similar in nature to the current approach in the Department of Education for arranging for catastrophic funding for high-cost children in school. The logic being that when these very expensive services do occur, individual providers are quite often disproportionately challenged to address them. This recommendation has not been implemented and its status is up in the air.

Second Recommendation: Expand funding for the autism waiver to fully serve the waiting list. The autism waiver program in Kansas is one of the more innovative approaches to providing early intervention through Medicaid waiver services in the country. That is the good news. The bad news is the tragic fact that after creating this program the State has not funded the individuals who are eligible for its services. Currently less than 50 are actually in service, more than 200 are on a waiting list. At this point, as many children are aging out of the waiting list as are entering it as they grow older without the benefit of early intervention. This is a shameful situation.

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__Third Recommendation:__ **Pass legislation which requires health insurance policies to cover the diagnosis and appropriate treatment for individuals with autism.** This is the recommendation that became "Kate's Law" as originally known in the 2008 & 2009 legislatures and did result in the passage of "test-track" legislation for individuals on the State employee's health plans. While the outcome of this coverage is just now being assessed, our expectation is that the cost benefits will be clearly seen and the wisdom of expanding this sort of expectation for all State mandated insurance programs will be become obvious.

__Fourth Recommendation:__ **Create and fund a scholarship program to support the education of professionals in the field of autism who agree to serve in underserved areas of the State.** The Task Force became keenly aware of the shortage of trained professionals in the area of autism and particularly so in rural and western parts of the State of Kansas. This recommendation was not implemented. The current approach relies on the market-based assumption that once services are funded, professionals will move to those areas to provide such services. While this might ultimately be a legitimate theory it provides cold comfort for families whose children are waiting for those markets to respond while their children pass the critical stages of their early childhood with no service.

__Fifth Recommendation:__ **Fully fund the DD waiting list and create adequate rates for the DD waiver services.** This recommendation has obviously not been implemented. Again, it should be crystal clear that much of the burden of the DD waiting list is being created by the growth of the autism disorder and the failure to provide appropriate early intervention services.

__The Final Recommendation__ of the Task Force was to call on the three agencies jointly responsible for addressing the autism issues: KDHE, Department of Education, & SRS to collaboratively **create a mapping website on the availability of services and supports across the State.** This recommendation has not been implemented.

In conclusion, Kansas has done a decent job of creating some of the basic elements for a system to support children and families with autism with both the waivers and the insurance bill; however it has failed to adequately fund these efforts and to carry through with the infrastructure changes that are essential for a truly effective system.

As you will hear from families today and tomorrow, this type of theoretical analysis pales in comparison to the day to day challenges which they face and to the grim reality that as the clock ticks moments of growth and opportunity are irretrievably lost for these children.

Thank you for your willingness to devote this time to these issues for these two days. It is critically important.

Testimony provided by:

William Craig, Ph.D.
President/CEO
Lakemary Center
Paola, Kansas

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Overview of Medicaid Home & Community Based Services Waivers Operated by DBHS/CSS & MH and KDOA
Updated 10-8-10

WAIVER	AUTISM	DEVELOPMENTAL DISABILITY	PHYSICAL DISABILITY	TECHNOLOGY ASSISTED	TRAUMATIC BRAIN INJURY	FRAIL ELDERLY (operated by KS dept. on Aging)	SERIOUSLY EMOTIONALLY DISTURBED (SED)	COMMUNITY-BASED ALTERNATIVES TO PRTF
Institutional Equivalent	State Mental Health Hospital Services	Intermediate Care Facility for Persons with Mental Retardation	Nursing Facility	Acute Care Hospital	Head Injury Rehabilitation Facility	Nursing Facility	State Mental Health Hospital	Psychiatric Residential Treatment Facility (PRTF)
Eligibility	➢ Time of diagnosis through 5 years of age ➢ Diagnosis of an Autism Spectrum Disorder or PDD-NOS ➢ Meet functional eligibility ➢ Eligible for State Institutional	➢ Individuals age 5 and up ➢ Meet definition of mental retardation or developmental disability ➢ Eligible for ICF/MR level of care	➢ Individuals age 16-64* ➢ Determined disabled by SSA ➢ Need assistance with the activities of daily living. ➢ Eligible for nursing facility care **Those on the waiver at the time they turn 65 may choose to stay on the waiver*	➢ Children under age 22 ➢ Dependent upon intensive medical technology ➢ Medically fragile ➢ Requires the level of care provided in an acute hospital	➢ Individuals age 16-65 ➢ Have traumatic, non-degenerative brain injury resulting in residual deficits and disabilities ➢ Eligible for in-patient care in a Head Injury Rehabilitation Hospital	➢ Individuals age 65 or older ➢ Choose HCBS ➢ Functionally eligible for nursing care ➢ No waiver constraints	➢ Children 4-18; under 4 /over 18 if age exception approved ➢ Choose HCBS ➢ Determined Seriously Emotionally Disturbed by CMHC ➢ Meet admission criteria for State Hospital	➢ Children 4-18; under 4 /over 18 if age exception approved ➢ Choose HCBS ➢ Meet admission criteria for PRTF through a screen by the CMHC ➢ Children/youth preparing to discharge from a PRTF are automatically eligible
Point of Entry	Preliminary Autism Application sent to the HCBS/Autism Program Manager	Community Developmental Disability Organization	Case management Entities	Case management Entities	Case management Entities	Case management Entities	CMHC Staff	CMHC Staff
Financial Eligibility Rules	➢ Only the individual's personal income & resources are considered ➢ Parent's income & resources are not counted, but are considered for the purpose of determining a family participation fee ➢ Income over $727 per month must be contributed towards the cost of care	➢ Only the individual's personal income & resources are considered ➢ For individuals under age 18, parent's income & resources are not counted, but are considered for the purpose of determining a family participation fee ➢ Income over $727 per month must be contributed towards the cost of care	➢ Only the individual's personal income & resources are considered ➢ For individuals under age 18, parent's income & resources are not counted, but are considered for the purpose of determining a family participation fee ➢ Income over $727 per month must be contributed towards the cost of care	➢ Only the individual's personal income & resources are considered ➢ For individuals under age 18, parent's income & resources are not counted, but are considered for the purpose of determining a family participation fee ➢ Income over $727 per month must be contributed towards the cost of care	➢ Only the individual's personal income & resources are considered ➢ For individuals under age 18, parent's income & resources are not counted, but are considered for the purpose of determining a family participation fee ➢ Income over $727 per month must be contributed towards the cost of care	➢ Only the individual's personal income & resources are considered ➢ Income over $727 per month must be contributed towards the cost of care	➢ Only the individual's personal income & resources are considered ➢ For individuals under age 18, parent's income & resources are not counted, but are considered for the purpose of determining a family participation fee ➢ Income over $727 per month must be contributed towards the cost of care	➢ Only the individual's personal income & resources are considered ➢ For individuals under age 18, parent's income & resources are not counted ➢ Income over $727 per month must be contributed towards the cost of care

WAIVER	AUTISM	DEVELOPMENTAL DISABILITY	PHYSICAL DISABILITY	TECHNOLOGY ASSISTED	TRAUMATIC BRAIN INJURY	FRAIL ELDERLY (operated by KS dept. on Aging)	SERIOUSLY EMOTIONALLY DISTURBED (SED)	COMMUNITY-BASED ALTERNATIVES TO PRTF
Services/ Supports Additional regular Medicaid services are provided	➢ Consultative Clinical and Therapeutic Services (Autism Specialist) ➢ Intensive Individual Supports ➢ Parent Support/and training ➢ Family Adjustment Counseling ➢ Respite Services ➢ **Functional Eligibility Specialist is a contracted services*	➢ Assistive Services ➢ Day Services ➢ Medical Alert Rental ➢ Sleep Cycle Support ➢ Personal Assistant Services ➢ Residential Supports ➢ Supported Employment ➢ Supportive Home Care ➢ Wellness Monitoring	➢ Personal Services ➢ Assistive Services ➢ Sleep Cycle Support ➢ Personal Emergency Response ➢ Personal Emergency Response Installation	➢ Case Management ➢ Specialized medical care (skilled nursing) ➢ Long term community care attendant ➢ Medical respite ➢ Home modifications	➢ Personal Services ➢ Assistive Services ➢ Rehabilitation Therapies ➢ Transitional Living Skills ➢ Sleep Cycle Support ➢ Personal Emergency Response ➢ Personal Emergency Response Installation	➢ Adult Day Care ➢ Assistive Technology* ➢ Attendant Care Services ➢ Comprehensive Support* ➢ Medication Reminder ➢ Nursing Evaluation Visit ➢ Oral Health* ➢ Personal Emergency Response ➢ Sleep Cycle Support* ➢ Wellness monitoring *demotes suspended service; must meet crisis exception	➢ Wraparound Facilitation ➢ Independent Living / Skill Building Services ➢ Parent Support and Training ➢ Short Term Respite Care ➢ Professional Resource Family Care ➢ Attendant Care	➢ Wraparound Facilitation ➢ Independent Living / Skill Building Services ➢ Parent Support and Training ➢ Short Term Respite Care ➢ Professional Resource Family Care ➢ Attendant Care ➢ Employment Preparation and Support ➢ Community Transition Supports
Average Monthly Number Persons Served FY 10	40	7669	6964	379	323	5813	3,582	130
FY 10 Expenditures (All funds)	$752,930	$311,275,963	$140,511,241	$25,053,641	$13,085,895	$74,476,067	$47,816,387	$1,523,205
Estimated Average Waiver expenditure Mo/year	$1569/$18,828	$3,382 / $40,589	$1,681 / $20,176	$5523/$66,276	$3,376 / $40,514	$ 1,068/ $12,812	$ 1,112/ $13,344	$ 980/ $11,760
Institutional Setting Total Cost / Annually Per Person		Private ICF/MR $13,606,580 / $79,571 Public ICF/MR (combined)* $54,088,890 / $154,540	Nursing Facilities $358,545,585/ $33,863 (Includes persons who are aging)		Head Injury Rehab Facility $10,047,478 / $257,628	Nursing Facilities $358,545,585/ $33,863 (Includes persons with Physical disabilities)	$24,420	$33,033

Data from IBARS (Kansas Internet Budget and Reporting System)

Note: Data for the SED waiver and PRTF CBA include all Mental Health Services (waiver and non waiver services) paid through the Managed Care Entity, Kansas Health Solutions. Data for the Institutional equivalent setting for the SED waiver and the PRTF CBA are from the most recent Federal Cost Neutrality Demonstration reports.

University of Kansas Medical Center
Linda S. Heitzman-Powell, Ph.D.
Director of Community Research and Training
Testimony to the Joint Committee on Children's Issues
Tuesday, December 7, 2010

Senator Lynn and the rest of the committee: thank you for the opportunity to testify today. I am Linda Heitzman-Powell, Director of Community Research and Training at the University of Kansas Medical Center. I hold a faculty appointment in the Department of Pediatrics at the University of Kansas Medical Center, as well as an adjunct position in the Department of Applied Behavioral Sciences at the University of Kansas. I hold a Ph.D. in Developmental and Child Psychology from the University of Kansas and am a Board Certified Behavior Analyst. In addition to my university position, I have maintained an active role in providing intervention services to children with an autism spectrum disorder in Kansas for the past 13 years. I have worked diligently over this time to advocate for access to evidence-based practices for all Kansas families.

Today, my testimony will focus on best practices for young children with an Autism Spectrum Disorder. Autism Spectrum disorders, or ASD, encompasses more than just classic autism. The spectrum includes Aspergers Syndrome (no evidence of early language delay), and Pervasive Developmental Disorder Not Otherwise Specified. My remarks will specifically address the current availability of services, to the best of my knowledge, that use "effective" or evidence-based practices. Sources include input from published intervention research, knowledge from my colleagues, and my experience as a researcher and clinician actively engaged in providing intervention services to families and children with ASD. While we have made some gains since the Task Force concluded, there are still major gaps in services that need to be addressed by the 2011 legislature.

Three things are relevant:

How do we define effective practice?
What are some effective, or evidence-based, practices specific to Autism Spectrum Disorders?
What is the current state of evidence-based practices in Kansas?

How do we define effectiveness?

Standards for defining effective practice include both research and clinical practice. Sufficient research using appropriate methods to show evidence for the intervention or practice is critical. The data or outcomes for participants show a positive improvement in important behavior such as social communication, adaptive behaviors, or job skills. A second way is to have a number of "clinical replications." This means there are a number of people in different geographical locations using an intervention or method with outcome data showing improvement, but without the experimental methods.

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Note the use of ***data*** in both sources of information. It cannot be emphasized enough that an "evidence-based" approach relies on the use of data to determine what is effective. The effectiveness of what we do for persons with disabilities is as important as accessing services. In putting forth a systematic effort to build capacity in our systems for evidence-based services, it is imperative that we do it using effective techniques and the use of data for making intervention decisions.

In the field of autism, determining what is effective or what works is sometimes challenging. This is because of the unique characteristics of the disorder related to problems in 4 key areas:

Social interaction and developing relationships,
Language and communication skills,
Behavior patterns such as repetitive behaviors, obsessions or rituals,
Sensory issues such as oversensitivity to bright lights, textures, noise levels.

In general, it is harder to reach, teach, and motivate individuals with an ASD, their behavior is resistant to change, and their behaviors can be much more challenging than those seen in their typically developing peers.

What works? What are some effective interventions for persons with ASD that are relevant to transition planning and services for adults?

Each individual with ASD accrues about $3.2 million in costs to society over his lifetime (includes loss in productivity and adult care; Ganz, 2008)

In the business world, effectiveness means cost savings. It is not apparent that we apply a cost-benefits approach in our treatment decisions. The cost-savings to society with the implementation of an evidence-based approach is estimated to be close to $33,000 per year or ***$2.5 million*** over the course of the life time of the individual (Jacobson, Mulick & Green, 1998).

We all care about people and the quality of life for persons with disabilities, but we can do a better job if we pay closer attention to the effectiveness of service through the use of interventions that work. A critical part for determining the effectiveness of service is the accurate collection of data ***and the use of those data to modify the intervention if it is not working or to change the intervention to increase independence.***

Interventions that help 'teach new skills' including those needed for successful integration into home, school, and community life:

From my work on the Best Practices Subcommittee of the Legislative Task Force on Autism (Heitzman-Powell, et. al, 2008) (provided), we synthesized the evidence available at that time. Our recommendations included:

Best Practice Recommendations based on a Synthesis of Sources

1. Use of ***a model based on the science*** of human behavior such as that found in an Applied Behavior Analysis model of intervention. Applied Behavior Analysis has been referenced

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throughout the literature as having the most scientific evidence to support the use of techniques found in intensive behavioral programs.

2. ***Entry into intervention as soon as an ASD diagnosis is seriously considered*** rather than deferring until a definitive diagnosis is made.
3. ***Intensive early intervention*** is recommended. Intensive intervention has been defined throughout the review as active engagement of the child at least 25 hours per week, 12 months per year, in systematically planned, developmentally appropriate community, home, and educational-based interventions designed to address identified objectives.
4. ***Instructional programs and curriculum address all areas of delay*** and specifically address core deficits of ASD (e.g., social, communication, and repetitive/stereotypic behaviors).
5. ***Ongoing measurement and documentation of the individual child's progress*** toward identified objectives are recommended.
6. Promotion of opportunities for interaction with ***typically developing peers***.
7. ***Problem or interfering behaviors are targets for reduction*** and/or replacement by using empirically supported strategies to teach socially valid replacement behaviors.
8. The staff members delivering the intervention have received ***specialized training*** in ASD that includes an experiential component.
9. ***Inclusion of a family component (including*** parent training as indicated); must involve family participation in development of goals, priorities and treatment plans and provide on-going parent support, training and consultation.

These recommendations were further supported from a significant national effort that was underway at the time, the ***National Autism Center's National Standards Project*** (2009) (provided). Two-thirds of the strategies that were identified by the ***NAC*** were from the behavioral literature, of the remaining third, 75% of the articles were primarily behavioral. The remaining research was from speech and special education with less that 10% from Theory of Mind. These interventions frequently included behavioral components (National Standards Project, 2009).

The strategies identified by the *NAC* as an "established" treatment included:

<u>Skill Building Strategies</u>

1. Behavioral package (231 studies in Applied Behavior Analysis, Behavioral psychology, Positive Behavioral Support)
   - Choice
   - Functional communication training
   - Differential reinforcement
   - Tokens
   - Modeling
   - Contingency management
   - Schedules
   - Redirection
2. Comprehensive Behavioral Treatment for Young Children (under age 8) (22 studies in primarily ABA using methods such as discrete trial and incidental teaching)
   - Targeting symptoms of ASD
   - Treatment manuals

    - Intensive
    - Measured overall effectiveness
3. Joint Attention Intervention (6)
4. Modeling (50 studies – often combined with behavioral strategies such as prompting and reinforcement)

Problem Behavior Strategies

1. Antecedent Packages (99 studies in primarily ABA and Positive Behavioral Supports)
    - Modifications of events that precede problem behavior
2. Behavioral package (Applied behavior analysis, Behavioral psychology, Positive Behavioral Support)
    - See above

Specific recommendations made by the ***NAC*** further support the use of these *Established Treatments* when making treatment decisions for individuals with ASD.

In 2001 the ***National Research Council*** recommended that services begin as soon as a child is suspected of having an ASD and that those services should include a minimum of 25 hours per week, 12 months a year. The recommendations included guidelines that services be systematic and developmentally appropriate and treatment objectives should target the core characteristics of ASD including communication, socialization, cognitive development, and play skills throughout the day. These strategies should also take a proactive approach to behavior management.

Following the lead of the National Research Council's (2001) recommendations the NAC (2009) states:

> "We argue that unless compelling reasons exist to do otherwise, intervention services should be comprised of Established Treatments and they should be delivered following the specifications outlined in the literature (e.g.., appropriate use of resources, staff to student ration, following the prescribed procedures, et.) (pg. 31)"

What's Available to all Kansas Children?

Military Demonstration Program

The Demonstration Program falls under the ECHO Military Insurance Program. This program serves any child with ASD provided one of the child's parents are active duty military. All Providers under this program must be approved and go through the credentialing process with TriWest. The amount of hours is based on a $36,000 yearly cap of approved funds per client. The demonstration project pays for the following service providers and services:

1. Demonstration Project **Tutor (range between 12 & 18 hours per week)**
2. Demonstration Project **Supervisor (approximately .5 hours per week)**

3-4

An interesting note is the current estimate of the prevalence of ASD in American society are 1:110; in the military those numbers are 1:88. While there is no research aimed at determining the differences in prevalence rates, based on personal experiences, I am familiar with families that were reservists that went active duty for the benefits for their children. I also have personal experiences with families who delay retirement for the benefits for their children.

Thus, while this program is a significant benefit to military families, this program is not available to all Kansas children.

Kansas Early Autism Wavier Program

The Kansas Early Autism Wavier Program falls under the umbrella of Home and Community Based Services of the Kansas Medicaid Program. The program currently provides services for:
Respite (168 hours per year or 3.2 hours per week),
Intensive Individual Supports,
Parent Support and Training (25 hours per week),
Autism Specialist (50 hours per year, <1 hour per week), and
Family Adjustment Counseling.

To be eligible for the program, the child must have an autism diagnosis, and complete the application process. Once the application is completed and approved, they will then be placed on a proposed recipient list. The program serves children birth through age 6.

Kansas Department of Social and Rehabilitation Services was forward-thinking in the adoption of an evidence-based approach. SRS staff not only held focus groups to hear the needs of the community, they also looked to the research for sound recommendations. All recent recommendations have stressed the need for well-trained staff for intervention implementation. All service providers must be approved and attend training in order to provide services. Currently the University of Kansas Medical Center and the Kansas Center for Autism Research and Training (KU/Life Span Institute) provides the state approved training for individuals interested in providing services for the Early Autism Waiver.

The collaborative K-CART training mission is to increase the number of qualified service providers to support home and community-based services, who can then facilitate program development, implementation, and coordination of interventions across multiple environments including home, community, and school settings.

Overall Objectives of the Autism Training Program

- To provide a structured learning program in the use of evidence- based practices with children with an autism spectrum disorder.
- To provide trainees an opportunity to engage with a child with an ASD to practice skills in a structured, supportive environment.
- To provide trainees with exposure to an interdisciplinary team approach to the treatment of children with an ASD.
- To provide trainees with exposure to multiple learning environments through on-the-job training placements.

Training consists of three components:

1. Training modules (ten) are web-based instructional units and provide the foundation for trainees to learn essential information for working with children and youth with autism (See Modules Content in Appendix A. Approx. 20 hours)
2. Experiential learning consists of hands on one-to-one teaching of a child with autism under the supervision of the K-CART Autism Training Program staff (Approx. 10 hours).
3. On the job training consists of hands on teaching of multiple children with autism in job sites. These job sites include home- and school-based sites that are recruited by the K-CART Autism Training Program staff (Approx. 18 hours).

Collaborating On the Job Training Sites

Kansas City Autism Training Center KcATC http://kcatc.net
Partners in Behavioral Milestones, Milestones Academy School
http://www.behavioralmilestones.com/
Community Living Opportunities http://www.clokansas.org/

For related publications and research projects, see "Sources."

While the KS Early Autism Waiver Program is extraordinarily helpful to recipients, currently there are 262 children on the proposed recipient list: only 45 positions have been funded. Thus, this program does not fill the gap in services experienced by Kansas families that have children with ASD. Even if only 5 additional families were added per year, this would begin to chip away at the number of families that are desperately waiting for funding so that their children may benefit from the effects of intensive early intervention services.

Insurance

Currently Kansas is poised to enact an insurance mandate for a pilot bill for state employees. This bill will provide reimbursement for (among other services), 1) Autism Specialist services (for consultation, training, program development and oversight, and assessment), and 2) Intensive Individual Support services (for implementation of the programs developed by the Autism Specialist).

Some insurance companies have looked to the KS SRS Early Autism Waiver and have duplicated those training requirements and service provisions. Mike Wasmer will discuss the current bill in more detail later.

While this is a toe in the door for service provision, it again, does not address the needs for the entire community of individuals with ASD in the state of Kansas.

Before I leave today, I would like to summarize the following:

1. Kansas has been responsive to the needs of the community in the enactment of an evidence-based approach for intervention services and training requirements for its' Early Autism Waiver.

States from as far away as Alaska have contacted me in an effort to replicate Kansas' efforts. However, there are only 45 funded positions.
2. Kansas again has begun to enact insurance reform which has the potential to affect more individuals with ASD. However, only members of the State employees' health plan are covered.
3. While there are other insurances, e.g. the Military's Demonstration project, they also are not available to non-military citizens of Kansas
4. Finally, the beneficial impact of early, intensive intervention cannot be over stated. I would like to leave you with a look at the effects of this type of service on 2 children.

They say a picture paints a thousand words – and nothing can express this more than seeing the transformation over time.

View Video Clips

In close, I appreciate the opportunity to present information to you today and encourage you to explore ways to be able to help all Kansas Children benefit from the positive impact of intensive intervention services for ASD.

Respectfully submitted,

Linda S. Heitzman-Powell, Ph.D., BCBA-D
Licensed Psychologist

Sources:

Ganz, (April, 2008). Archives of Pediatrics & Adolescent Medicine, Ganz; Science Daily, Feb. 29, 2008).

Heitzman-Powell, L.S., Perrin, N., Heinz, L., Wegner, J., Rinkel, P., Miksch, P., et. al. (2008). *Best Practices for Autism Treatment in Kansas*. Best Practices Subcommittee of the Kansas Legislative Task Force on Autism, Report of the Kansas Autism Task Force Submitted to the 2009 Kansas Legislature.

Jacobson, Mulick & Green (1998). Cost benefit estimates for early intensive behavioral intervention for young children with autism – general model and single state case. *Behavioral Interventions, 13,* 201-226.

Luiselli, Russo, Christian, & Wilczynski, eds. (2008). *Effective Practices for Children with Autism: Education and Behavioral Support Interventions that Work*

National Autism Center, (2009). *National Standards Project.* Randolph, MA

National Research Council (2001). *Educating children with autism.* Committee on Educational Interventions for Children With Autism, Division of Behavioral and Social Sciences and Education. Washington, DC: National Academy Press.

Training

Related Publications

Buzhardt, J., & Heitzman-Powell, L. (2005). Training Behavioral Aides with a Combination of Online and Face-to-Face Procedures. *Teaching Exceptional Children, 37, 5,* 20-26.

Buzhardt, J., & Heitzman-Powell, L. (2006). Field Evaluation of an Online Foster Parent Training System. *Journal of Educational Technology Systems*, *34, 3,* 297-316.

Related Research Projects

NIDRR/United States Department of Education
H133G090136, Heitzman-Powell, PI (10/01/2009-9/30/20012)
Evaluation of the Online and Applied System for Intervention Skills (OASIS) Training Program for Parents of Children with an Autism Spectrum Disorder via Telemedicine Service Delivery.
NIDRR/United States Department of Education
H133G060238, Heitzman-Powell, PI (10/01/2006-9/30/2009)
Combining Technologies to Maximize Outcomes: Online and Telemedicine Training Program for Parents of Children with Autism.

Kansas Instructional Support Network

Funded through the Kansas State Department of Education's Special Education Services

Special Education Services for Students with ASD in Kansas

- Kansas School Districts provide services to students who are determined eligible for special education services based upon need, not educational or clinical label. The IEP provides parents and educational service providers the process to share information regarding the present level of performance, derive goals and benchmarks from that information, tie those goals to existing state standards and then determine the hours of service to be provided through special education. Once the services to be provided are determined, the team then identifies the least restrictive environment in which the services can be delivered and the environment in which the student can make educational progress. The Individuals with Disabilities Education Act mandate this process.
- In Kansas, the increase in the number of students reported to KSDE as having an ASD as their primary disability has been significant. ASD is the fastest growing disability group served by schools. In response to this unprecedented growth, KSDE has annually increased the resources that it puts toward the training of in-service teachers and the resources that it puts towards technical assistance to schools, through the Kansas Instructional Support Network, the Multi-Tier Systems of Support (MTSS) and through its' support of the Autism Internet Modules (autisminternetmodules.org).
- KISN is part of the Technical Assistance Statewide Network. Our charge is to provide training and technical assistance in effective practice to Kansas's schools. KISN adheres to the National Professional Development Center's Evidence-Based Practices. For more information of EBP and the NPDC on ASD please see: http://autismpdc.fpg.unc.edu/content/briefs
- The training that KISN provides is aligned with the CEC, NCATE approved National Competencies for Teachers of Autism (the complete list of those competencies can be downloaded at:

Attachment 4
JCCI
12-7-10

http://www.cec.sped.org/Content/NavigationMenu/ProfessionalDevelopment/ProfessionalStandards/

- Training on EBP is of little value unless the practices are put into place with fidelity. KISN, in an effort to move services providers from a "knowledge level" to a "skill level" of implementation provides on-site coaching in each of the practices we train. KISN coaches use the implementation checklists developed by the National Professional Development Center on ASD to determine the fidelity of implementation. That checklist is shared with the teacher, the building level administrator and the special education administrator.
- Training takes place on four distinct levels:
    - State—face-to-Face Training For example: Summer Institute Autism Specialists Summit, KISN Training Series.
    - Regional- Transition Assessment, Diagnostic Team Development
    - AIT are teams developed from existing district level resources and are usually comprised of an educator, school psychologist, SLP and an OT or PT. Coaching: KISN provides onsite coaching to the
    - Individual Student- KISN provides Intense Support Teams. KISN also provides training via webinar twice a month
    - KISN also provides training via webinar twice a month
- KISN also provides technical assistance by providing resources through our on-line lending library: http://kansasasd.com/node/122 and through referral to other services via telephone and email.
- Another form of Technical Assistance is on-site consultation for an individual student. Generally, districts request this level of assistance when they have exhausted their local resources and are not making the progress they hope to make.

Summary:

In the first 5 months of this fiscal year, KISN has

- Presented at 9 Conferences
- Provided 8 statewide trainings, 7 Regional Trainings and 5 District Level Trainings

- Provided 63 assessments
- Consulted in 88 classrooms
- Completed 47 of 90 Fidelity Checks associated with Summer Institute
- Distributed 286 Library Materials and handled 606 request for information and/or referral.
- Provided 3 Intense Support Teams
- Broadcast 8 webinars
- Distributed 10 Newsletters
- Provided coaching on assessment tools 37 times

More than 3000 people have attended training/presentations provided by KISN during FY2010.

Although KISN is the "autism" project, we understand and support the stance that children are not their labels, rather they are individuals whose diverse needs will never be able to be captured by a name, nor a designation from a diagnostic manual. In fact, a young man with autism named Justin has said repeatedly, labels are for cans, not people. As we provide training, we consistently remind participants that strengthening the entire educational system is the best way to provide for those with the most significant needs. It is our desire to have children served in the least restrictive environment possible, to that end it is important that those environments remain vibrant. There are no "autism specific" interventions; there is only best practice, based upon student needs, strengths and interests.

Again, Thank you for the opportunity to address the committee, of there are any questions, I would be happy to try and answer them.

Attachment 5
JCCI
12-7-10

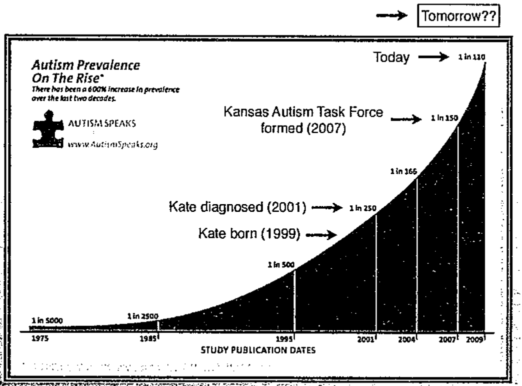
Health Insurance for Autism Spectrum Disorders in Kansas

A Discussion of HB 2160 and the Recommendations of the Kansas Autism Task Force

Presented to the Joint Committee on Children's Issues
December 7, 2010

Michael L. Wasmer, DVM
Founder, Kansas Coalition for Autism Legislation

www.kscoalitionforautism.org



→ Tomorrow??

*Autism Prevalence On The Rise**
There has been a 600% increase in prevalence over the last two decades.

AUTISM SPEAKS
www.AutismSpeaks.org

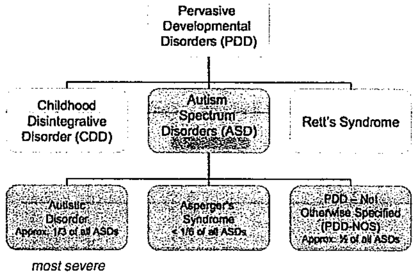
Today → 1 in 110

Kansas Autism Task Force formed (2007) → 1 in 150

Kate diagnosed (2001) → 1 in 250

Kate born (1999) →

Pervasive Developmental Disorders

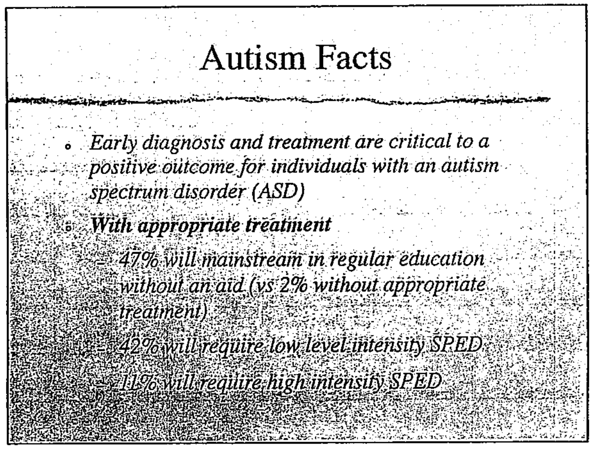


Pervasive Developmental Disorders (PDD)

- Childhood Disintegrative Disorder (CDD)
- Autism Spectrum Disorders (ASD)
  - Autistic Disorder Approx. 1/3 of all ASDs
  - Asperger's Syndrome < 1/6 of all ASDs
  - PDD – Not Otherwise Specified (PDD-NOS) Approx. ½ of all ASDs
- Rett's Syndrome

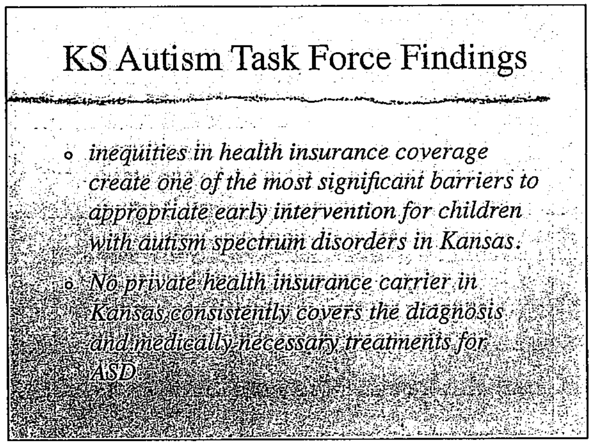
most severe

2



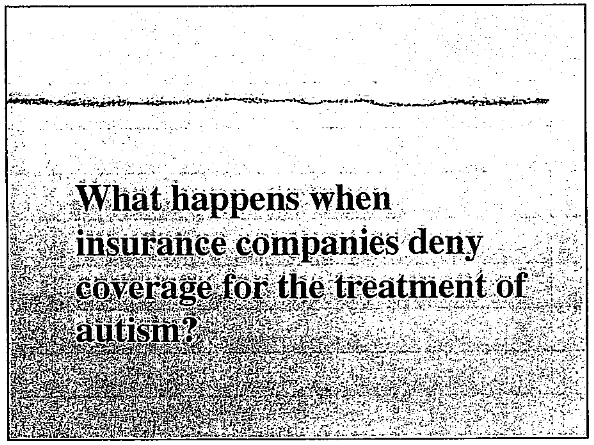
Autism Facts

- *Early diagnosis and treatment are critical to a positive outcome for individuals with an autism spectrum disorder (ASD)*
- ***With appropriate treatment***
  - *47% will mainstream in regular education without an aid (vs 2% without appropriate treatment)*
  - *42% will require low level intensity SPED*
  - *11% will require high intensity SPED*



KS Autism Task Force Findings

- *inequities in health insurance coverage create one of the most significant barriers to appropriate early intervention for children with autism spectrum disorders in Kansas.*
- *No private health insurance carrier in Kansas consistently covers the diagnosis and medically necessary treatments for ASD*



What happens when insurance companies deny coverage for the treatment of autism?

3-57

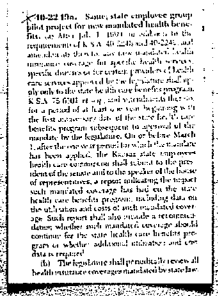
Financial Ruin

- *The out of pocket cost of treatment often exceed $50,000 per year*
- *Financially devastating to families - most go without or receive a fraction of prescribed treatment*
- ***<u>Without</u> appropriate treatment**, the lifetime cost to the state has been estimated to be **$3.2 million** <u>per child</u> with ASD*

KS Task Force Recommendation

- *SB 12 & HB 2367*
- *financial cap of $75,000 <u>only on ABA</u>*
- *unlimited coverage for other medically necessary autism treatments (e.g. ST, OT)*
- *through age 21*
- *exempt from the "pilot project" statute*

The "Pilot Project" Staute



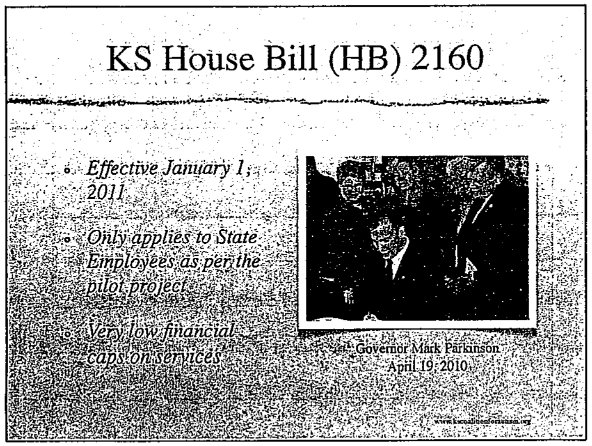
40-2249a. Same; state employee group pilot project for new mandated health benefits. (a) After July 1, 1999, in addition to the requirements of K.S.A. 40-2248 and 40-2249, and amendments thereto, any new mandated health insurance coverage for specific health services, specific diseases or for certain providers of health care services approved by the legislature shall apply only to the state health care benefits program, K.S.A. 75-6501 et seq., and amendments thereto, for a period of at least one year beginning with the first anniversary date of the state health care benefits program subsequent to approval of the mandate by the legislature. On or before March 1, after the one year period for which the mandate has been applied, the Kansas state employees health care commission shall submit to the president of the senate and to the speaker of the house of representatives, a report indicating the impact such mandated coverage has had on the state health care benefits program, including data on the utilization and costs of such mandated coverage. Such report shall also include a recommendation whether such mandated coverage should continue for the state health care benefits program or whether additional utilization and cost data is required.

(b) The legislature shall periodically review all health insurance coverages mandated by state law.

- *KSA 40-2249a*
- *to assess cost and utilization of proposed coverage*

www.kscoalitionforautism.org

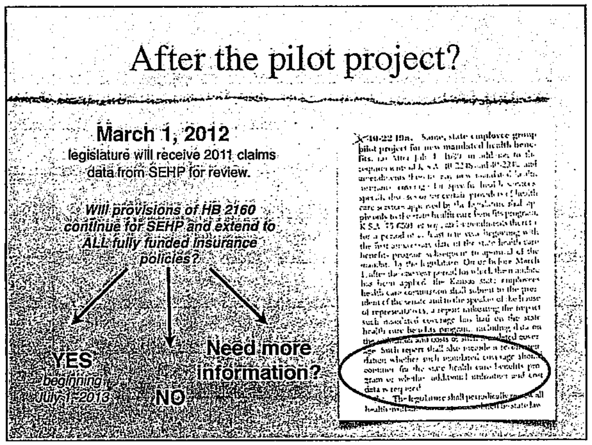
5-4



KS House Bill (HB) 2160

- *Effective January 1, 2011*
- *Only applies to State Employees as per the pilot project*
- *Very low financial caps on services*

Governor Mark Parkinson
April 19, 2010



After the pilot project?

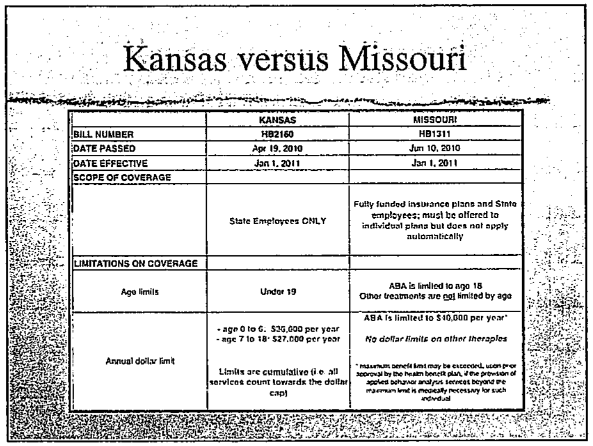
March 1, 2012
legislature will receive 2011 claims data from SEHP for review.

Will provisions of HB 2160 continue for SEHP and extend to ALL fully funded insurance policies?

YES
beginning July 1, 2013

NO

Need more information?

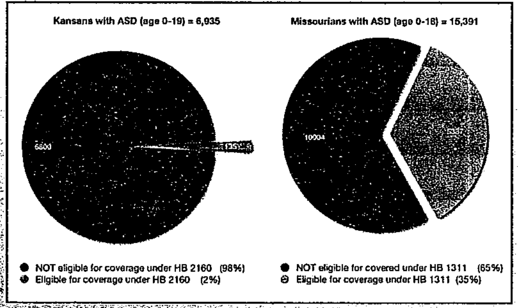


Kansas versus Missouri

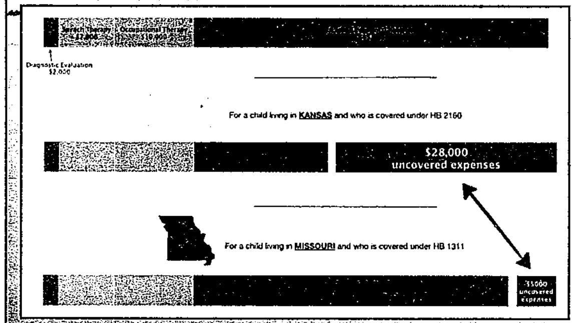
	KANSAS	MISSOURI
BILL NUMBER	HB2160	HB1311
DATE PASSED	Apr 19, 2010	Jun 10, 2010
DATE EFFECTIVE	Jan 1, 2011	Jan 1, 2011
SCOPE OF COVERAGE		
	State Employees ONLY	Fully funded insurance plans and State employees; must be offered to individual plans but does not apply automatically
LIMITATIONS ON COVERAGE		
Age limits	Under 19	ABA is limited to age 18 Other treatments are not limited by age
Annual dollar limit	- age 0 to 6: $36,000 per year - age 7 to 18: $27,000 per year Limits are cumulative (i.e. all services count towards the dollar cap)	ABA is limited to $40,000 per year* *No dollar limits on other therapies* * maximum benefit limit may be exceeded, upon prior approval by the health benefit plan, if the provision of applied behavior analysis services beyond the maximum limit is medically necessary for such individual

5-5

Scope of Coverage: KS vs MO



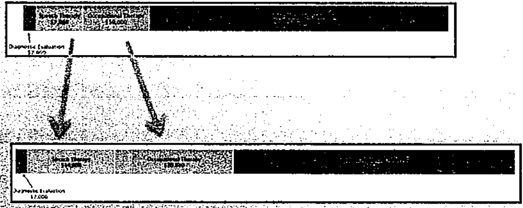
Limitations on Coverage: KS vs MO



For a child living in **KANSAS** and who is covered under HB 2160

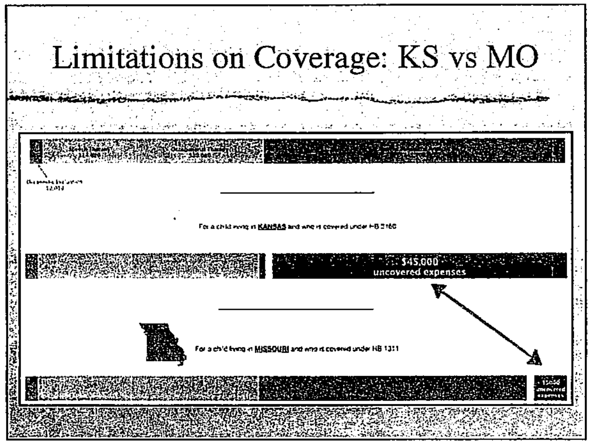
For a child living in **MISSOURI** and who is covered under HB 1311

Another Example



5-6

Limitations on Coverage: KS vs MO

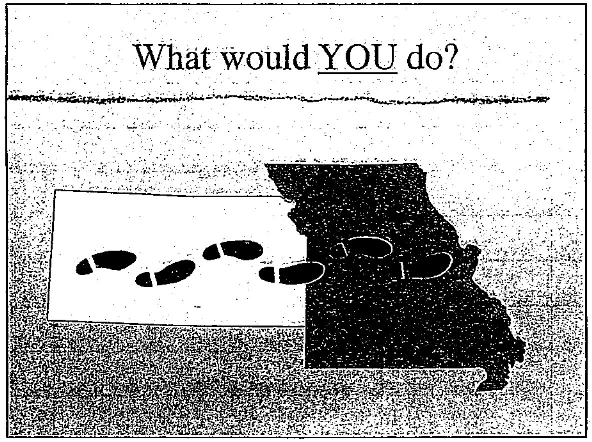


For a child living in KANSAS and who is covered under HB 2160

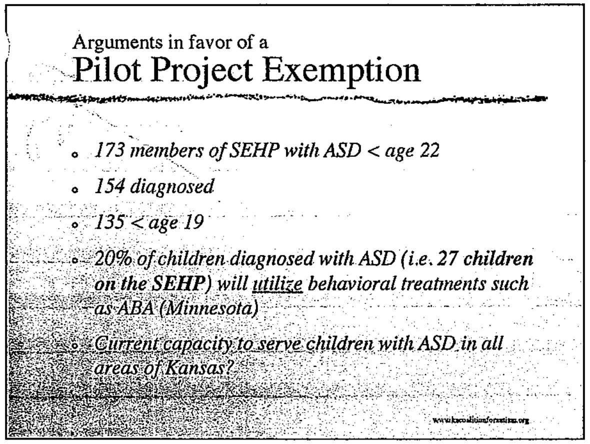
$45,000
uncovered expenses

For a child living in MISSOURI and who is covered under HB 1311

What would YOU do?



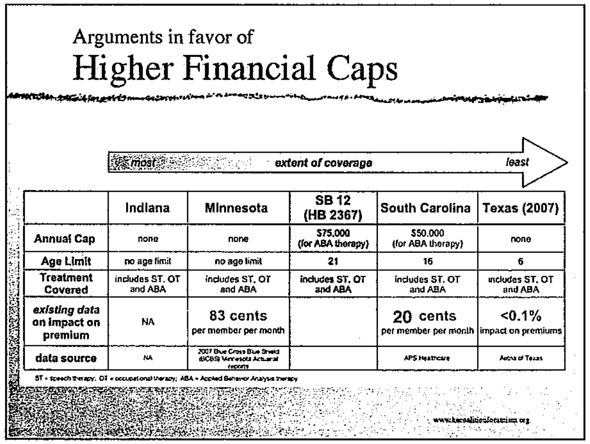
It is imperative that the 2011 Kansas Legislature enact a bill that is comparable to Missouri HB 1311 this session



Arguments in favor of a

Pilot Project Exemption

- *173 members of SEHP with ASD < age 22*
- *154 diagnosed*
- *135 < age 19*
- *20% of children diagnosed with ASD (i.e. 27 children on the SEHP) will utilize behavioral treatments such as ABA (Minnesota)*
- *Current capacity to serve children with ASD in all areas of Kansas?*



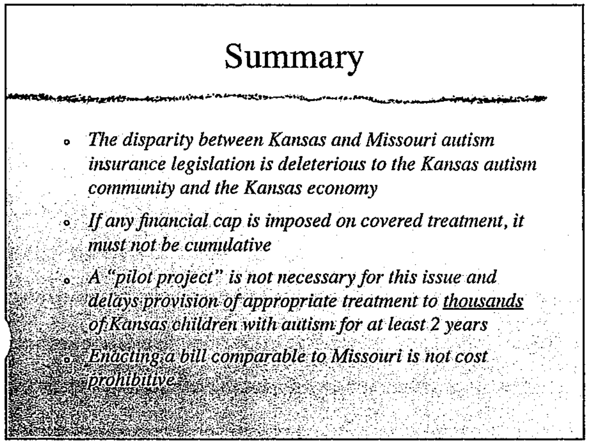
Arguments in favor of

Higher Financial Caps

most — *extent of coverage* — *least*

	Indiana	Minnesota	SB 12 (HB 2367)	South Carolina	Texas (2007)
Annual Cap	none	none	$75,000 (for ABA therapy)	$50,000 (for ABA therapy)	none
Age Limit	no age limit	no age limit	21	16	6
Treatment Covered	includes ST, OT and ABA	includes ST, OT and ABA	includes ST, OT and ABA	includes ST, OT and ABA	includes ST, OT and ABA
***existing data* on impact on premium**	NA	83 cents per member per month		20 cents per member per month	<0.1% impact on premiums
data source	NA	2007 Blue Cross Blue Shield (BCBS) Minnesota Actuarial reports		APS Healthcare	Aetna of Texas

ST = speech therapy; OT = occupational therapy; ABA = Applied Behavior Analysis therapy



Summary

- *The disparity between Kansas and Missouri autism insurance legislation is deleterious to the Kansas autism community and the Kansas economy*
- *If any financial cap is imposed on covered treatment, it must not be cumulative*
- *A "pilot project" is not necessary for this issue and delays provision of appropriate treatment to thousands of Kansas children with autism for at least 2 years*
- *Enacting a bill comparable to Missouri is not cost prohibitive*

The Kansas Coalition for Autism Legislation (KCAL)

www.kscoalitionforautism.org

Michael Wasmer
wasmer_ms@mac.com
913-626-0668

Attachment 6
JCCI
12-7-10

Insurance Coverage for Autism: A National Perspective

December 7, 2010
Judith Ursitti, CPA
Regional Director
State Advocacy Relations
Autism Speaks

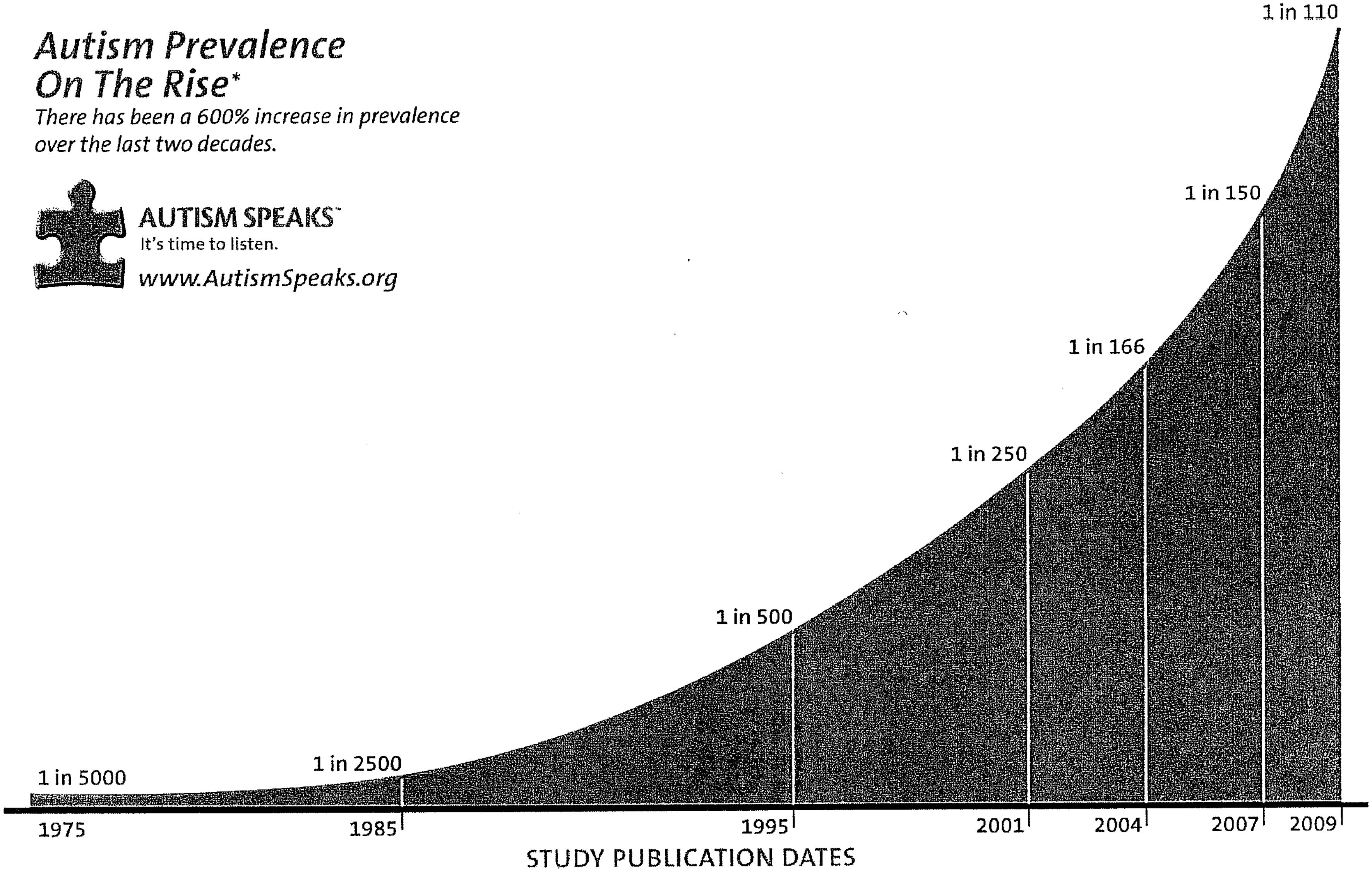
12/7/10

6-2

*Autism Prevalence On The Rise**

There has been a 600% increase in prevalence over the last two decades.

AUTISM SPEAKS™
It's time to listen.
www.AutismSpeaks.org

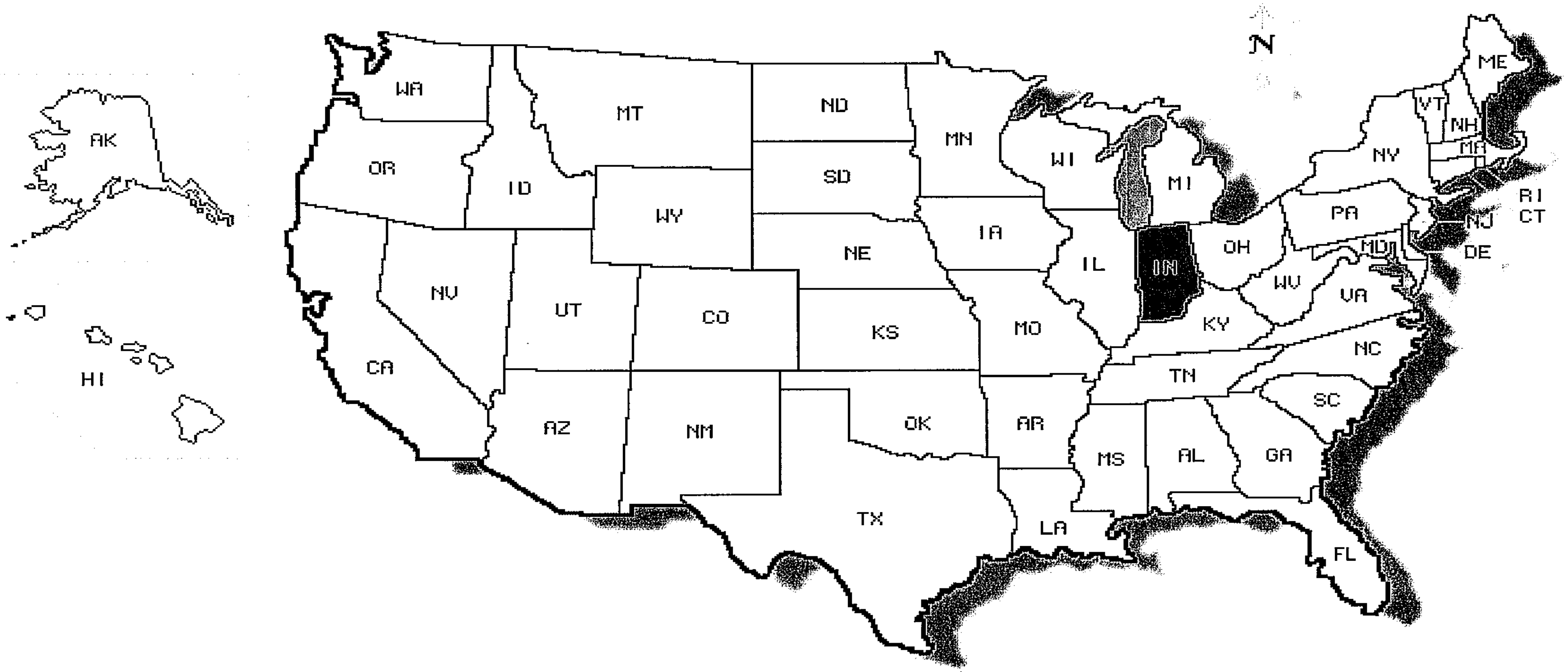


*Recent research has indicated that changes in diagnostic practices may account for at least 25% of the increase in prevalence over time; however much of the increase is still unaccounted for and may be influenced by environmental factors.

Outline

6-3

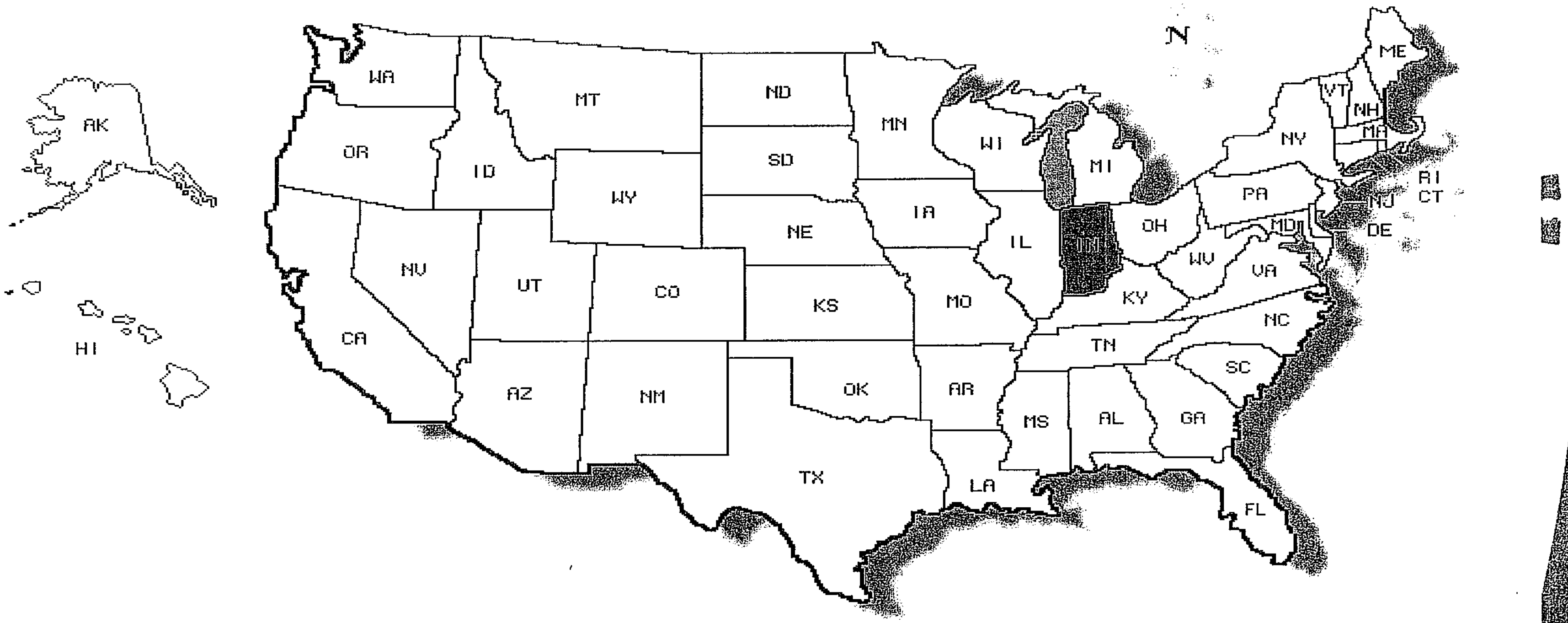
2001 Snapshot



7-20-10

4-9

2002 Snapshot

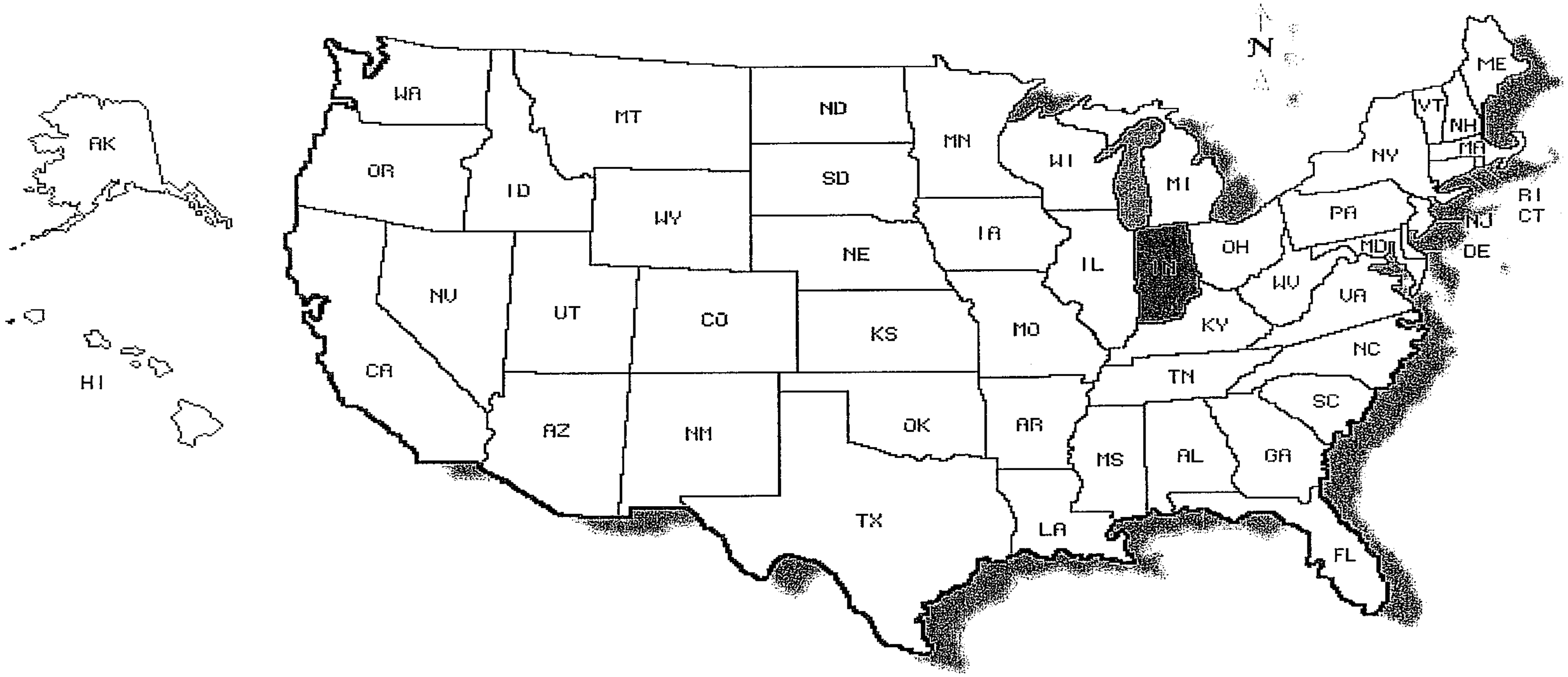


7-20-10

Jack, born in 2003

9-7

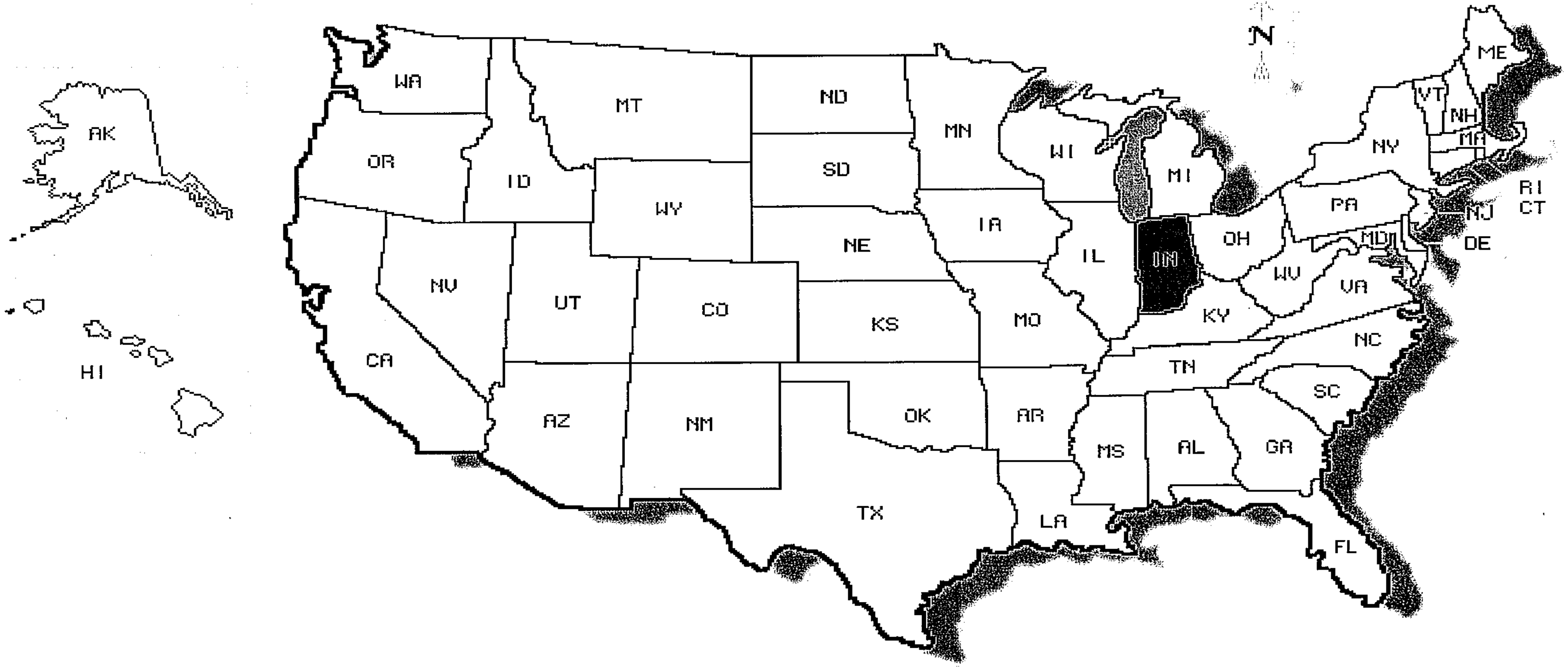
2003 Snapshot



7-20-10

6-7

2004 Snapshot



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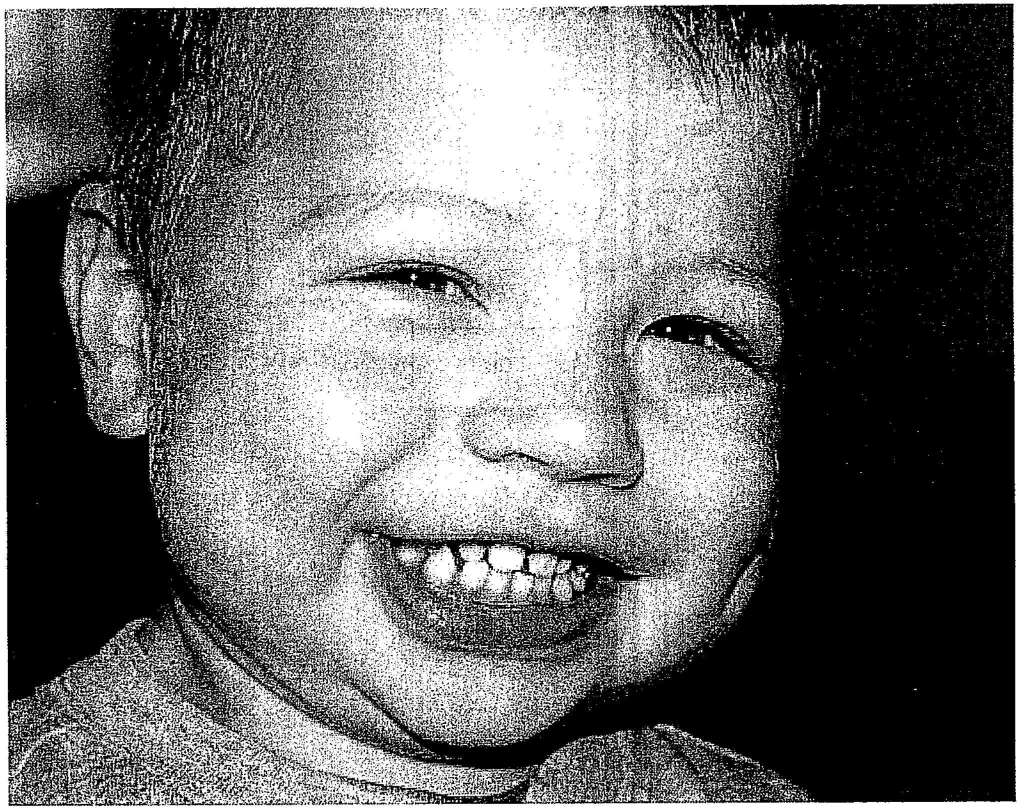
Jack, diagnosed with autism in 2005



6-9

Autism Speaks

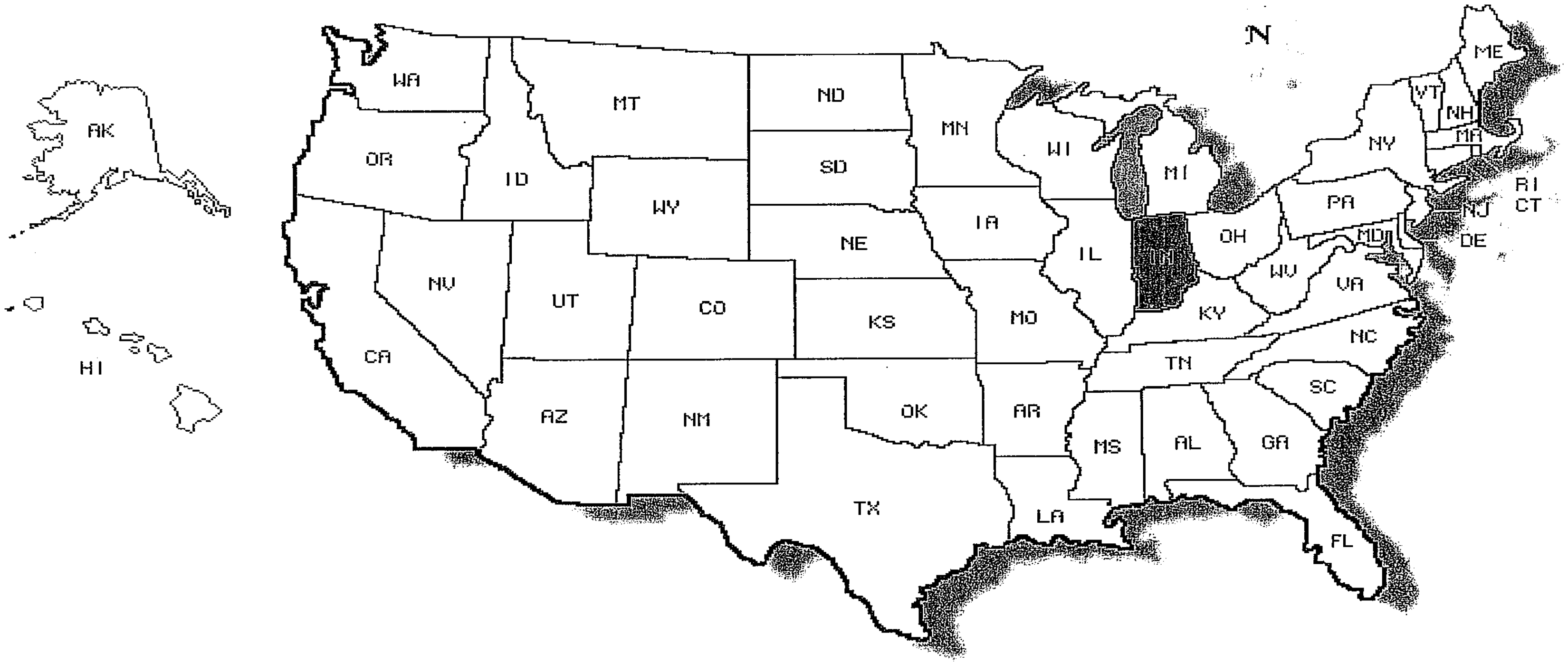
Autism Speaks – Founded in 2005,it is the world's largest autism advocacy organization - and is dedicated to increasing awareness of autism spectrum disorders, to funding research into autism, and to advocating for the needs of affected families

www.autismvotes.org

www.autismspeaks.org

AUTISM SPEAKS
It's time to listen
www.AutismSpeaks.org

2005 Snapshot



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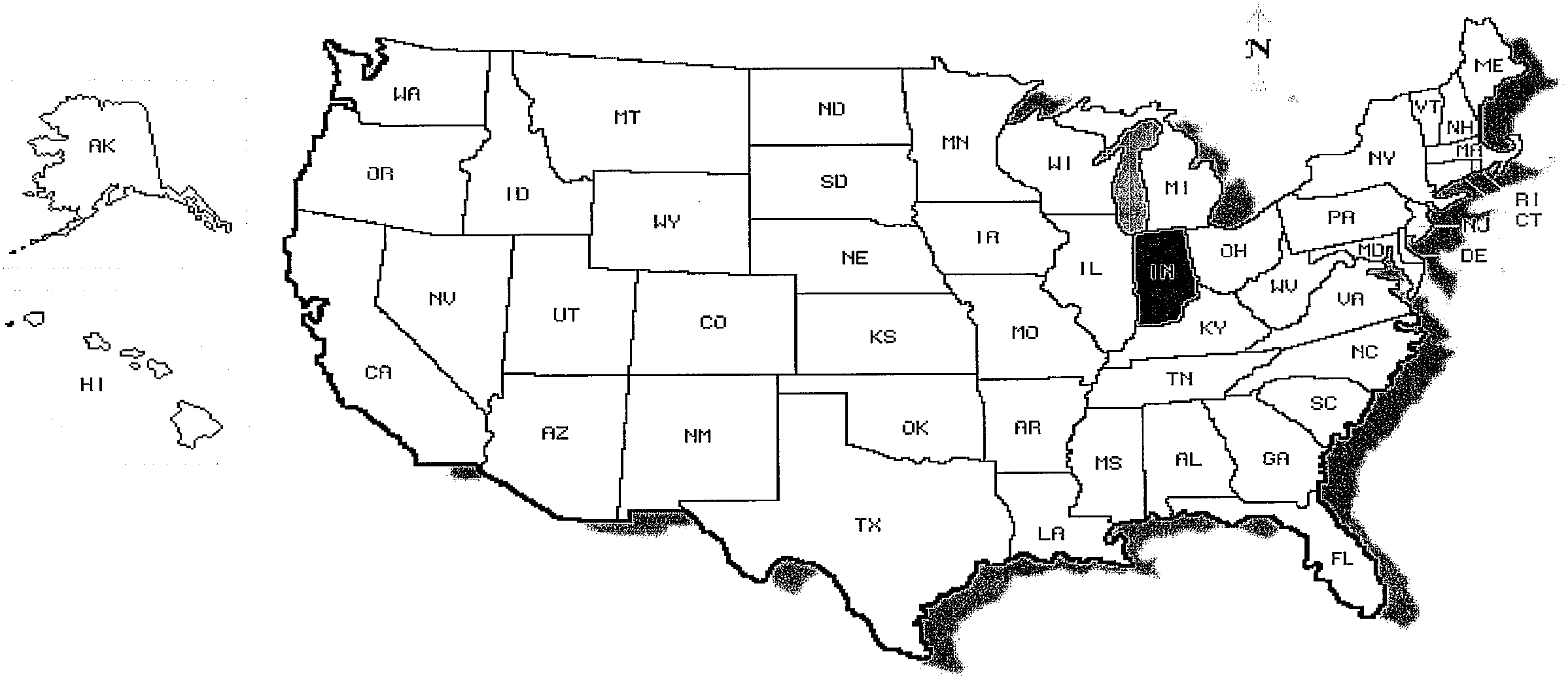
2006 Snapshot



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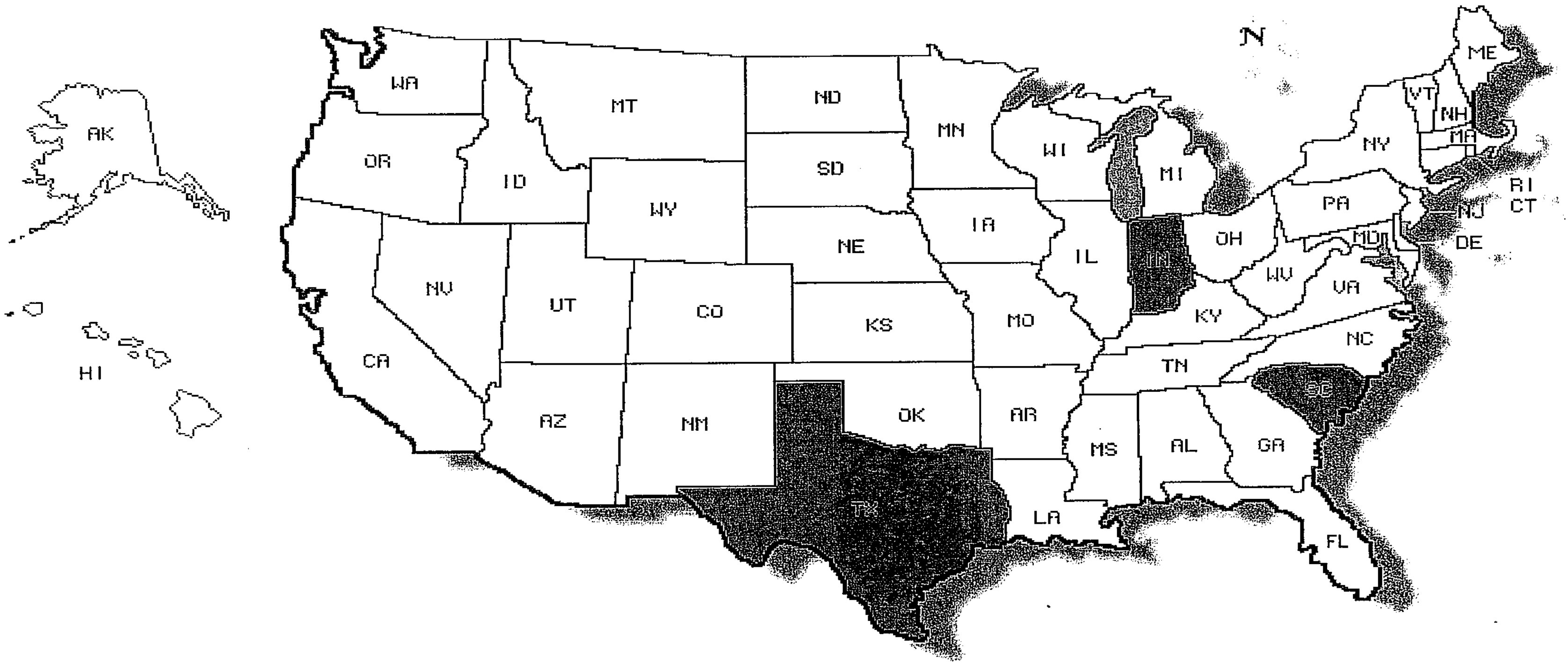
6-12

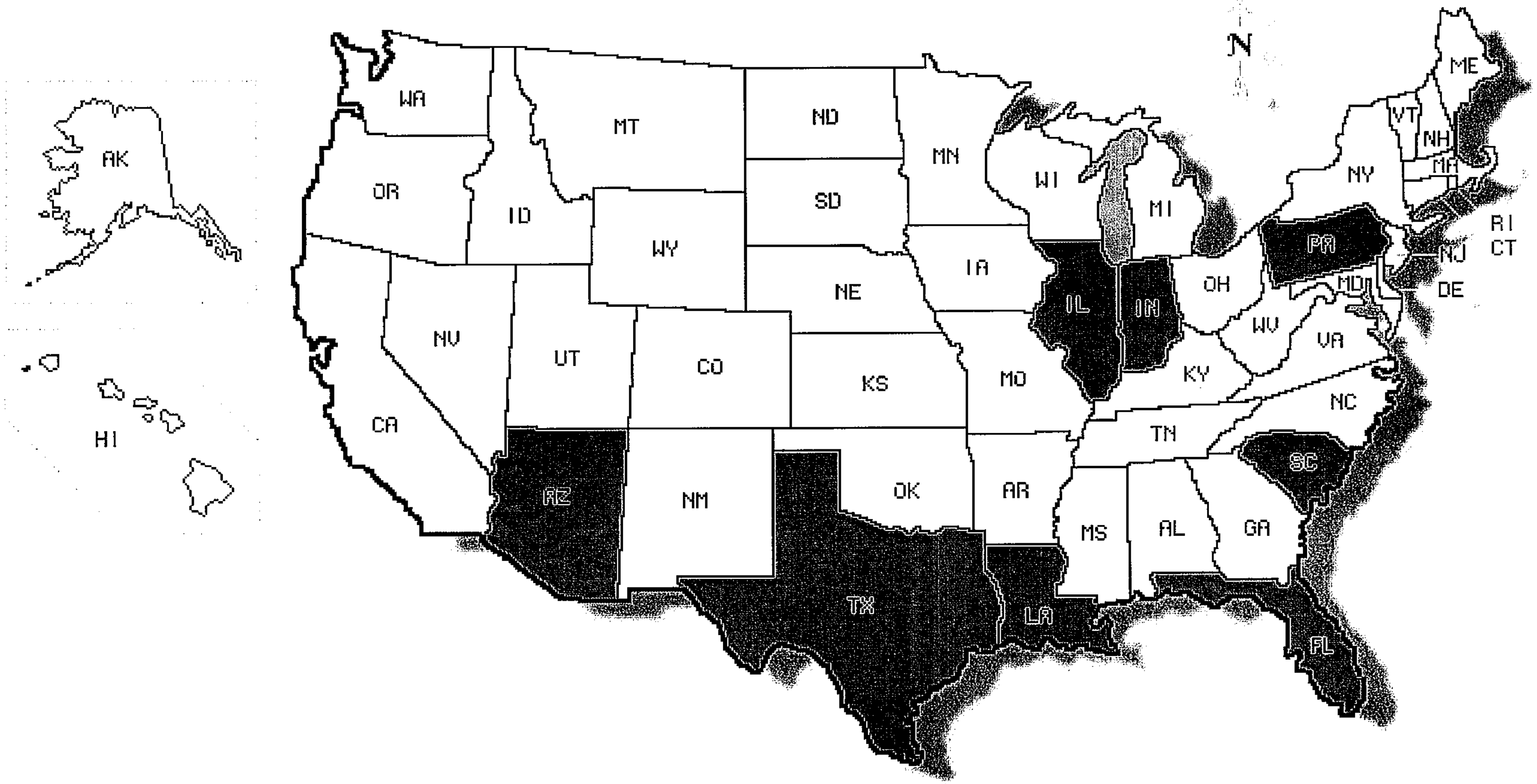
2007 Snapshot



5-29-10

6-13

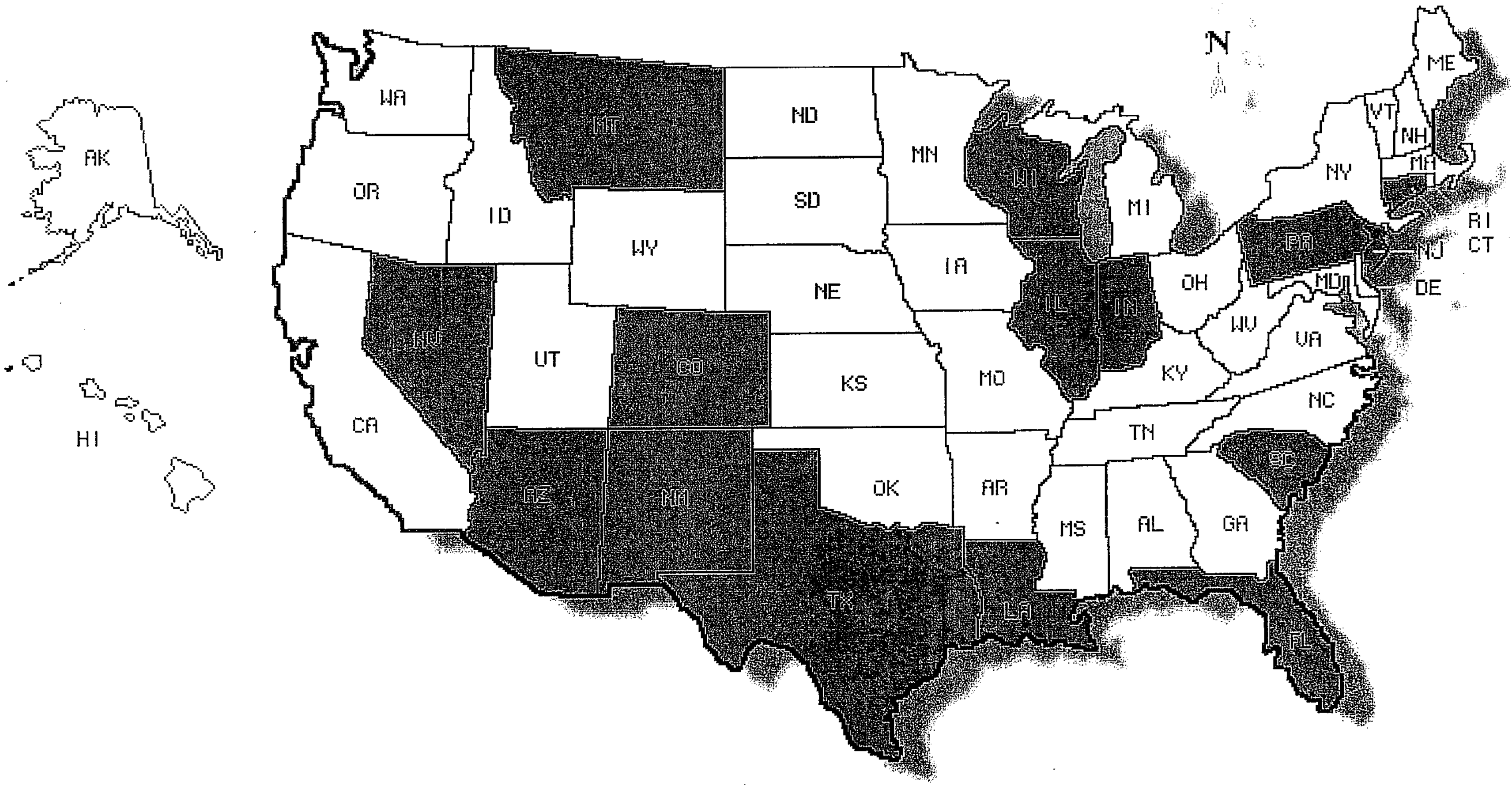
2008 Snapshot



5-29-10

41-9

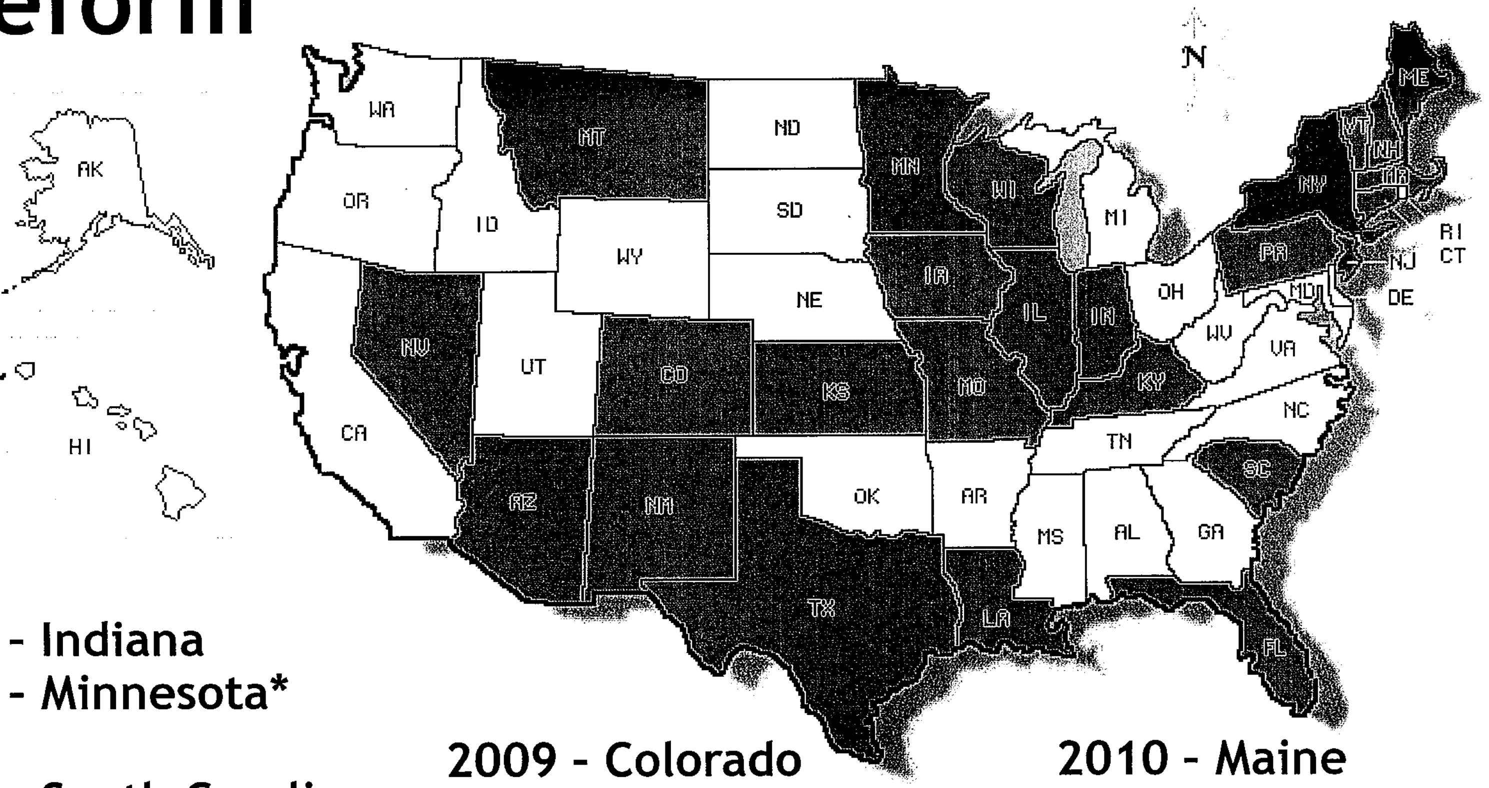
2009 Snapshot



7-20-10

6-15

States with Autism Insurance Reform



2001 - Indiana
2001 - Minnesota*

2007 - South Carolina
2007 - Texas

2008 - Arizona
2008 - Florida
2008 - Louisiana
2008 - Pennsylvania
2008 -- Illinois

2009 - Colorado
2009 - Nevada
2009 - Connecticut
2009 - Wisconsin
2009 - Montana
2009 - New Jersey
2009 - New Mexico

2010 - Maine
2010 - Kentucky
2010 - Kansas^
2010 - Iowa^
2010 -- Vermont
2010 - Missouri
2010 - New Hampshire
2010 -- Massachusetts

6-16

Autism Spectrum Disorder

- Curable? No
- Treatable? Yes

- Impaired Communication
- Impaired Social Interaction
- Repetitive or Stereotyped Patterns of Behavior
- Narrow Range of Interests

- Four times more common in boys than girls

Applied Behavior Analysis (ABA Therapy)

- One-on-one therapy based on principles of repetition, reinforcement, and extinction.
- When an environment supports a set of behaviors, they increase. When an environment does not support behaviors, they tend to extinguish and fade away.

81-7

ABA Therapy Is Not Experimental

- “Thirty years of research demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior.”

  Report of the Surgeon General of the United States, 1999

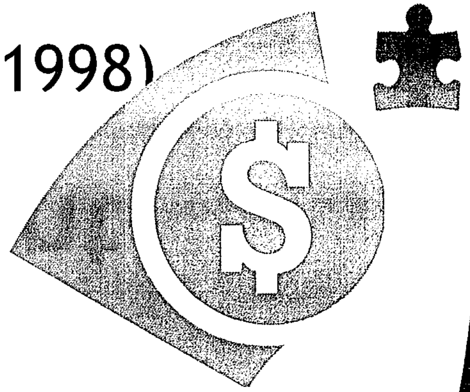
- “ABA therapy is not experimental or investigational in nature.”

  McHenry v. PacificSource Health Plans *(D. Oregon, Jan. 5, 2010)*

Societal Costs of Autism

- Harvard School of Public Health (Ganz, 2006)
- $3.2 million per person over lifetime
  - Includes direct and indirect costs, such as lost productivity

- Pennsylvania (Green, Jacobson & Mulick, 1998)
- Over $1 million per person



“The treatments you want covered are educational in nature, not medical.”

Educational?

- Diagnosed by doctor
- Wrong analytical framework
- Under IDEA, public schools must provide a “free, appropriate” education to children with special need.
  - Quality and quantity of school services to children with autism varies by district
  - Schools not charged with ameliorating condition
  - Health-related treatments differ from school services in scope, nature, and intensity

- The school system should not bear the brunt of caring for children with autism while the private health system enjoys a pass.

"I've heard that the treatment you want coverage for is experimental and/or ineffective."

Ineffective?

- Such policy statements are simply not supported by science.

"The effectiveness of ABA-based intervention in ASDs has been well documented through 5 decades of research . . . . Children who receive early intensive behavioral treatment have been shown to make substantial, sustained gains in IQ, language, academic performance, and adaptive behavior as well as some measures of social behavior, and their outcomes have been significantly better than those of children in control groups."

American Academy of Pediatrics

4-24

Experimental?

"Thirty years of research demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior."

Report of the Surgeon General of the United States, 1999

“We don’t make insurers pay for treatment by <u>non-licensed providers</u>.”

12.7

Provider Credentials
www.BACB.com

The Behavior Analyst Certification Board, Inc.® (BACB®) is a nonprofit corporation established as a result of credentialing needs identified by behavior analysts, state governments, and consumers of behavior analysis services.

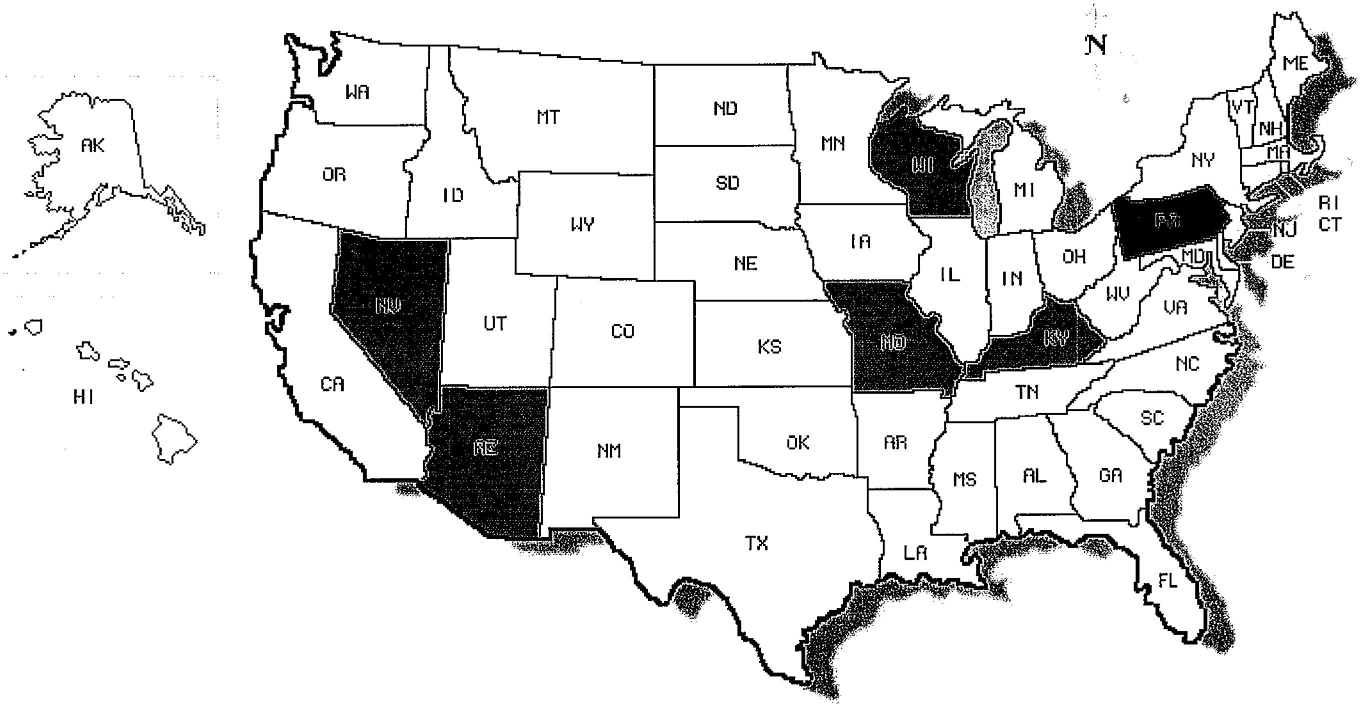
The BACB's mission is to develop, promote, and implement a voluntary international certification program for behavior analyst practitioners. The BACB credentials Board Certified Behavior Analyst® BCBA®) and Board Certified Assistant Behavior Analyst® (BCaBA®).

NCCA

NCCA ACCREDITED PROGRAM

Insurance States that License Behavior Analysts

- ● - License
- ● - "Behavior specialist
- - License/no insurance



5-29-10

I'm really sympathetic, and I think your kids should get treatment, but it's just too expensive .

6.29

South Carolina State Employee Health Plan

- Population
  - State has 4.5 M
  - State employee health plan has 350,000 members
  - 63,000 kids age 2-15
  - $50,000 cap on ABA
  - To age 16
- Original Projected Cost: $18.9 million

  Revised: $9 million
- Actual cost in 2009

  $856,371

  PMPM: 20 cent

6-3

Actual Claims Data
BCBS of Minnesota

- In effect for nearly 10 years
- No dollar cap; no age cap
- Premium impact PMPM = $0.83
- Average annual cost of ABA = $30,000

12/7/10

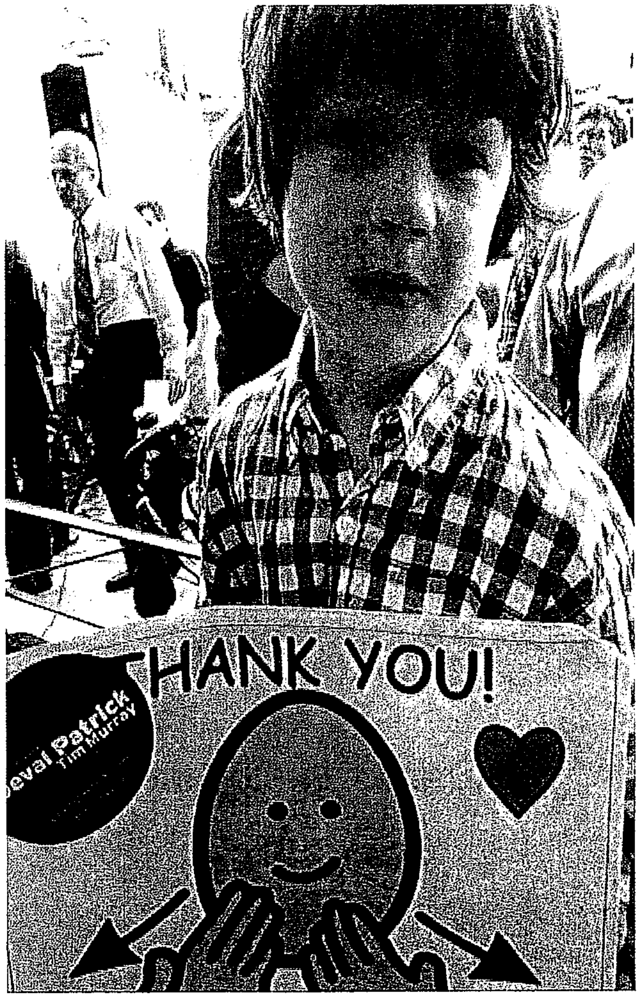
Self Insured Companies Providing Benefit

- Microsoft
- Home Depot
- Intel
- Arnold & Porter
- Halliburton
- Eli Lilly
- Deloitte
- Ohio State University
- IBM
- Lexington Medical Center
- University of Minnesota
- Progressive Group
- Michelin
- Greenville Hospital System
- DTE Energy
- Princeton University

12/7/10

Much has been accomplished...

And much remains to be done.



"[N]o disability claims more parental time and energy than autism."

New York Times,
12/20/04

Testimony by: **Lisa, Blake, and Loren Wendelburg**
Phone: 913-248-8071 Email: lwendelburg@kc.rr.com

I. Diagnosis

A. Loren was diagnosed with PDD/NOS, which falls under the autism spectrum at KU Med when he was 3 yrs old.
B. Early diagnosis important to start early treatment

II. Treatment-

As parents we were overwhelmed how to proceed
A. KU Recommended ABA 20-40 hours per week
B. Found a highly qualified professional to begin a home program of ABA
C. Hired and managed a home team of professionals

II. Progress from 3 years old to 5 years old

A. Loren began ABA with delays in Speech –
When 3 and was 1 ½ years behind in speech.
B. With ABA program he gained 3 years of speech in 3 months!
C. He worked 7 days a week all day
D. Other skills other kids take for granted, Loren had to work hard to achieve, such as riding a bike, doing "thumb's up", responding to his name, looking in someone's eyes, sitting in a chair for more than a minute.

III. Kindergarten through 4th grade- in Shawnee Mission School District

A. Able to be in a regular education classroom in with some assistance
B. Able to keep up and even excel in academics
C. Required assistance with social skills and executive functioning skills
D. Not all these school years perfect but we were able to at least work with building level school team.
E. Loren had some wonderful teachers who understood the importance of working with home team
F. We provided assistance to school staff and it was welcomed
G. Sent school staff to workshops, purchased books, supplies, education materials, flew in experts, not just to help Loren but all children with ASD's
H. Speech Language Pathologist had given up on how to teach social skills - provided her with literature and information and she used the information to help other children in the school.
I. We were constant volunteers in the school and did anything we could to help all children.
J. Through these years Loren continue to go to Shawnee Mission Schools in regular education classroom by day and continued home ABA program in evenings, week ends, and holidays and he continued to progress

Attachment 7
JCCI
12-7-10

   a. He had made real friends who adored him
   b. Excelled at reading and story telling
   c. Learned to play piano and sing well
   d. Auditioned and received a part in a local theatre's musical

IV. 5th grade year- Loren was 10 years old

A. As first semester progressed, our son came home more distraught.
   a. He was not sleeping, having night terrors, with nausea and vomiting,
   b. Not wanting to go to school
   c. Usually loved going to school

B. Met with SMSD personnel including Resource Room teacher, Principal, Special Education Director for our area.

C. Loren went to principal to advocate for himself.
   a. Loren had trusted the principal
   b. Loren told principal, teachers bullying him
   c. Principal scolded Loren for suggesting such a thing was happening.

V. Email from parent of a classmate

A. Received morning of December 2, 2008

B. Email outlines Loren's classmate coming home on numerous occasions in tears at treatment he witnessed by teacher toward our son

C. LOREN TO READ EMAIL FROM THIS PARENT (ATTACHED)

D. LOREN TO EXPRESS HOW MADE HIM FEEL TO BE ABUSED BY TEACHER.

E. I immediately pulled Loren from class/ school and met with principal

F. We met with Shawnee Mission School District personnel

G. Ultimately we attempted to arrange to not have this teacher involved with our son's education any longer.

VI. SRS investigated abuse

A. A report was filed with SRS Abuse Hotline by Loren's case manager regarding the abuse by this teacher of Shawnee Mission Schools

B. SRS findings arrived- after approximately 90 days

C. SRS FINDINGS (ATTACHED)- Read finding

D. Irony is this is the teacher that taught anti-bullying classes to the children

E. Shawnee Mission School District appears to only have policies regarding student on student bullying and not teacher on student bullying and/ or abuse.

F. Read and provided SMSD a copy of SRS findings but they continue to deny any wrong doing.

G. SRS reporting confusing and misleading "Unsubstantiated" even if abuse occurred but not a threat to "other" children.

H. SRS reporting confusing for Police Departments as we found with Lenexa Police Department who were suppose to investigate our son's abuse.

VII. Shawnee Mission School District refused to remove abusive teacher from our son's classroom- even after SRS finding

A. Only choices SMSD gave us to educate our son
  a. Return to abusive teacher's class
  b. Be taught in a separate smaller room by himself with para without his classmates or friends.

B. SMSD could not keep our son safe from this abusive teacher so we were forced to remove him from SMSD and he has been home schooled this past year and a half.

C. Diagnosed with Post Traumatic Stress Disorder- long rode healing
Still nightmares/ may never be able to be in another school/ lost trust

VII. SRS Appeal

A. Tried to appeal to show teacher was a threat to other children
B. READ SRS APPEAL info (ATTACHMENT)
C. Even if this teacher (Knox) found to be a threat to other children, and put on Abuse Registry she would not lose her teacher's license.
D. Called person here in Topeka over teacher's licensure and that is correct.
E. Other states in surrounding area- all tougher on abusive teachers than Kansas.

VIII. Proposed changes needed for our children on autism spectrum:

**Educating children on the autism spectrum is a difficult but rewarding journey for parents and the children themselves.
**Having appropriate professionals working with our children and for our children is critical whether they be teachers or SRS social workers.

1. **ABUSIVE TEACHERS IN KANSAS SHOULD LOSE THEIR LICENSE TO TEACH IN KANSAS.**
   A budget neutral step in right direction to improve education in Kansas for all children.
2. **CHANGE SRS REPORTING SYSTEM SO NOT MISLEADING/ CONFUSING**
   Eliminate confusing words "Unsubstantiated" and "Substantiated"
   Help protect children with ASD's in our society that need protecting
   Problem when Lenexa Chief of Police is confused by SRS report

Loren final words:
"My brain may work different from yours
But my heart works the same as yours."

Thank you for allowing us to speak today and we will look forward to hearing about these changes happening to help education and protection of our children with ASD's.

[redacted]
Fw: J[redacted]'s class
December 1, 2008 11:24:26 PM CST
Lisa Wendelburg <lwendelburg@kc.rr.com>
[redacted]

lisa,

[redacted]

--- On **Mon, 12/1/08,** [redacted] wrote:

> From: [redacted]
> Subject: J[redacted]'s class
> To: "Chris Lash" <rslash@smsd.org>
> Date: Monday, December 1, 2008, 11:21 PM
>
> Mr.Lash,
>
> J[redacted] has mentioned to me several times this year how disturbed he is by Mrs. Knox's treatment of Loren Wendelburg. I know J[redacted] is an overly sensitive child, and I have tried to explain it away by telling him that we all have frustrating days, and as a teacher, it would be very hard to work with 20 kids for 8 hours everyday!!! But today he came home nearly in tears. These were his words: "Mom it disgusts me how Mrs. Knox treats Loren, why doesn't somebody do something. How can anyone be allowed to treat a child like Loren with such meanness?" So, I'm doing something, even if it's only another letter to you.
>
> He says she "screams at him everyday and takes him into the hallway to scream some more. She takes away his "fiddle-stick" which is something Mrs. M or Mrs. G[redacted] would never do." Apparently, this is his pencil that he has for comfort;, and of course J[redacted] would sympathize, being a diagnosed OCD child. "She gets in his face and leans into his face while yelling at him."
>
> This doesn't sound like BIST. This sounds like a classic bully, doing what she has done to students who can't defend themselves for the last 6 years. I know I have mentioned this before; and I also know I can't be the only one who sees her behavior as unacceptable. I have never witnessed bullying at Rising Star, EXCEPT from Knox.....and she has it down to a science. She **only** picks on students who can't defend themselves. Ryan [redacted] was her special victim last year, it only makes sense that Loren is her victim this year.
> Her employment as an educator of young children is beyond my comprehension.
>
> This is at least the 10th time J[redacted] has come home disturbed by this situation. His statements are completely unsolicited, and follow my question "How was your day buddy?". I guess what really prompted me to document this now were my son's prayers, as he asked God to give Loren "strength" during language class. When your son throws in "language class" right there between "protecting our troops and protecting his grandparents", it sends up a red flag. If J[redacted] is frightened of this person....can you imagine how Loren feels????? I have yet to mention this to the Wendelburgs, but I think they have a right to know how J[redacted] views this situation. I realize that J[redacted] is an extremely sensitive 10 year old boy. And I also know the weight of his viewpoint means nothing compared to the tenure of an educator deep within in a system that is designed to protect incompetency.....but I would be remiss as a mother to sweep this under the rug, yet again.
>
> Sincerely,
> [redacted]

7-4

ate of Kansas
Department of Social & Rehabilitation Services
Children and Family Services

NOTICE OF DEPARTMENT FINDINGS
Family Reports

C [illegible] 2
July 2004
Page 1 of 2

Date of Mailing: 3 / 11 / 09 SRS Office: Johnson County

TO:	Blake and Lisa Wendelburg	FROM:	Monica Gildner, LBSW
		TELEPHONE #:	913-826-7395
ADDRESS: Street/P.O. Box	7326 Oak View St.	ADDRESS: Street/P.O. Box	8915 Lenexa Dr.
City	Shawnee State KS	City	Overland Park State KS
ZIP	66216	ZIP	66214

The Kansas Department of Social And Rehabilitation Services has completed its investigation and have made the following decisions:

Child's Name	Allegation	Finding	Alleged Perpetrator OR Substantiated Perpetrator *
Loren Wendelburg	Physical Abuse Emotional Abuse	Unsubstantiated Unsubstantiated	Carol Knox

*Substantiated Perpetrators have the opportunity to appeal agency findings. See reverse side.

Services Recommended	☒	NO	☐	YES Recommended services listed:	

Basis of Decision:

SRS completed an investigation on a report received on December 3, 2008 alleging physical and emotional abuse of the above-named child by his teacher, Carol Knox. Based on the information gathered during the investigation regarding the allegations of physical abuse, there is not clear and convincing evidence to indicate that Carol Knox physically abused Loren Wendelburg according to KAR 30-46-10. Therefore, the allegation is unsubstantiated.

KAR 30-46-10 defines emotional abuse as "the infliction of mental or emotional injury on a child or the causation of a child's deterioration…This term may include…any act or omission that impairs a child's social, emotional, or intellectual functioning…" Based on the information gathered during the investigation, there is clear and convincing evidence that Carol Knox's actions inflicted mental or emotional injury to Loren Wendelburg, causing impairment of his social, emotional, or intellectual functioning, thereby meeting the KAR definition for emotional abuse. However, for purposes of placing Carol Knox on the Kansas Child Abuse and Neglect Registry, there is not clear and convincing evidence that Carol Knox is a danger to all children, as defined by the Agency's Policy and Procedure Manual, Section 2502. Therefore, the allegation of emotional abuse of Loren Wendelburg by Carol Knox is unsubstantiated.

7-5

2502 Allowable Case Findings

Unsubstantiated

The facts or circumstances do not provide clear and convincing evidence to meet the KSA and KAR definition of abuse or neglect; or there is clear and convincing evidence that abuse or neglect did occur based on the KSA and KAR definitions, but there is not **clear and convincing** evidence to conclude that the perpetrator poses a danger to children.

not "all"

Substantiated

The facts or circumstances provide clear and convincing evidence to conclude abuse or neglect **DID** occur based on the KSA and KAR definition of abuse or neglect; and

clear & convincing evidence the alleged perpetrator's actions or inactions caused the identified harm to the child and poses a danger to children.

The following acts by a perpetrator potentially indicates the perpetrator poses a danger to children and may result in a substantiated case findings.

Any non-accidental or intentional act or failure to act toward a child which:

- Results in death or physical injury. Physical injury could include, but is not limited to; fractures, bruises on child's face, head, abdomen, bruises of different shades indicating a pattern of abuse, bruises with distinct shapes indicating use of objects (belt, cords, whips, sticks), injury requiring medical care, burns, injury resulting in severe or prolonged pain, injury which interferes with normal activity, multiple significant injuries.
- Requires hospitalization (admission for treatment or observation, whether received or not).
- Requires surgery or medical treatment (whether received or not) of injuries which are disfiguring or which inflicts severe pain or prolonged or repetitive pain.
- Results in serious or permanent impairment of the child's emotional, intellectual or social development or functioning.

(b) To initiate or not to initiate an investigation, prosecution or other proceeding before the state agency, another agency or a court.

6. A second reason why this appeal cannot be sustained by either L.W. or his mother is that neither of them have standing. They are attempting to appeal from a non-action. They argue that because they filed this appeal, and hence are now referred to as "appellants", that they have somehow been transformed into parties with standing.

7. In order to appeal from an SRS finding one must have standing. In the words of the statute, SRS must make a decision which "determines" one's "legal rights, duties, privileges, or immunities" before such a person has standing to pursue an administrative appeal. See K.S.A. 75-3306(i). Also see the definition of "order" at K.S.A. 77-502.

8. It isn't SRS which "permits [L.W.'s] abuser to remain teaching." Assuming, arguendo, that SRS issued a finding that Carol Knox abused L.W., this would not require the school to fire Ms. Knox, or to reassign her. The only legal effect of an adverse SRS child abuse finding is to prevent one from being involved in child day care. See K.S.A. 65-516.

Whereupon, after being advised in the premises, the presiding officer dismisses this matter because the appellant cannot require that SRS change its non-finding.

IT IS SO ORDERED.

Appeal Rights and Other Administrative Relief

Pursuant to K.S.A. 77-527, either party may request a review of this initial order by filing a petition for review with the State Appeals Committee. A petition for review must be filed within 15 days from the date this initial order was served. Failure to timely request a review by the State Appeals Committee may preclude further judicial review. The petition for review shall be mailed or personally delivered to: State Appeals Committee, Office of Administrative Hearings, 1020 S. Kansas Avenue, Topeka, Kansas 66612-1327.

If neither party requests a review by the State Appeals Committee, then pursuant to K.S.A. 77-530, this initial order becomes final and binding on both parties on the 30th day following its service.

Pursuant to K.A.R. 30-7-77, if a petition for rehearing is desired, it must be filed with the Office of Administrative Hearings within 15 days after service of the initial order. The petition must state the specific grounds upon which a rehearing of the presiding officer's initial order is requested. The filing of a petition for rehearing is not a prerequisite for review at any stage of the proceedings. The filing of a petition for rehearing does not stay any time limits or further proceedings that may be conducted.

December 7, 2010

Kansas Legislature
Joint Committee on Children's Issues

Testimony by:

Jeanie Zortman, Chair Kansas Governor's Commission on Autism

Jeanie Zortman
11322 Middle Road
Dodge City, Kansas 67801

jeaniezortman@yahoo.com

620-225-2440 home/fax 620-253-4295 cellular

Attachment 8
JCCI
12-7-10

Introduction: Jeanie Zortman, most importantly I am Mikeala's mom. I am the Chair of the Kansas Governor's Commission on Autism.

The Governor's Commission on Autism is made up of parents and professionals in the area of autism spectrum disorder. The members of the Commission are appointed by the Governor.

Kansas Governor's Commission on Autism

Jeanie Zortman, Chair/Parent

Sarah Bommarito, Occupational Therapist

Lee Stickle, KSDE

Shirley Erickson, Parent

Rebecca Flaton-Koehler, Speech Language Pathologist

Dr. Matt Reese, Psychologist, KU Med

Mary Schlyer Woodworth, MSW

Stephen Stein, parent

Michael Wasmer, parent

Mr. Marc Shiff , KDHE

Representative Melody C. McCray-Miller

Dr. Trisha L. Self, Speech and Language Pathologist, WSU

Michael Donnelly, Director Vocational Rehabilitation

Nanette L. Perrin, ABA

Kathy Ellerbeck, MD

SRS Support Person
Pamela S. Keller, LMSW
Autism Waiver/ ICF/MR Program Manager

http://www.srs.ks.gov/agency/css/Pages/Autismwaiver/KansasGovernor%27sCommissiononAutism.aspx

- In 1987 approximately 15 in every 10,000 children were diagnosed with autism. In 1987 Kansas Legislators passed House Concurrent Resolution 5017 that implemented an Autism Task Force. The Governor's Commission on Autism was established to be responsible to monitor to future needs of persons with autism. The Task Force of 1987 projected that 3,654 Kansas adults and children were identified with autism. Those individuals have grown into adults and into mid-life.

- In 1998 resources from the CDC indicated that from 1987 through 1998 the incidence of autism increased 633%, and determined that 1 in every 500 children were diagnosed with autism.

- In 2007 the CDC reported 1 in every 150 children were diagnosed with autism, the ratio of boys to girls was 4:1. Kansas Legislators passed SB138 that implemented an Autism Waiver and formed current Kansas Autism Task Force. January 1, 2008 the Autism Waiver was implemented and 25 recipients were selected. July 2008, 20 addition recipients were funded.

- October, 2009 the CDC reported the number of children diagnosed with autism increased to 1 in every 110 children 1 in every 70 boys.

- April, 2010 Kansas Legislature passed the Autism Insurance legislation HB 2160. Effective January 1, 2011: Mandate only applies to state employee health care plans. Covers $36,000 per year up to age 7 and $27,000 per year between the ages 7 and 19. (HB2160)

- Today, a new case of autism will be diagnosed nearly every 20 minutes; there are 24,000 new cases diagnosed in the U.S. today. Autism is the fastest growing developmental disability in the U.S. today. Currently, there are 254 children on the waiting list for the Kansas Autism Waiver.

- 2010, the Governor's Commission on Autism reports: Collaborative efforts of University of Kansas, Center Children's Health and Development (CCHD) and Kansas Instructional Support Network (KISN) have trained and supported diagnostic teams throughout Kansas (63f the 105 counties)

- The CCHD 900 inquiries were received interested in an ASD assessment; 600 children were suspected of being diagnosed with ASD. The average age diagnosed was 2 years of age the oldest being 7 to 8 years of age. KISN reports ASD assessments were completed on 88 children statewide. Currently efforts are being made by The Governor's Commission to accurately convey autism diagnosis statistics from other diagnostic providers statewide as well as individuals receiving assessments in border states. (Children's Mercy Hospital, Denver Children's Hospital, Mental Health and Medical Professionals)

- Kansas State Department of Education indicated we had 2545 students reported through MIS to KSDE with Autism

USD 202	Turner	20
USD 229	Blue Valley	194
USD 233	Olathe	165
USD 259	Wichita	237
USD 305	Salina	49
USD 308	Hutchinson	34
USD 489	Hays	22
USD 497	Lawrence	126
USD 500	KCK	94
USD 501	Topeka	95
USD 512	SMSD	176
Total		1212

47.6% of students reported to KSDE with ASD live in these suburban areas. 1,333 kids in areas outside of these areas.

- Autism is a lifelong developmental disorder. No cause or cure has been discovered. Early Intervention, individualized education, speech and occupational therapies are essential. Precedence must be set in developmental awareness; inclusion; seamless transition, vocational rehabilitation, employment opportunities, adult services and the right to live independently as full citizens in all Kansas communities. The Governor's Commission's set several goals and a mission of clarity in developing, mapping out a comprehensive state plan that defined objectives containing foundational soundness; competence, sustainability, and capacity. The Commission addressed the lifespan of autism.

Early Childhood age 0-3

School Age 3-21

Adult 16-64

Elderly-End of Life

Lifespan

The logic model included what Kansas has accomplished, as well as what needs to effectively serve the future of Kansans; adults, children and their families; whether they are the 15 in 10,000 or the 1 in 110, and make assurances we are prepared to meet our state's future needs. Members of Governor's Commission on Autism; parents; individuals with ASD; educators; professionals; Kansas legislators; as well as Kansans throughout the state recognize we must work harder and accomplish more to assure that Kansans with disabilities will have the opportunity and resources to build skills and relationships necessary to participate and engage fully in their preferred life-style within their communities during every stage of their life.

We must adopt the *Army Ranger Creed: Never shall I fail my comrades, Rangers lead the way; and make it our own: Never shall we fail our children, Kansans lead the way.*

"If I could snap my fingers and be nonautistic, I would not - because then I wouldn't be me. Autism is part of who I am." --Temple Grandin

Today, our state, our nation must do nothing less than what Kansans do every day. We lean into the wind. We live the lesson of Shamgar; get started, work with what you have and get the job done. We do more with less and work smarter.

In 2011 we will face the challenges as a state and as a nation. We all experience difficulties, but Kansans have always found our way to the stars. Priorities in our state funded expenditures will require doing what is right for Kansas in your district in your community but it is important to remember we are all a Kansas community.

I would like to express my gratitude to the Governor's Commission on Autism members for all their many hours of hard work and dedication to the state of Kansas.

12/6/10

Attn: Dee McKee

Fax 785-784-7542

We have lost the $2,186,454 due to maintenance of effort. If we do not receive a supplemental appropriation for $16,710,878 for the current school year, we will lose that money due to maintenance of effort.

The two charts should explain this issue.

Dale Dennis

Attachment 9
JCCI
12-7-10

Special Education Maintenance of Effort

Fiscal year 2010

Percent reduction in special education state aid	12.8% *
Percent reduction in general fund expenditures	12.3%
Difference	.5%
Federal aid reduction .005 x $433,384,160	$2,186,454 **

*Special education state reduction for all state agencies, less gifted
**May not compute due to rounding

Special Education Maintenance of Effort

Fiscal year 2011

Percent reduction in special education state aid	12.6%
Percent reduction in general fund expenditures	8.7%
Difference	3.9%
Federal aid reduction .005 x $433,384,160	$16,710,878 *

*May not compute due to rounding.

Special Note: If you consider reappropriation for FY 2011,this amount will increase to approximately $27,000,000.

TESTIMONY

JOINT COMMITTEE ON CHILDREN'S ISSUES

DECEMBER 7, 2010

PERSONNEL and PROFESSIONALS

Dr R Matthew Reese

Director: Center for Child Heath and Development

Co-Director: Kansas Center for Autism Research and Training

Children with an Autism Spectrum Disorder need highly skilled personnel and professionals working with them. Many children with a variety of difficulties get better in spite of the lack of skilled teachers and professionals working with them due to developmental maturation. This is not true in the case of Autism Spectrum Disorders (ASD). These children often do not improve without assistance from skilled providers. Fortunately, with intensive teaching by skilled providers as many as 50% of children with autism do not need extra and costly support by the time they reach first grade and those who do need support require less assistance.

To be effective in reducing the need for costly support when the child with ASD is older, we must identify children early and have trained personnel and professionals working with them and providing parent support and teaching. This requirement has posed two problems 1) effective training of personnel and professionals; 2) availability of personnel and professions to go through training. We have made tremendous advances in Kansas in overcoming the first problem as evidenced by the following:

1. KISN and CCHD collaborative to train teams throughout the State to screen, diagnose, and use effective practices with children with ASD. We have trained over half of 75 infant-toddler and school aged teams in Kansas and linked them to physicians in their community or CCHD physicians through telemedicine. (see attached map)
2. The CCHD received a Combating Autism MCH grant two years ago to increase the capacity of professionals who can screen, diagnose, and provide treatment to children with ASD. Graduate and Post-graduate students are provided with a year of interdisciplinary training in ASD to increase the capacity in Kansas. This didactic and practicum training has been modified so that students can participate in the lectures and observe CCHD clinics over Interactive TV. Some of these students have been physicians and nurses working with the KISN teams.
3. The Autism Medicaid Waiver has provided training to personnel and professionals who are equipped to provide support to families.

The major problem that remains is "What if there is no one to train"? This is particularly evident in rural areas where there is a lack of ABA specialists, Speech and Language Pathologists, Occupational Therapists, Social Workers and Psychologists. Our Kansas Universities have produced excellent professional. Graduates from Departments of Special Education, Applied Behavioral Sciences,

Attachmt 10
JCCI
12-7-10

Occupational Therapy and Speech and Language are being recruited nationally and have started programs such as the May Institute, Princeton Child Development Center, and the Marcus Institute. We need to keep this talent in the state particularly in underserved areas.

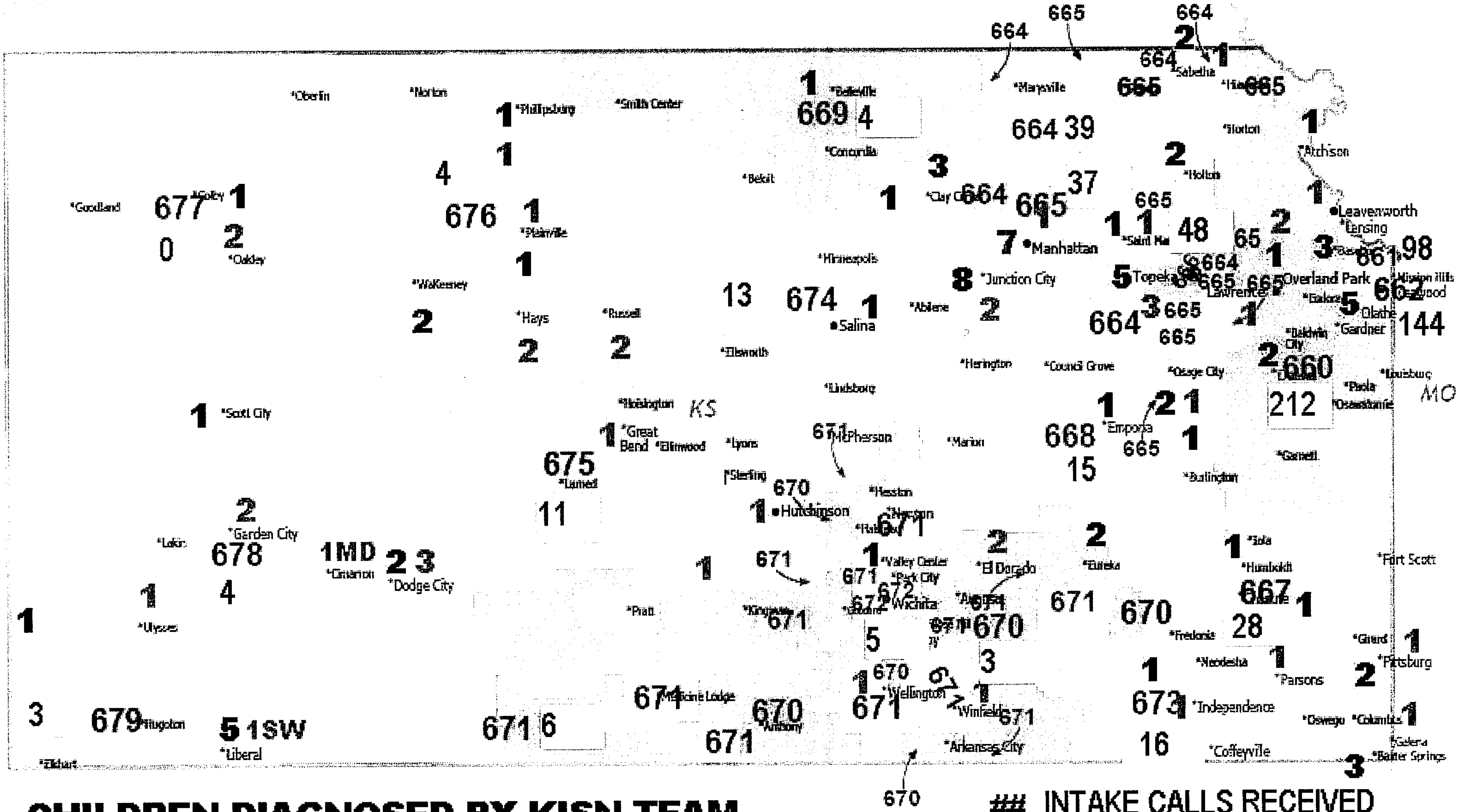
In 2008, our committee met with the Kansas Board of Regents and drafted legislation for a scholarship bill that would pay tuition and fees for students in areas such as Applied Behavioral Science, Speech and Language Pathology, Occupational Therapy, Social Work and Psychology who were trained in autism if they agreed to provide treatment and education in underserved areas. We asked for five scholarships which were around $150,000 total. The Board of Regents indicated there was already a teacher scholarship bill and some of those scholarships could go toward ASD trained teachers. We were told that we needed to develop a system for children with ASD for these graduate to work in. Legislators felt that graduates would leave their workplace after they fulfilled their requirement without a support system for them to work in. We now have a system of KISN/CCHD trained teams and the Autism Medicaid Waiver. Some of those teams desperately need members with expertise in areas such as Applied Behavioral Science, Occupational Therapy, Speech and Language Pathology, Social Work and Psychology.

Attracting graduate and undergraduate students to careers in ASD is only one piece of the puzzle. We also need paraprofessionals in schools and in-home therapists. Our committee on personnel and professional discussed the need to develop a career ladder in which the curriculum developed can be disseminated and there is a career ladder to obtain graduate and graduate degrees. We recommended putting ASD curriculum for personnel training in community colleges and providing salary incentives for individuals taking this training. This would provide local expertise and a possible career path in applying for scholarships to obtain undergraduate and graduate degrees in ASD.

Our committee also discussed keeping personnel and professionals current in techniques. KISN conducts annual summer institutes. K-CART has held an annual Autism Conference. Last year's conference was held in Wichita and this year in Overland park at the KU Edwards campus and Johnson County Community College.

We have made tremendous strides in helping families but have a long journey ahead of us to insure that all families of individuals with autism have equal access to services no matter where they live.

10-3



CHILDREN DIAGNOSED BY KISN TEAM

TRAINED KISN TEAMS

INTAKE CALLS RECEIVED BY CCHD - KUMC

Map on next page:

CALLS RECEIVED BY CENTER FOR CHILD HEALTH AND DEVELOPMENT BY 3 DIGIT ZIP AREA and KISN TRAINING TEAM ACTIVITIES

CALLS RECEIVED 1/1/10 – 12/6/10 BY CCHD BY 3-DIGIT ZIP AREA

ZIP CODE	# OF CALLS*	Cities
660	212	Lawrence, Leavenworth, Olathe, Ottawa, Paola
661	98	Kansas City, KS
662	144	Johnson County, Overland Park, Shawnee
664	39	Ft. Riley, Juntion City
665	37	Manhattan, Silver Lake
666	48	Topeka
667	28	Chanute, Ft. Scott, Humboldt, Iola
668	15	Burlington, Emporia
669	4	Concordia
670	3	Wellington
671	6	Fall River, Kingman, Pratt
672	5	Wichita
673	16	Coffeyville, Independence, Parsons
674	13	Abiline, Clay Center, Salina
675	11	Great Bend, Larned
676	4	Hays
678	8	Cimarron, Dodge City, Garden City
679	3	Elkhart, Liberal

2009

9rs0005

PROPOSED BILL NO. ____

AN ACT concerning colleges and universities; relating to fees and tuition; establishing the autism service scholarship program.

Be it enacted by the Legislature of the State of Kansas:

Section 1. Sections 1 through 8, and amendments thereto, shall be known and may be cited as the autism service scholarship program act. The provisions of the autism service scholarship program act shall expire on June 30, 2014.

Sec. 2. As used in the autism service scholarship program act:

(a) "Autism" means all disorders within the autism spectrum including, but not limited to, autism, Asperger's disorder, Rett's disorder, childhood disintegrative disorder, pervasive developmental disorders and pervasive developmental disorder not otherwise specified, as such terms are specified in the diagnostic and statistical manual of mental disorders, fourth edition, text revision (DSM-IV-TR), of the American psychiatric association, as published in May 2000, or later versions as established in rules and regulations adopted by the behavioral sciences regulatory board pursuant to K.S.A. 74-7507, and amendments thereto.

(b) "Act" means the autism service scholarship program act.

(c) "Program" means the autism service scholarship program.

(d) "Executive officer" means the chief executive officer of the state board of regents appointed under K.S.A. 74-3203a, and amendments thereto.

(e) "Institution" means a state educational institution as defined by K.S.A. 76-711, and amendments thereto, and Washburn university.

(f) "Qualified student" means a person who: (1) Is a resident of the state of Kansas; (2) has been accepted for admission to or is enrolled in an institution in a course of instruction leading to licensure as a professional who is pursuing a bachelor's or master's degree in an allied health care degree program, including, but not limited to, speech therapy, occupational therapy, psychology, applied behavioral sciences and social work programs, with an emphasis in autism and who agrees to provide services to children with autism; and (3) has qualified for the award of a scholarship under the service scholarship program on the basis of having demonstrated scholastic ability, or who has previously so qualified and remains qualified for renewal of the scholarship on the basis of remaining in good standing and making satisfactory progress toward completion of the requirements of the course of instruction in which enrolled.

(g) "Underserved area" means a geographic area of the state in which there is a critical shortage of professionals who provide services for children with autism as determined and specified by the state board of education.

Sec. 3. (a) There is hereby established the autism service scholarship program. A scholarship may be awarded to any qualified student and may be renewed for each such student who remains qualified for the scholarship. Determination of the students qualified for such scholarships shall be made by the executive officer. Scholastic ability shall be determined on the basis of any one or more of the following: (1) High ACT or SAT score; (2) rank in high school graduation class; (3) cumulative high school or college grade point average; (4) academic letters of recommendation; or (5) any other indicator of scholastic ability which the state board of regents determines to be demonstrative of potential for successful completion of a course of instruction leading to licensure as a professional who provides services for children with autism. To the extent practicable and consistent with qualification factors, consideration shall be given to qualified students who are members of ethnic minority groups.

(b) Within the limitations of appropriations therefor, the number of scholarships awarded and the amount awarded to each applicant shall be determined by the executive officer. The amount awarded shall be specified in the agreement. The amount awarded may vary depending upon the number of hours and the program in which the applicant is enrolled. For academic year 2009-2010, the amount awarded shall not exceed $3,000 each semester or its equivalent. For academic year 2010-2011 and each year thereafter, the maximum amount that may be awarded shall be increased by an amount equal to the percentage increase in the CPI (urban) during the preceding fiscal year as certified to the executive officer by the director of the budget on August 15 of each year.

(c) If a student is not enrolled in an institution on a full-time basis, a student shall complete the course of study within the time period specified in the agreement and shall receive a proportionate amount of the scholarship allowed under subsection (b) based upon the number of hours enrolled in an academic period, and computed as a fraction of the total number of credit hours required for full-time enrollment.

Sec. 4. (a) An applicant for designation as a qualified student and for the award of a scholarship under the program shall provide to the executive officer, on forms supplied by the executive officer, information required by the executive officer.

(b) As a condition to awarding a scholarship under this act, the executive officer and the applicant shall enter into an agreement which shall require the applicant to:

(1) Complete the required course of instruction as specified in the agreement;

(2) obtain and maintain necessary licensure and endorsement as specified in the agreement;

(3) engage in providing services for children with autism in Kansas in an underserved area and comply with such other terms and conditions as may be specified by such agreement;

(4) commence providing services for children with autism in Kansas on a full-time basis for a period of not less than the length of the course of instruction for which the scholarship was awarded or commence providing services on a part-time basis in Kansas in accordance with the agreement and continue providing services on such part-time basis for a period of time that is equivalent to full-time, as determined by the state board of regents, multiplied by the length of the course of instruction for which the scholarship was awarded within six months after licensure and continue for the period of time required by the agreement;

(5) maintain records and make reports to the executive officer as required by the executive officer to document the satisfaction of the obligations under this act and the agreement; and

(6) upon failure to satisfy an agreement to engage in providing services for children with autism in an underserved area as specified in the agreement and for the required period of time under any such agreement, repay to the state amounts as provided in section 5, and amendments thereto.

Sec. 5. (a) Except as provided in section 8, and amendments thereto, upon the failure of any person to satisfy the obligation under any agreement entered into pursuant to the program, such person shall pay to the executive officer an amount equal to the total amount of money received by such person pursuant to such agreement plus accrued interest at a rate which is equivalent to the interest rate applicable to loans made under the federal PLUS program at the time such person first entered into an agreement plus five percentage points. Amounts of payment under this section shall be adjusted proportionately for full years of the obligation that have been satisfied. Installment payments of any such amounts may be made in accordance with the provisions of the agreement entered into by the scholarship recipient or if no such provisions exist in such agreement, in accordance with rules and regulations of the state board of regents, except that such installment payments shall commence six months after the date of the action or circumstances that cause the failure of the person to satisfy the obligations of such agreements, as determined by the executive officer based upon the circumstances of each individual case. Amounts paid under this section to the executive officer shall be deposited in the autism service scholarship repayment fund in accordance with section 7, and amendments thereto.

(b) The state board of regents is authorized to turn any repayment account arising under the program over to a designated loan servicer or collection agency, the state not being involved other than to receive payments from the loan servicer or collection agency at the interest rate prescribed under this section.

Sec. 6. The state board of regents shall adopt rules and regulations for administration of the autism service scholarship program and shall establish terms, conditions and obligations which shall be incorporated into the provisions of any agreement entered into between the executive officer and an applicant for the award of a scholarship under the program. The terms, conditions and obligations shall be consistent with the provisions of law relating to the program and shall include, but not be limited to, the circumstances under which eligibility for financial assistance under the program may be terminated, the amount of financial assistance to be provided, the circumstances under which obligations may be discharged or forgiven, the amount of money required to be repaid because of failure to satisfy the obligations under an agreement and the method of repayment.

Sec. 7. (a) There is hereby created in the state treasury the autism service scholarship

10-9

program fund. The executive officer shall remit all moneys received under the autism service scholarship program, which are paid because of nonattendance or discontinuance by scholarship recipients, to the state treasurer in accordance with the provisions of K.S.A. 75-4215, and amendments thereto. Upon receipt of each such remittance, the state treasurer shall deposit the entire amount in the state treasury to the credit of the autism service scholarship program fund. All expenditures from the autism service scholarship program fund shall be for scholarships awarded under the program and shall be made in accordance with appropriation acts upon warrants of the director of accounts and reports issued pursuant to vouchers approved by the executive officer or by a person designated by the executive officer.

(b) There is hereby created in the state treasury the autism service scholarship repayment fund. The executive officer shall remit all moneys received under the autism service scholarship program, which are for payment of amounts pursuant to section 5, and amendments thereto, to the state treasurer in accordance with the provisions of K.S.A. 75-4215, and amendments thereto. Upon receipt of each such remittance, the state treasurer shall deposit the entire amount in the state treasury to the credit of the autism service scholarship repayment fund. All expenditures from the autism service scholarship repayment fund shall be for scholarships awarded under the autism service scholarship program and shall be made in accordance with appropriation acts upon warrants of the director of accounts and reports issued pursuant to vouchers approved by the executive officer or by a person designated by the executive officer.

Sec. 8. (a) Except as otherwise specified in the agreement, an obligation under any agreement entered into under the autism service scholarship program shall be postponed: (1) During any required period of active military service; (2) during any period of service as a part of volunteers in service to America (VISTA); (3) during any period of service in the peace corps; (4) during any period of service commitment to the United States public health service; (5) during any period of religious missionary work conducted by an organization exempt from tax under section 501(c)(3) of the federal internal revenue code as in effect on December 31, 2000; (6) during any period of time the person obligated is unable because of temporary medical disability; (7) during any period of time the person obligated is enrolled and actively engaged on a full-time basis in a course of study leading to a degree in the field of service which is higher than that formerly attained; (8) during any period of time the person obligated is on job-protected leave under the federal family and medical leave act of 1993; or (9) during any period of time the state board of regents determines that the person obligated is unable because of special circumstances. Except for clauses (6), (8) and (9), an obligation under any agreement entered into as provided in the program shall not be postponed more than five years from the time the obligation was to have been commenced under such agreement. An obligation under any agreement entered into as provided in the autism service scholarship program shall be postponed under clause (6) during the period of time the medical disability exists. An obligation under any agreement entered into as provided in the program shall be postponed under clause (8) during the period of time the person obligated remains on FMLA leave. An obligation to engage in providing services for children with autism in accordance with an agreement under the program shall be postponed under clause (9) during the period of time the state board of regents determines that the special circumstances exist. The state board of regents shall adopt rules and regulations prescribing criteria or guidelines for determination of the existence of special circumstances causing an inability to provide services as specified in the agreement, and shall determine the documentation required to prove the existence of such circumstances.

(b) An obligation under any agreement entered into as provided in the program shall be satisfied: (1) If the obligation has been completed in accordance with the agreement; (2) if the person obligated dies; (3) if, because of permanent physical disability, the person obligated is unable to satisfy the obligation; (4) if the person obligated fails to satisfy the requirements for a graduation after making the best effort possible; (5) if the person obligated fails to satisfy all requirements for licensure in Kansas or has been denied licensure after applying for a license and making the best effort possible to obtain such license; or (6) if the person obligated is unable to obtain employment in an underserved area as specified in the agreement after making the best effort possible to obtain such employment and the person obligated otherwise completes the terms, conditions and obligations of the agreement.

Sec. 9. This act shall take effect and be in force from and after its publication in the statute book.

Attachment 11
JCCI
12-7-10

Preventing Unnecessary Seclusion & Restraint in Schools

D R C
DISABILITY
RIGHTS
CENTER*of*KANSAS

EQUALITY ♦ LAW ♦ JUSTICE

Rocky Nichols
Executive Director
Voice - 1-877-776-1541; TDD – 1-877-335-3725
www.drckansas.org; rocky@drckansas.org

Joint Committee on Childrens' Issues, December 7, 2010

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Where at on Seclusion/Restraint in Ks

2005 – Kansas Senate considers bill to regulate seclusion and restraint in schools (SB 241).

Senate Comm. recommends SBOE (State Board of Education) develop policies and rules and regs

2007 – Non-binding "guidelines" passed by SBOE on the use of Seclusion and Restraint (S/R) in schools.

- SBOE comes within 1 vote of passing binding regulations.

Since 2007 – KSDE have tracked some limited data on Seclusion, but not Restraint (which is more damaging)

Parents & Students have had no protections against these dangerous tactics – this must change.

Seclusion & Restraint in Schools – The Final Frontier

Why are binding requirements in schools on Seclusion and Restraint (S/R) so important?

- Schools are literally the "Final Frontier" of places where seclusion and restraint are not regulated.

S/R is *closely regulated* in Kansas hospitals, PRTFs, long-term care facilities, intermediate care facilities, day care, etc. Everywhere but schools.

- Kids spend the most time at school, but receive the least protection for the use of these dangerous tactics (S/R).

The Final Frontier Continued ...

Currently, no state or federal law governing use of Seclusion or Restraint in schools

Bill has passed US House (introduced in US Senate) ... but it is unclear if Congress will act on this issue.

We should not wait for an act of Congress to protect our students and teachers against these dangerous and deadly tactics

These are dangerous tactics that need to be controlled through binding law/rules to protect students, teachers and parents.

Dangerous tactics, regulated elsewhere

Many injuries & deaths due to S/R. 130 people in US died during 5 year period from S/R (HHS/CMS).

Hartford Courant Paper – exposed problems in S/R

http://www.pcma.com/crisis_intervention_news/deadly_restraint/index.stm

http://www.pcma.com/crisis_intervention_news/deadly_restraint/faces.stm

S/R is closely regulated and controlled in almost every other setting that youth with disabilities are served -- state hospitals, PRTFs, long-term care facilities, ICFs/MR, providers of services paid by SRS, etc … why not schools?

Why do we allow the place where children spend the most time (schools) be the place where they get the least protection?

2009 GAO Report found "hundreds of cases" of abuse and death related to S/R. GAO found no data collection, no federal restrictions, and "widely divergent" state protections

A few words about Kansas Data (or lack thereof)

Kansas only tracks some limited data on the use of seclusion,

No auditing to ensure effectiveness of data

Restraint is not tracked, though KSDE is considering

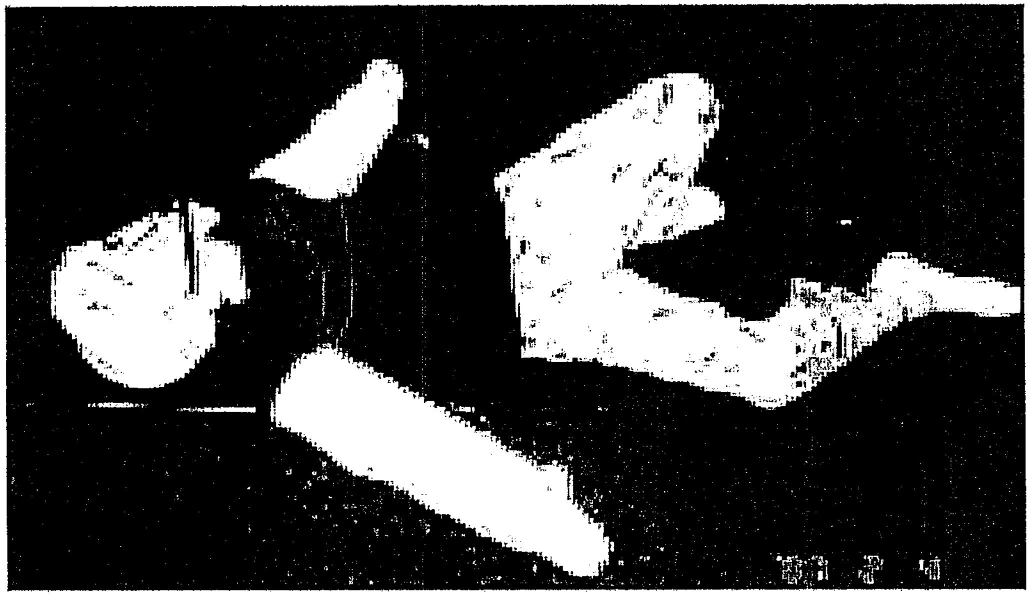
- **Asking this Committee endorse collecting restraint data**
- **Asking this Committee endorse consideration of this issue 2010**

Limited data shows that participating districts have reported increase in use of seclusion over 2008-2009 school year

Limited data suggests that the Guidelines have not resulted in effective standards of practice in Kansas with regard to S/R

No school-building specific or school-district specific data is provided to the public

11-7



"They killed his spirit long before his body."

JANET ROACH

mother of Matthew Goodman, shown at about age 4

"Matthew Goodman, a teen with autism, spent the last 16 months of his life heavily sedated, in arm splints and a helmet, in New Jersey. The restraints were supposed to keep him from picking at an injury, but his mother believes they contributed to his death at age 14." – Columbus Dispatch 4/24/2005

130 S/R deaths from 1999 to 2004.

www.pcma.com/crisis_intervention_news/deadly_restraint/faces.stm

Harm of S/R in Schools - Nationally
Cedric Napoleon - Texas death

11-9

Harm of S/R in Schools – Nationally
Jonathan King – Georgia death

11-10

Harm of S/R in Schools - Nationally
Seclusion Room in Tennessee

Harm of S/R in Schools

Kansas Specific Examples

Matthew, a child with cerebral palsy in Scott City, Ks, was secluded in a restroom with a toilet for days, where he was forced to eat and do his work. His mom was forced to change schools to protect her son.

A Salina parent reported that their child was locked in a dog kennel as a form of seclusion. KSDE refused to investigate, claiming its outside the scope of their regulations and no federal standards exist.

School personnel strap Ian, a child with Autism in Cheney, in his stiff wooden chair to keep him from fidgeting. He's forced to watch the other kids play. His parents are never told and find out by sheer will.

11-12

Harm of S/R in Schools

Kansas Specific Examples (cont.)

An Emporia child on the Autism spectrum spends up to 5 hours a day in seclusion, 4 days a week.

Zach, a child with disabilities in Chanute, Ks, was injured by an untrained aid with an improper hold.

A Doctor at KU Med Center writes to a school in Johnson County to stop putting a child with PTSD in a seclusion room because it worsens his emotional disabilities. The school increases its use after receiving the letter. The family is forced to move to a different school district to stop the abuse.

Harm of S/R

Staff get hurt, too.

- Assumption – S/R keep staff safe, but the opposite is true
- Data isn't tracked in schools, but for every 100 mental health aides, 26 injuries reported do to the use of S/R (1996 survey)
- MH aide that engages in S/R more dangerous job than lumber, construction & mining
- When S/R use is reduced, injuries to staff and consumers decrease.

Growing National Consensus to Limit S/R

This consensus needs to extend to schools. Consensus clearly shows that the requirements must be binding to ensure adequate protections

President Bush's New Freedom Initiative -

"... Seclusion and restraint are safety interventions of last resort; they are not treatment interventions. In light of the potentially serious consequences, seclusion and restraint should be used only when an imminent risk of danger to the individual or others exists and no other safe, effective intervention is possible."

Federal Govt / HHS Official Policy – S/R must be dramatically reduced & eventually eliminated.

Growing National Consensus on S/R

Child Health Act of 2000 – limits use of seclusion and restraint to "emergency" situations for young people up to age 21 in public facilities and other settings.

National State Mental Health Program Directors Position – "seclusion and restraints, including 'chemical restraints,' are safety interventions of last resort and are not treatment interventions. Seclusion and restraint should never be used for the purposes of discipline, coercion, or staff convenience, or as a replacement for adequate levels of staff or active treatment."

Many other states have adopted similar regulations limiting S/R in schools, regardless of party or ideology (conservative - Texas, moderate – Maine, and liberal states – Massachusetts.

Growing National Consensus on S/R

American Psychological Assoc. (APA),

American Medical Assoc. (AMA),

American Academy of Pediatrics (AAP),

American Academy of Child and Adolescent Psychology (AACAP)

International Society of Psychiatric-Mental Health Nurses (ISPN)

- All these groups have taken positions that restraint should be a tactic of last resort and as emergency interventions to maintain safety (try least restrictive first)
- All call for staff training, other protections, etc.

11-17

Growing National Consensus on S/R

Autism National Committee – call on Congress and State Legislatures to limit restraint on children w/ disabilities (brief, emergencies only involving serious threat of injury to self or others, etc.). Recommended standardized reporting procedure.

Child Welfare League of America – call for minimum national standard on training, research on crisis prevention models, etc.

School & Disability Support for US House Bill

Another indicator of consensus … Over 100 school and disability groups endorsed the US House bill (HR 4247), including:

- National School Boards Association,
- Autism Society,
- National Association of School Psychologists,
- United Cerebral Palsy,
- National Association of Secondary School Principals,
- AFT (largest teacher's union in US),
- Easter Seals
- National Disability Rights Network & and many more…

11-19

Examples of *minimum* elements and components of effective Seclusion/Restraint (S/R) requirements:

Use S/R only when student is a danger to self or others

Threshold for S/R use: "imminent risk of physical harm to self or others."

This means: immediate and impending threat of a person causing substantial physical injury to self or others

Outlaw mechanical and chemical restraint

Mechanical restraint – any device or object used to limit a person's movement

Exception- that a protective or stabilizing device ordered by a licensed professional or required by law (used as it is intended) is not considered mechanical restraint

Key Minimum elements continued …

Use of S/R is an intervention of last resort, other interventions must be tried first

Restraint is a safety intervention only - not treatment or educational intervention

Establish right in law to be free from unreasonable, unsafe, & unwarranted use of S/R

S/R not to be used unless other less restrictive behavior intervention strategies identified in IEP/BIP implemented and were ineffective

Don't use S/R when there's a medical contraindication

Key Minimum Elements Continued…

Require staff training prior to use of S/R

Require staff to observe and hear the student while in the Seclusion room

Prohibit locked seclusion rooms

Require parental notification of S/R

Require student-level data tracking of both the incidences of S/R (track trends and data to impact future policies)

Issue public reports for accountability

Key Minimum Elements Continued...

Joseph Ryan & Reece Peterson (University of Nebraska at Lincoln), Physical Restraint in Schools 2003, found that basic elements of Restraint law/reg includes:

Definitions of terms

Requirements for staff training

Standards/thresholds when Restraint can be applied

Reporting Requirements

Key Minimum Elements Continued…

NDRN S/R Committee Guiding Principles:

- School-wide use of positive behavioral supports (PBS) and well trained staff
- S/R = measures of last resort; only for emergency & substantial threat of serious harm to self and others. Not therapeutic interventions, safety interventions.
- Training of staff (PBS, safe use, etc.)
- Constant supervision of S/R during & after use
- Staff must follow specific policies
- Use of S/R is a failure of the schools PBS system
- On-going Goal = reduction of S/R & improve PBS
- Don't use when medical contraindication
- Parents must play an integral role
- Notify parents

Thank you … what we are asking

- Asking this Committee in its report to the Legislature to call for KSDE to start collecting restraint data, in addition to seclusion data, and that school district specific data be released to the public
- Asking this Committee in its report call for "serious consideration" of this issue
  - We understand that you may not have enough information to endorse a specific bill. However, we ask that you call for consideration of this S/R issue in the 2011 session.

11-25

Preventing Unnecessary Seclusion & Restraint in Schools

DRC DISABILITY RIGHTS CENTER of KANSAS

EQUALITY ♦ LAW ♦ JUSTICE

Rocky Nichols
Executive Director
Voice - 1-877-776-1541; TDD – 1-877-335-3725
www.drckansas.org; rocky@drckansas.org

Joint Committee on Childrens' Issues, December 7, 2010

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KANSAS
DEPARTMENT OF SOCIAL
AND REHABILITATION SERVICES

Don Jordan, Secretary

Joint Committee on Children's Issues

December 7, 2010

Autism Waiver

Deputy Secretary Ray Dalton

For Additional Information Contact:
Katy Belot, Director of Public Policy
Patrick Woods, Director of Governmental Affairs
Docking State Office Building, 6th Floor North
(785) 296-3271

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KANSAS
DEPARTMENT OF SOCIAL
AND REHABILITATION SERVICES

Joint Committee on Children's Issues

December 7, 2010

Chairwoman Lynn and members of the Committee, thank you for the opportunity to appear before you today. I am Ray Dalton, Deputy Secretary of Disability & Behavioral Health Services at the Kansas Department of Social and Rehabilitation Services. Today I will present information regarding the Autism Waiver which serves persons with an autism spectrum disorder.

Background

Medicaid waivers are federally approved requests to waive certain specified Medicaid rules. For instance, federal Medicaid rules generally allow states to draw down federal Medicaid funds for services provided in institutions for persons with severe disabilities. Many of the community supports and services provided to persons with disabilities such as respite care, attendant care services, and assistive services, are not covered by the regular federal Medicaid program. HCBS waivers give the state federal approval to draw down federal Medicaid matching funds for community supports and services provided to persons who are eligible for institutional placement, but who choose to receive services that allow them to continue to live in the community. The Centers for Medicare and Medicaid Services (CMS) requires that the cost of services paid through HCBS waivers be, on the average, less than or equal to the cost of serving people in comparable institutions.

Autism Waiver

The autism waiver is the newest of our HCBS waivers with the first funding approved for FY 2008. The target population for the autism waiver is children with autism spectrum disorders (ASD), including autism, Aspergers' Syndrome, and other pervasive developmental disorders. The diagnosis must be made by a licensed medical doctor or PhD psychologist using an approved autism specific screening tool.

Children are able to enter the program from the age of diagnosis through the age of five. Children receiving services through this waiver would be eligible for placement in a state mental health hospital if services were not provided through the waiver. A child will be eligible to receive waiver services for a time period of three years with an exception process in place to allow children who demonstrate continued improvement to continue services beyond the three year limit.

Services provided through this waiver are:

- Consultative Clinical and Therapeutic Services (Autism Specialist)
- Intensive Individual Supports
- Parent Support/and training
- Family Adjustment Counseling
- Respite Services

The autism waiver was implemented on January 1, 2008. At that time 25 children were selected through a random process to receive services based on available funding. The other applicants were placed on the waiting list. The 2008 Legislature approved funding for an additional 20 children to be served by the autism waiver in FY 2009. The waiver is now serving 45 children. There are 259 children waiting for services through this waiver. Since this waiver was implemented, 166 children have aged off of the waiting list before services could begin. The total expenditure for the waiver in FY2010 was $743,673 with the average monthly cost per person being $1,546.

For this waiver a total of $4,882,668 AF or $2,078,064 SGF would be required to eliminate the waiting list. In calculating the estimated cost to eliminate the waiting lists SRS utilized the current average cost per consumer and the SGF needed is based on the normal state FMAP that will be in effect in FY 2012.

This concludes my testimony and I will be glad to answer any questions you may have.

Kansas Center for Autism Research and Training
Sean Swindler, Director of Community Program Development and Evaluation
Testimony to the Joint Committee on Children's Issues
December 7th, 2010

Thank you for the opportunity to testify today. I am Sean Swindler, Director of Community Program Development and Evaluation at the Kansas Center For Autism Research and Training (K-CART). As well as being the parent of a 9 year old with Asperger Syndrome, for 5 years I was Assistant Director of Community Disability Network in Johnson County, where I had the experience of providing targeted case management on the MR/DD Waiver as well as providing special education advocacy services for families, many of whom have children and transition-age young adults on the Autism Spectrum. I also have a Masters Degree from the University of Kansas in Special Education with an emphasis in transition.

I am here today to talk to you about the state of services for adults with Autism Spectrum Disorders (ASD). We know that we have a wave of children who have been diagnosed with Autism in the last 15 years. Our communities are not ready for this wave. Many adults with Autism face unique challenges in pursuing education, employment and becoming a part of the community. Among these challenges: social skills both in the community and in the workplace; pursuing post-secondary or career-education opportunities; and when receiving services, having supports trained to meet the needs of people with Autism.

While every person is unique, we do know how to provide the necessary supports for people with ASD to be successful in school, in the transition process and when developing services in the community. The challenge is that many adults with ASD do not have access to these kinds of supports, or if they do, the capacity of the system is not there to support them. I want to give you some examples of where this disconnect happens:

Waiting List. For adults with Autism who qualify for the MR/DD Waiver, the waiting list presents an enormous barrier. Others will speak in detail about the impact of this tomorrow, but I want to emphasize that the years of investment in special education services to support the individual toward greater independence are essentially lost when there is a 3-5 year gap in services. This represents an enormous loss of investment, and an enormous hardship for families. It also means that when services are finally in place, service providers often have to start from scratch to develop a plan to support the person and work on replacing the skills lost during the time on the waiting list. This further stretches system capacity with regard to having enough providers trained to work with adults with Autism. ***What is the cost to the system in lost investment and need for re-training once services are in place by having this gap in service delivery?***

System Capacity. For children and adults, especially in rural areas, there are just not enough providers across all systems – MR/DD providers, school transition specialists, mental health, vocational rehabilitation – trained in providing services to adults with Autism and especially adults with challenging behaviors. The unique needs of children and young adults with Autism provide a number of challenges for families, schools, communities and child and adult services. As has been demonstrated by children and adults who have been successful, these are challenges we can meet, given families, schools, communities and service providers have timely access to training and support. The lack of capacity in the system for children continues into adulthood.

Mental Health. For adults with ASD, especially adults with more significant cognitive disabilities or who are non-verbal, is can be difficult to access mental health supports. Adults with ASD who have a dual diagnosis may not respond in the same way to traditional programs and treatment options. Likewise, adolescents with ASD and a co-occurring mental health diagnosis that have primarily been served by the mental health system through the SED Waiver or other programs do not have an equivalent adult level of service available and often need more and different kinds of supports than traditional adult mental health programs provide. These adults may tend to need

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the kinds of direct support available under the MR/DD Waiver. ***Is there a need for a specialized service to provide ongoing support after young adults transition out of the SED Waiver and other children's MH services?***

Employment. Many adults with ASD have solid job skills that would translate well into the working world, but are not successful obtaining or maintaining employment due to issues around social skills and the hidden social curriculum of the workplace. Understanding how to interact with co-workers and negotiate workplace politics, necessary even in entry level jobs, is a skill that with which adults with ASD will need support and assistance. ***Is there a role in the VR system for employment service providers specifically trained in ASD?***

Transition from school. By and large, while every child is unique, we know the elements toward putting together a solid transition program. This includes:

- Having a seamless service system to transition from school to adult supports or to post-secondary opportunities such as community college.
- Cross-training of personnel to ensure a smooth transition from school to adulthood or between school settings
- Building a comprehensive support plan that includes accommodations such as visual schedules, a structure that meets the person's needs, and an adequate behavioral support plan if needed.
- Ensuring young adults have training and practice in social skills and have had the opportunity to develop a peer network, including natural supports in their community.
- Ensuring the person has an opportunity to practice self-advocacy and self-determination skills to increase independence.

For students with ASD, especially those students with challenging behaviors, capacity does not exist in many places to provide an effective transition program as described above, leading either to the student leaving school early or dropping out, or without an employment or post-secondary opportunity. Note that students with ASD who do not qualify for an IEP do not have access to this level of transition supports.

Cross-system issues. When students do qualify for an IEP, many students with ASD who experience behavioral issues are served in behavior disorder programs with children who have emotional disturbance or mental health support needs, but who need different kinds of supports than ASD kids. Some children with ASD are being referred to juvenile justice for behaviors that are well within the expectation for their ASD diagnosis. This can happen with adults with ASD as well, whose lack of ability to understand social language can be misinterpreted by community members or first responders. Likewise, when children enter the justice system or present significant challenges to their family with regard to ability to support challenging behaviors, children can end up in out of home placements. As these children become adults, the lack of system capacity and lack of available supports is likely to show up in hidden costs across other support systems. ***What costs, due to lack of system capacity to support families and schools for children with ASD, are showing up in other child and adult support systems?***

I have discussed a number of challenges. I want to discuss 2 efforts to positively impact the lives of adults with Autism and discuss some positive steps that are being taken.

On November 13th, 2009, K-CART hosted Advancing Futures for Adults With Autism (AFAA). Kansas City was one of 16 sites nationally participating in a national town hall dedicated to determining how to support the increasing numbers of adults with autism. Below is the URL for the national town-hall and the results of this meeting:

www.afaa-us.org

Over 60 families, providers, educators and adults with Autism participated at our site's town hall, making the Kansas City site one of the three largest out of the 16 nationally. While it was important for people locally to have a voice in setting the national agenda, we felt we should take the opportunity to address systems locally. At the end of the meeting, we compiled a list of local priorities (attached) to begin to address how to impact our systems locally to improve the lives of adults with Autism. While not a scientific survey, this list is a good starting place for discussing the needs of adults with Autism.

As our group has continued to meet, we are pursuing some unique initiatives as pilot projects to provide better quality of life and opportunities for adults with ASD:

1) K-CART will offer an information line for adults with ASD and their families, to both provide an opportunity to provide more consistent information and gather some real data on the support needs of adults with Autism;
2) In collaboration with other area service providers, develop a private pay service option to provide a basic level of system navigation support and assistance in life planning for adults with ASD who may not qualify for services. It is hoped that this could become a model for efficiently serving this population and assisting adults with ASD to better access existing generic and natural supports in the community.
3) Development of training to create capacity to provide this service.

The other project K-CART has been involved with has been collaboration with Johnson County Community College to assist in the development of a support system for young adults with ASD attending JCCC. This group has members with ASD and peer mentors, students without ASD who are volunteering to attend the group to improve social opportunities. JCCC already has a solid program in place to support adults with ASD academically and this is now in place, again hopefully as a model program to be replicated, to provide that social support. While a new program, we have already seen an impact individually on those involved with the group with regard to social growth and self-confidence. As the group continues we will hope to quantify this and provide evidence for this as a critical component for young adults with Autism.

The opportunities provided children with ASD through their school transition programs and into young adulthood directly impact the success of these children as adults and the system capacity. While not an exhaustive list, the following are some critical steps toward building a better community of support for adults with ASD:

1) End Waiting Lists for services. Uncountable dollars of investment in special education are lost when young adults with Autism have to wait 3-5 years to receive services.

2) Make sure insurance providers are providing families access to proven early intervention and other services for children with Autism. This alone would dramatically increase system capacity.

3) Increase access to trained behaviorists for families, mental health centers and adult service providers and for families receiving Medicaid by building statewide capacity to ensure this service can be provided.

4) Create a service to provide additional assistance in system navigation and supports for young adults with ASD who have been served by the mental health centers or the foster care system as children.

Contact information:
Sean Swindler
Kansas Center for Autism Research and Training
Director of Community Program Development and Evaluation
Mail Stop 4003, 3901 Rainbow Blvd.
Kansas City, KS 66160
PH 913-945-6840
FAX 913-588-5916
E-mail: sswindler@kumc.edu

ADVANCING FUTURES
for ADULTS *with* AUTISM

Advancing Futures For Adults with Autism, Kansas City, local issues summary

(=number of responses)

Cross-Cutting Issues/Areas of Need

- School to career/independence transition programs specific to autism (26)
- Transportation (20)
- Rural vs. urban needs/capacity (14)
- Overall capacity (training) to serve all adults w/Autism (13)
- parent training (11)
- Flexible funding streams focus on individual/money follows person/waiting lists (10)
- Autism groups and AGENCIES need to work together/coordinate efforts (6)
- behavioral supports/therapeutic services for adults/funding for/dual diagnosis (5)
- effort needs to be bi-state/recognize differences between states (3)
- needs of military families

Comments:

Awareness of Asperger diagnosis for adults
create an annotated bibliography of ALL innovative services throughout the area
work with other disability advocacy groups
day care for children

Community Life Issues/Areas of Need

Social Skills/relationship training or groups (5)
Self-Advocacy (5)
First Responder training (5)
Recreation (3)
Life skills training/on-going (2)
Community Awareness training to highlight positive contributions of people with Autism

Employment Issues/Areas of Need

- innovative/individualized/autism-specific job development and employment trng (31)
- access and support for college and post-secondary programs (6)
- job coach training/capacity to serve all people with Autism (7)
- competitive employment opportunities (4)
- more employers needed (2)

Comments

Can we replicate SAARC?
Agency specializing in 18-21 transition services?
Include self-employment opportunities

Housing Issues/Areas of Need

Supportive/innovative communities in which to live/increased opportunities for independent living for ALL people with Autism (32)
Affordable housing (4)

Comments

Need to develop models
Mission project frequently referenced

KANSAS
DEPARTMENT OF SOCIAL
AND REHABILITATION SERVICES

Don Jordan, Secretary

Joint Committee on Children's Issues

December 8, 2010

Developmental Disability Waiver

Deputy Secretary Ray Dalton

For Additional Information Contact:
Katy Belot, Director of Public Policy
Patrick Woods, Director of Governmental Affairs
Docking State Office Building, 6th Floor North
(785) 296-3271

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KANSAS
DEPARTMENT OF SOCIAL
AND REHABILITATION SERVICES

Joint Committee on Children's Issues

December 8, 2010

Chairwoman Lynn and members of the Committee, thank you for the opportunity to appear before you today. I am Ray Dalton, Deputy Secretary of Disability & Behavioral Health Services at the Kansas Department of Social and Rehabilitation Services. Today I will present information regarding the Developmentally Disabled Waiver which serves persons with a developmental disability.

Background

Medicaid waivers are federally approved requests to waive certain specified Medicaid rules. For instance, federal Medicaid rules generally allow states to draw down federal Medicaid funds for services provided in institutions for persons with severe disabilities. Many of the community supports and services provided to persons with disabilities such as respite care, attendant care services, and assistive services, are not covered by the regular federal Medicaid program. HCBS waivers give the state federal approval to draw down federal Medicaid matching funds for community supports and services provided to persons who are eligible for institutional placement, but who choose to receive services that allow them to continue to live in the community. The Centers for Medicare and Medicaid Services (CMS) requires that the cost of services paid through HCBS waivers be, on the average, less than or equal to the cost of serving people in comparable institutions.

Developmental Disability (DD) Waiver

The DD waiver serves individuals 5 years of age and up who meet the definition of mental retardation or developmental disability and are found eligible for Intermediate Care Facility for the Mentally Retarded (ICF/MR) level of care. Services provided through this waiver are:

- Assistive Services
- Day Services
- Medical Alert Rental
- Sleep Cycle Support
- Personal Assistant Services
- Residential Supports
- Supported Employment
- Supportive Home Care
- Wellness Monitoring

As of November 1, 2010, there were 2,403 people on the waiting list receiving no waiver services, and another 1,015 people receiving some services who were waiting for additional services.

The age breakdown for those individuals on the waiting list is:

- 5 years of age through age 17 – 1,420
- 18 years of age through age 64 – 1,985
- 65 years of age and older – 13

SRS maintains one statewide waiting list for HCBS-DD services which includes both the unserved and the underserved. A person's position on the waiting list is determined by the request date for the service(s) for which the person is waiting. Each fiscal year, if funding is made available, people on the statewide waiting list are served, beginning with the oldest request dates at the top of the list.

An additional $3.3 million SGF was allocated to the DD waiver for FY 2011. SRS is in the process of working with the Community Developmental Disability Organizations to offer services to individuals on the waiting list. It was originally estimated that at least 145 individuals will be served with this funding. Because the average cost of the people on the top of the waiting list had a lower cost per person than the people currently on the waiting list, 244 people have been offered and accepted services.

For this waiver a total of $115,297,432 AF, or $49,070,587 SGF would be required to eliminate the waiting list. In calculating the estimated cost to eliminate the waiting lists SRS utilized the current average cost per consumer and the SGF needed is based on the normal state FMAP that will be in effect in FY 2012.

During FY 2010, $311,275,963 was paid through the DD waiver to serve an average of 7,669 people a month.

On January 1, 2010 and on February 1, 2010, there were waiver changes implemented by SRS to assist in avoiding further overspending. The waiver changes included:

- On January 1, 2010, Oral Health Services were eliminated.
- On February 1, 2010, Temporary Respite Care services were eliminated.

SRS Fee Fund

Over the past several years SRS fee fund balances have been used to fill the gap between available SGF and waiver spending and the funds allocated for the HCBS Waivers. The fee fund balance has now been depleted and SRS will be $11 million short for FY 2012. SRS has requested an enhancement to replace the $11 million shortfall in the FY 2012 budget submission. The shortfall in the DD waiver is $20.5 million all funds, $8.5 million SGF.

SRS's options regarding changes that may be made to fill this gap are limited by federal regulations that have been implemented through the Recovery Act and the Affordable Care Act. These regulations do not allow states to change the waiver eligibility requirements without loss of federal funding. Under the Recovery Act the number of persons served by the waivers may not drop below the number of individuals that were being served on July 1, 2008. The only options that are available to SRS to control spending are through serious rate reductions and then to evaluate what additional service limitations could be implemented.

This concludes my testimony and I will be glad to answer any questions you may have.

INDEPENDENCE
INCLUSION
INNOVATION

INTERHAB

December 8th, 2010

TO: Senator Julia Lynn, Representative Mike Kiegerl, Chairs, and Members of the Joint Committee on Children's Issues

FR: Matt Fletcher, Associate Director, InterHab

RE: Developmental Disability Funding and Waiting List Issues

Thank you Senator Lynn, Representative Kiegerl, and members of the Committee for the opportunity to speak to you today regarding the challenges facing the Kansas community-based developmental disability service system. These challenges threaten not only the viability of the community-based DD system for all Kansans with developmental disabilities, including children who will need this system to be secure for many years to come.

The network of community supports for persons with developmental disabilities remains one of the most successful partnerships between communities and the Legislature in Kansas history. Community supports were borne out of locally-realized necessity, and the realization that institutions were no longer the best choice for Kansans with developmental disabilities. Within the span of a few decades, a mass exodus occurred as thousands of persons with developmental disabilities passed through the once-locked doors of State institutions and into an uncertain but compelling future in communities across Kansas. As they did so, they changed

However, the community-based system has become the victim of its own widespread success. Because it excelled in such a quiet and steady pace in providing opportunities for Kansans with developmental disabilities in communities across the State, policymakers in Topeka increasingly focused their attention to other issues. As a result, increases in funding for the community network began to lag. As funding lagged, lists began to form of those Kansas children and adults with developmental disabilities who needed help but would have to wait because not enough resources existed for them. At first these lists were small – but in a matter of a few short years, they were allowed to grow to thousands.

By the beginning of the new millennium, updates to funding had lagged to such a great degree that the community network could no longer even keep pace with inflationary costs each year. As this occurred, providers found it increasingly difficult to offer competitive wages to the direct care workers who are so vital to community care, resulting in high turnover and low continuity of care. This erosion of the human resource 'infrastructure' so vital to the community network led the interim Legislative Budget Committee in 2006 to recommend a bold plan to re-build that infrastructure and eliminate the State's two waiting lists for services. These recommendations were built upon the philosophy that the Legislature could not address these issues separately; that the human resource infrastructure so vital to community-based supports must be built up to adequately meet existing service needs in concert with efforts to end waiting lists and bring thousands of new individuals into the service system.

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700 SW JACKSON ST., SUITE 803 TOPEKA, KANSAS 66603 |P|785.235.5103 |F|785.235.0020 WWW.INTERHAB.ORG

Quality-Based Community Expansion:

The Kansas Developmental Disabilities (DD) Reform Act (KSA 39-1806), passed in 1995, mandates development of a community network of supports that foster independence, inclusion, integration and productivity for Kansans with developmental disabilities. Significant and sustained efforts must be undertaken by the State of Kansas, in partnership with community providers, in order to build the infrastructure required to carry out this commission.

We believe in a simple but critical premise – that waiting lists and rate increases must be addressed in combination if the State and its Community partners are to significantly expand community services for persons with developmental disabilities. The members of InterHab have given a name to this approach – "Quality-Based Community Expansion" or "Q-Base".

Proposing new resources to fund "stand alone items" ignores the reality that waiting list funding alone will not enable community service providers to meet the needs of persons on the waiting lists.

- In several areas of the State, providers are unable to hire staff to serve new consumers due to low starting wages.
- Other providers are without enough supervisory staff, due to turnover, to safely oversee a business expansion.
- Requests that a provider serve a person with challenging behavioral issues may be turned down due to the relative inexperience of existing staff, or
- Other requests that a provider serve a person with challenging medical issues may be turned down due to a shortage of persons on staff with adequate training to safely provide the ancillary support tasks of tube feeding or tracheotomy-cleaning.

To provide increasing amounts of services requires the State/community partnership to expand service capacity and enhance service quality in amounts commensurate with the needs of persons to be served, ahead of the curve of service expansion.

To increase service without this consideration invites quality erosion and exacerbates safety risks to all consumers, not just the consumers funded by new waiting list dollars.

The State's Waiting Lists:

State and community leaders must better assess and present the characteristics of persons' needs who are waiting for services. Merging the two lists into one list would acknowledge that individuals' needs cannot be arbitrarily prioritized by who is and who isn't currently receiving some services.

State and community leaders must also re-emphasize the generic community supports that do exist, and persons waiting for services, and their advocates, must be assisted in accessing such generic supports. Generic supports can, and often do, mitigate some of the negative effects of waiting for service, and sometimes can become a non-paid alternative to paid services.

Capacity Expansion:

Community service providers have few tools with which to develop the human resource capacity needed to serve significant new numbers of persons, given that the principal energy of human resource professionals in the system is spent in the constant battle to overcome high-turnover and staff shortages that arise as a direct result of low wages.

True capacity building can only result from significant upward adjustments in the wage base to reduce the stigmatization of such jobs as low-wage, no-advancement jobs. Reducing such stigma removes the initial barrier faced by HR staff, i.e. that persons entering the job market routinely do not apply for our jobs because they are known to be hard jobs with low pay.

Obviously, the foundation of HR capacity building is the foundation upon which the community service policies rise or fall. It is critical, but still woefully under-addressed, that the State must provide resources adequate to enable service providers to recruit, train, and retain high-quality direct care staff. Current reimbursement rates are neither adequate nor reasonable to make better wages and benefits possible.

While the provider assessment concept you will hear more about today from Tom Laing is a vitally important first step in providing an increase in reimbursement rates, it must not be seen as a magic bullet which will make it possible for the legislature to not provide funding increases in the future.

2006 Legislative Budget Committee Recommendations:

Your peers have already done the hard work and drawn up a blueprint for building capacity in the community-based DD system and eliminating the waiting lists which now number more than 4,000 people. In 2006, the Legislative Budget Committee recommended a three-year plan which would have built human service capacity on the front end, and finished strong with the elimination of waiting lists. We encourage the Legislature to dust off that blueprint and re-commit itself to the recommendations of the report. While the budget numbers would need to be updated, and perhaps even the number of years outlined in the plan modified, the recommendations contained within the report are a solution for ensuring that the Kansas community-based system of supports remains viable for Kansans with developmental disabilities in the future.

I know that, given the current fiscal climate the state faces, legislators may ask "why now?" I would argue that not acting now will ultimately cost the State more:

- ***Institutional care costs more*** - If the community network is allowed to erode, the only other option for persons with developmental disabilities will be institutional care – a model which will continue to be significantly more costly to Kansas taxpayers. Annual cost of care at Parsons State Hospital: $135,415. Annual cost of care at KNI: $169,725. Estimated average annual cost in the community: $35,663.

- ***"Graduating to the living room" squanders tax dollars*** - Imagine paying for special education services for a child with a developmental disability through two decades of schooling, from pre-school to high school graduation. Now, imagine throwing much of that investment away because supports aren't available to that child once they graduate from school. This example is, in fact, repeated every day in Kansas. To find multiple examples, one simply need to look at the State's DD waiting lists, which now total more than 4,000 persons with developmental disabilities. The skill sets learned through years of special education can be quickly lost, if not reinforced once the child leaves the special education system. With no funding for these ever-growing waiting lists, more and more Kansas children "graduate to the living room" while they wait for services to become available. While they wait, the investment Kansas taxpayers have made in them erodes. It's a shameful thing to do to a human, and it's a shameful waste of Kansas tax dollars.

Conclusion:

The members of InterHab stand ready to work with the Kansas Legislature, should it choose to prioritize the formation of a multi-year plan to address the capacity needs of the DD system and eliminate the State's waiting lists. We are excited and encouraged by these hearings, and hope they signal the beginning of a significant recommitment to ensuring the future viability of community-based supports for Kansans with developmental disabilities.

Thank you for the opportunity to speak with you today.

Legislative Budget Committee

PUBLIC DEVELOPMENTAL DISABILITIES SYSTEM

CONCLUSIONS AND RECOMMENDATIONS

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

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

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

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

Proposed Legislation: None.

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BACKGROUND

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

COMMITTEE ACTIVITIES

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

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

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

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

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

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

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

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

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

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

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

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

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

CONCLUSIONS AND RECOMMENDATIONS

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

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

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

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

15-7

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Quality-Based Community Expansion - "Q-Base"

The Kansas Developmental Disabilities (DD) Reform Act (KSA 39-1806), passed in 1995, mandates development of a community network of supports that foster independence, inclusion, integration and productivity for Kansans with developmental disabilities. Significant and sustained efforts must be undertaken by the State of Kansas, in partnership with community providers, in order to build the infrastructure required to carry out this commission.

While small increases in needed resources have been championed by the legislature in recent years, no organized effort has been initiated by policy makers to either address the glaring needs of the community DD system or meet the mandates of the KS DD Reform Act. Strong leadership is now needed to steer the State into a new era of sustained investment in a community-based system of supports for Kansans with developmental disabilities that will finally answer the call of the KS DD Reform Act.

The beginning steps of such a sustained effort must include the elimination of the State's waiting lists for DD services, which now number more than 4,000 children and adults with developmental disabilities.

However, policy makers must understand that in order to end the State's waiting lists, community service capacity must be dramatically enhanced - both programmatically and in terms of human resources infrastructure.

The following is a broad proposal that we believe must be embraced if we are to meet the mandates of the DD Reform Act. This proposal is based on a simple but critical premise, i.e. waiting lists and rate increases must be addressed in combination if the State and its Community partners are to significantly expand community services for persons with developmental disabilities.

Proposing new resources to fund "stand alone items" ignores the reality that waiting list funding alone will not enable community service providers (CSP) to meet the needs of persons on the waiting list, e.g.:

- In several areas of the State CSPs are unable to hire staff to serve new consumers due to low starting wages.
- Other CSPs are without enough supervisory staff, due to turnover, to safely oversee a business expansion.

- Requests that a CSP serve a person with challenging behavioral issues may be turned down due to the relative inexperience of existing staff, or

- Other requests that a CSP serve a person with challenging medical issues may be turned down due to a shortage of persons on staff with adequate training to safely provide the ancillary support tasks of tube feeding or tracheotomy-cleaning.

To provide increasing amounts of services requires the State/Community partnership to expand service capacity and enhance service quality in amounts commensurate with the needs of persons to be served, <u>ahead</u> of the curve of service expansion.

To increase service without this consideration invites quality erosion and exacerbates safety risks to all consumers, not just the consumers funded by new waiting list dollars.

Only with sufficient rate increases, in combination with creative and flexible program management, can the State/Community partnership insure a quality-based approach to community service expansion.

InterHab proposes that any new system dollars – for waiting list reduction and rate increases – be creatively utilized to address four program components:

- Stewardship
- Quality enhancement
- Capacity expansion
- Waiting lists

Community Stewardship:

Community leadership have long been tasked with combining state/federal resources with local resources to make community DD programs work to the maximum attainment of the statutory and regulatory expectations of the participating funding authorities. To that extent, the following are the stewardship activities that we believe are vital to assure the long term financial sustainability for the coming years:

- State and community efforts must be increased to assure an expanded effort in the community to promote employment and employment related training for persons with developmental disabilities.

- Programs such as 'tiny-k' infant and toddler services which perform vital early intervention for children with disabilities and their families must be enhanced, thereby ensuring a better quality of life for thousands of Kansas children who could be diverted from further need of State-funded assistance.

- State and community efforts must collaboratively develop new family service models that satisfy basic family needs, in order that families are not diverted into the most available funding stream (the current HCBS DD Waiver) but are assisted by options (including the Family Subsidy model, a new Family Services waiver, or other models).

- State and community efforts must be redoubled to increase the maximization of freedom and control that someone can bring to their life.

- State oversight must position its structure, within the philosophical framework of the Developmental Disability Reform Act, to be supportive of community flexibility in adjusting programs, services and staffing to suit the wide spectrum of both proven current needs and possible future needs of populations served.

Quality Enhancement:

The State and community collaboration of the past, which ushered in a high degree of professionalism and expertise in all areas of the delivery of community services and supports, has taken a back seat to a struggle to maintain 21st century quality enhancement momentum with 20th century resources. This trend must be reversed.

Further, additional emphasis and resources must be brought to bear on the State's efforts to encourage self-advocacy among Kansans with Developmental Disabilities.

Finally, in order to fill a vital community education and oversight role, the State should pursue creation of a Kansas DD Ombudsman. This ombudsman would provide information to persons served and their families regarding community service and provider options, as well as collect needed data on community provider customer service, quality of service and service access issues.

A significant resource commitment must be made in the following areas of training:

- Training initiatives to assist in the delivery of high-quality services to the increasing numbers of persons with health, behavioral or age-related challenges,

- Training initiatives to upgrade the skill-set of every supervisor of community direct care staff, and

- A comprehensive review must be undertaken to assess the core quality related proficiencies of the current network of service providers.

The expansion of services, the expansion of non-licensed providers, and the lack of adherence to core standards among newly licensed providers – all of these factors give rise to a concern among community leadership that standards of service intended to safeguard the interests of consumers have been sacrificed due to resource shortages. Minimum standards must be established, and reimbursement rate structures must reflect a commitment to such standards.

In the era of increased self-sufficiency among persons receiving service, ensuring the adherence to statutory and departmental quality benchmarks such as the core components of the DDRA (integration, inclusion, independence and productivity) is vital. The State must undertake a development process to implement full oversight of these new service choices, in order to determine that established statutory and departmental outcomes are met.

The State's Waiting Lists:

State and community leaders must better assess and present the characteristics of persons' needs who are waiting for services. Merging the two lists into one list would acknowledge that individuals' needs cannot be arbitrarily prioritized by who is and who isn't currently receiving some services.

State and community leaders must also re-emphasize the generic community supports that do exist, and persons waiting for services, and their advocates, must be assisted in accessing such generic supports. Generic supports can, and often do, mitigate some of the negative effects of waiting for service, and sometimes can become a non-paid alternative to paid services.

Capacity Expansion:

Community service providers have few tools with which to develop the human resource capacity needed to serve significant new numbers of persons, given that the principal energy of human resource professionals in the system is spent in the constant battle to overcome high-turnover and staff shortages that arise as a direct result of low wages.

True capacity building can only result from significant upward adjustments in the wage base to reduce the stigmatization of such jobs as low-wage, no-advancement jobs. Reducing such stigma removes the initial barrier faced by HR staff, i.e. that persons entering the job market routinely do not apply for our jobs because they are known to be hard jobs with low pay.

Obviously, the foundation of HR capacity building is the foundation upon which the community service policies rise or fall. It is critical, but still woefully under-addressed, that the State must provide resources adequate to enable service providers to recruit, train, and retain high-quality direct care staff. Current reimbursement rates are neither adequate nor reasonable to make better wages and benefits possible.

HR capacity building is additionally needed to enable focusing in the following ways:

- To ensure that community developmental disability service providers are reimbursed at a rate which allows them to offer wages and benefits commensurate with attracting and retaining quality direct support staff.

- To utilize higher qualified and/or more experienced staff for the increasing numbers of consumers served whose diagnostic characteristics include (a) significant health needs, (b) increases of the early onset of age-related illness, principally Alzheimer's and other forms of dementia, (c) behavioral challenges of such significance that the failure to provide adequate staff to serve such persons could easily constitute risks to the consumers or the community at large;

- To increase the development of community generic support to help meet individual needs with non-paid services; and,

- To better educate community employers to see workers with DD as a resource to be utilized, and to provide the informal short term assistance to make that happen, as well as the intermittent long-term follow up to assure the viability of those employment experiences.

- To fully-fund supported employment services for persons with developmental disabilities in order to assist them in becoming independent, contributing members of their communities.

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KANSAS DEVELOPMENTAL DISABILITY UPDATE

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COMMUNITY CAPACITY

Despite the fact that community providers have successfully transitioned hundreds of persons out of costly institutions, the state has fallen woefully behind in adequately funding the community system. **Compare these changes since 1993:**

- **State's DD Tech I position increased more than 75%**
- **Inflation increased more than 52%**
- ***The HCBS MR/DD waiver increased only 29% from rate increases given by the Legislature.***

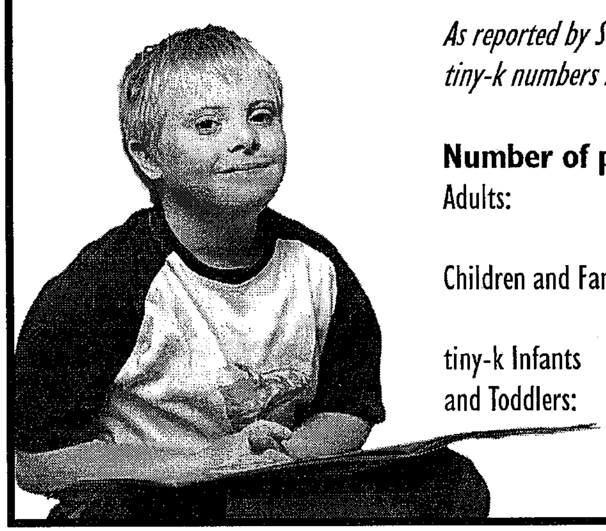
WAITING LISTS

The lists of persons with developmental disabilities has grown steadily since 1996. Currently, SRS maintains two waiting lists. One for children and adults who receive no services at all, and another for children and adults who need additional services to live successfully in our communities. Every year, approximately 300 new persons are added to the list.

Unserved Waiting List*:	**2,942 Children & Adults**
Underserved Waiting List*:	**1,594 Children & Adults**
TOTAL:	**4,536 Children & Adults**

**As of September 2, 2010*

THE PEOPLE



As reported by SRS September 2, 2010.
tiny-k numbers reported by KDHE January 8, 2009:

Number of persons receiving services:

Adults:	7,532
Children and Families:	1,224
tiny-k Infants and Toddlers:	6,643

THE PRICE

Community services are underfunded compared to institutional services. Compare the average annual per-person funding:

Parsons State Hospital:	**$135,415**
KNI:	**$169,725**
Community DD Services:	**$35,663**

Direct care workers at the State's two DD institutions make a starting wage of $12.35 per hour.

Direct care workers doing the similar work in your community make an average wage of $8.78 per hour.

INDEPENDENCE
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INTERHAB

December 8, 2010

TO: Joint Committee on Children's Issues

FR: Tom Laing, Executive Director, InterHab

RE: Provider assessments for HCBS services

Thank you, Senator Lynn and Representative Kiegrl, for holding this hearing.

We appreciate the committee's recognition of the importance of home and community based developmental disability services for children and adults. We hope our testimony and that of others from whom you have heard, will be helpful. The need for quality-based community expansion is evident, and we appreciate that the inaction of the past is not the plan you have in mind for the future.

We are optimistic that the administration and the legislature will take a new look and refine the planning efforts of previous legislatures, as Matt Fletcher has proposed. In addition, our association members and a number of stakeholders continue to seek ways to help to address the twin challenges of waiting lists and system capacities, I will present one such idea today on behalf of InterHab.

The 2010 Legislature enacted and the governor signed provider assessment legislation for adult care services in Kansas. That legislation is already strengthening services for Kansas seniors by making it possible for providers to prevent quality erosion due to a lack of funding. We believe that legislation's success has further established the "proving ground" for provider assessments.

It is our hope that the success of this funding methodology will encourage you and your colleagues to enact a provider assessment law for community services for Kansans with developmental disabilities.

The current CMS rule allows for provider assessments for hospitals, adult care homes and intermediate care facilities. It is our belief that CMS will adopt a rule allowing HCBS DD provider assessments in the coming months. Adoption of legislation in 2011 would immediately allow us to benefit from the new rule, rather than waiting for another year to go by.

Attachment 16
JCCI 12-8-10

700 SW JACKSON ST., SUITE 803 TOPEKA, KANSAS 66603 |P|785.235.5103 |F|785.235.0020 WWW.INTERHAB.ORG

Why a provider assessment?

- A provider assessment is an innovative way to utilize current resources in the community to bring new HCBS income to the State community service providers. It is an innovation that was enacted for hospitals and adult care home services, and has worked.
- These resources invested in a dedicated manner to rates will make possible the first meaningful step in many years to provide needed upgrades for the community, where current State investments have resulted in a widening disparity of more than $4.00/per hour less for the average community wage earner, compared with State institutional wages which start at nearly $13 (for the same kinds of Direct Support Professional services).
- An assessment of 5.5% would enable an infusion of up to $25 million to Kansas, making possible a rate increase estimated at 7-8%. (We would still be far behind in comparison to all economic indices for the recent decades, but such a rate increase would certainly help in our efforts to finance the continuing rise in the ordinary costs of doing business, and especially in helping community service providers to retain their best professionals in the field.)
- A provider assessment will invest in the maintenance of quality care (helping our state meet its statutory mandates to support these programs) and at the same time will enhance our share of Federal Medicaid dollars which will help the Kansas economy.
- We recognize the financial challenges facing the new Administration and the Legislature, and believe that the adoption of a provider assessment fee will allow the legislature to focus new SGF resources in 2011 on the waiting list challenge.
- The provider assessment proposal, if adopted, will benefit all Kansans with developmental disabilities who are served in the community, and will assist all providers of service, at no additional cost to state taxpayers.

Status of Advocacy at CMS to Allow HCBS DD Provider Assessment financing methodology:

Talks have continued during the past year with CMS to advocate that they allow a HCBS DD provider assessment rule. Such a fiscal policy would be consistent with state and federal policies which favor "least restrictive settings". Any fair examination of the question will sustain our belief that financing policies should be consistent with program policies. They are currently not consistent, but a new rule allowing provider assessments would remedy that inconsistency.

Provider assessments were first authorized in the early 90s to help States make Medicaid a more affordable and flexible funding source. The emphasis was on hospitals, nursing homes and intermediate care facilities (ICFs). (At that time, ICFs were the principal programs utilized for persons with DD.) Therefore, ICFs were named in the original law allowing for provider assessments.

At that time, few states had significant investments in HCBS DD services; therefore, there was no clamor for additional funding latitude for HCBS. Today ICF service has shrunk dramatically. The challenge for Kansas and her sister states is focused on adequate funding for expansion of HCBS services.

Fortunately, when Congress allowed for provider assessments, it also allowed that new classes of service could be added by agency rule.

It is that rule-making process with which our national advocates are currently engaged, i.e. to establish by rule the addition of HCBS DD to the ranks of eligible programs to be considered for provider assessments. We are as optimistic today as we were during last session that CMS will make the change needed to allow a provider assessment to be effectively adopted in Kansas.

<u>A provider Assessment for HCBS DD service providers:</u>

Since June we have begun talking to providers that belong to other associations, as well as those not aligned with a professional association. There is a broad receptivity to this initiative. The details will be shaped by such collaboration, and by any additional information we can get from CMS developments.

It is our expectation we will be providing you and other legislators with drafts of consensus supported legislation for your consideration in the coming months, in time for consideration early this session.

<u>Thank you for this invitation to appear before your committee, and for your continuing interest in finding ways to tackle the financial challenges that face the community DD network.</u>

Testimony to Joint Committee on Children's Issues
By Jason and Angi Blakely
Parents of Connor
December 9, 2010

Chairman Lynn and members of the committee, we appreciate the opportunity to speak to you today about the challenges and difficulties of raising and taking care of a child with Developmental disabilities and how the decrease in funding and the waiting list has impacted our lives and the ability we have to care for our child.

Our son Connor just turned seven the 26th of November. He attends Nike Elementary in Gardner, Kansas. He has many friends and has not met a person that he can't get to smile. He is the happiest boy and full of so much love. We could not imagine our life without him. He currently has an IEP through the school system and receives physical therapy, occupational therapy and speech therapy. He also recently started receiving music therapy and adaptive PE. He spends most of his days in the special ed room but is integrated into the first grade class when appropriate. He currently receives no other services besides what the school provides. He has no Medicaid, no SSI and no in home supports or case management. He has been on the waiting list for services through the CDDO since he was five. He was denied Medicaid due to our income at that time. We did receive a small check every 3 months when he turned five. We were grateful for this. It barely covered his meds and diaper expenses and doctor visits. We received approximately three of these checks when funding was cut and it was taken away from us.

Connor was born with a condition called Septo Optic Dysplasia. This is a brain disorder that can cause blindness, hormone imbalances, and brain malformations. Currently Connor suffers with a missing septum pellucidum, partial growth of the corpus callousm, diabetes insipidus (a deficiency of the anti-diuretic hormone) and seizures. All of these can be contributed to the septo optic dysplasia. We are very grateful that with this diagnose Connor was blessed with normal vision. Though he does suffer from a retinal coloboma, which is a small hole in one of his retinas

Connor is non-verbal and was diagnosed with mental retardation and ADHD at 3 yrs old. Connor is full of energy and is capable of wearing any one out in just a short matter of time. He is not toilet trained and does not currently use eating utensils. He was born with a bilateral cleft lip and cleft palate, which he has had four surgeries to help correct. He loves to put everything in his mouth, play with TV's, open and shut doors and cabinets and climb on tables and furniture. It is almost impossible to get Connor to engage in any sort of proper play or interaction at home.

Attachment 17
JCCI 12-8-10

Our ultimate goal in life is to care for our son in our home. Though due to his increase in non functional behaviors and increase in his size this has gotten very hard. Due to his increase in strength and size it is becoming very difficult for me to handle him and take care of all of his needs. I am currently in physical therapy for my back and neck and a lot of this is due in part from lifting Connor into his car seat, his chair for dinner, and bathing him and diaper changes since he becomes uncontrollable at times during these activities. He currently sees a behavior specialist and a psychiatrist. We have tried many medications to help with his hyperactivity and his OCD. Unfortunately none of these have helped. We recently made the decision to place Connor in a inpatient psychiatric unit to show the doctors exactly what we deal with every day and hopefully get Connor and us some more help at home. After one night of Connor being on the psychiatric unit the first thing the Drs. asked us was what do you do with Connor at home and how are you and your husband being able to handle this day to day. They stated that there has to be something done to get some more assistance with Connor at home to help deal with his behavior and that from what they can see if we are not able to get some type of assistance with Connor, that it is only setting up a unsafe situation for Connor and the whole family. We also have a three year old daughter which Connor is becoming more and more aggressive with, pulling hair and grabbing her around the neck and pushing her down. Our daughter is also picking up on some of Connor negative behavior.

I work part time and my husband works full time. Things are tough at home for all of us at most times. We are limited to what we can go out and do with Connor due to his behavior. He requires one on one care at home just to keep him safe. This is really becoming a hindrance to all of our lives and making our daily life very stressful and sometimes seems overwhelming and a fear that this is not going to get any better. I believe we all deserve more. When I think of all the things we are being denied while on the waiting list, i.e. case management, medical card, in home behavioral support and respite care, I often wonder how anyone could let this happen to a sweet, innocent boy like Connor. We know he has a lot of potential in life, but unfortunately is being held back by limited resources. We try to do all we can for our son and there is nothing we would want to deny him that could make life easier for him. Though finances only go so far.

I hope this has given you all some insight into our lives with our special boy Connor. He and all other children with developmental disabilities can teach us all a great lesson in life if they only have the chance to reach their full potential. We want to truly thank you for letting us tell our story about Connor and hope that in some way this may help all the families that struggle with the pressures, fears, stress, and unknowing of raising a child with developmental disabilities.

With deepest gratitude for this opportunity,
Jason, Angi, Connor, and Trinity Blakley.

Testimony to the Joint Commission on Children's Issues

By Edie M. Nicholls

Parent of Kelli Nicholls, an Individual with Cri-du-Chat (Cry of the Cat) Syndrome

December 8, 2010

Chairperson Lynn and members of the Committee, I sincerely appreciate the opportunity to speak with you today about the daily challenges of being a parent of a "special needs" daughter. If you asked Kelli, she would probably say she has her own challenges having a mother of a "special needs" person!

My world changed dramatically on the day my first child, Kelli, was born on October 26, 1984. I was 25, married to a wonderful man, and about to start the exciting adventure of motherhood. Kelli was a beautiful baby, with a head full of coal black hair—just a little thing weighing in at 5 lbs, 11 oz. She was three weeks early, so her being small wasn't so alarming. She also had double inguinal hernias, also common in late pre-term babies. It was after her hernia surgery the day after Thanksgiving in 1984, when we found out that out lives were about to be turned upside down. Although chromosome testing was more cumbersome 26 years ago, the people at Children's Mercy Hospital in Kansas City were pretty sure that our precious angel had Cri-du-Chat (also known as Cry of the Cat) Syndrome. One of the first noticeable characteristics of this syndrome is an eerie cat-like cry, which her father and I had attributed to her being early. We were given a choice at Children's Mercy; to take her home (she would probably die in her sleep from aspiration), or send her to the Johnson Crib Care Home, an institution for infants, in Lee's Summit, Missouri. We were highly encouraged to choose latter—that way we would not get too attached to someone who would never progress past a 6-week infant stage. Someone who would never eat, speak, walk, be potty trained, or tell me she loved me.

Kelli's father and I founded the first and only national support group for her syndrome, The 5p- Society (www.fivepminus.org). We started with 13 families and now have over 500 families in our international database. For years, I would counsel new parents as they received the devastating news that their child(ren) were diagnosed with this syndrome.

Kelli was enrolled in the Infant Development Center at Shawnee Mission Hospital at the ripe old age of 5 months. It is my firm belief that she has progressed as far as she has because of early intervention. Even though I entered her bedroom with trepidation each morning, expecting to find her dead in her crib, we persevered and she graduated from the IDC. She went to pre-school and grade school in Olathe, Kansas, and high school and the Access Program through the Blue Valley School system.

When Kelli was about 9 years old, we made a trip to Wichita, Kansas, to the Institute of Logopedics. We were considering placing her at that time as her behavior was pretty challenging. We decided to keep pushing—my then husband and I told each other that we would know in our hearts when it was time to make that move. I believe the time has finally come.

Attachment 18
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During that time, we had two more children—Kevin and Ethan, who have always lived with the knowledge that their sister was different. But she has been their "normal".

Three of my dreams for Kelli have come true—ones that I thought were lost the day we got the diagnosis of Cri-du-Chat Syndrome. She has been the flower girl in a wedding (it's a "mom" thing), she went to the prom, and most importantly, she tells me that she loves me.

In 1999, my then husband and I built our dream home. This home included a swimming pool (swimming is Kelli's favorite thing to do—we knew we wouldn't be paying for a college education), and an apartment in the basement for a caregiver for when the time came that we could no longer care for Kelli ourselves, but she would still be able to be in the home. Our master bedroom was even on the first floor so we wouldn't have to climb steps when we got old—when we left that house, we would all be going to "the home" together!

But dreams change, houses get sold, people leave, and the ones who are left pick up the pieces and go on. I have been a single mom to Kelli and her brothers since April, 2002. It has been difficult and without the help of HCBS, I'm not sure how I would have made it.

I have been employed for the last 12 years by Saint Luke's Hospital of Kansas City, as, of all things, a Patient Advocate! (I think they figured they wouldn't have to train me for the job!) I am protected by FMLA which I use on an intermittent basis for Kelli's needs. I rarely have time left over after her doctor's appointments or sicknesses, to use any personal time for myself or my other family. My elderly mother has been very sick since September and I have had to find additional child care for Kelli when I needed to be with my mother. I realize that there are no guarantees in life, life is not fair, no one is guaranteed a free ride and on and on. But I am tired. I know that it is not your responsibility to help, but it sure would be a welcome respite.

I am here today because there comes a point in the lives of parents with special needs children when we say, "I simply cannot do this anymore. It's not that I don't WANT to do it anymore, there is just nothing left." It comes at different points for different families, but the sure thing is that it does come.

I have three care providers that I use for help with Kelli because the average teenage babysitter will not cut it. That means that I have to plan well in advance for an outing. My husband left 8 years ago—forget about dating and trying to find another life partner. For those of you with children, please try to imagine trying to find childcare for 25 years. Just the thought of it is exhausting. One time the Kansas City Star did an article at the beginning of summer about how hard it was to find summer child care. I wrote that editor and told them what hard was really about. They came out and did a story on the trials and tribulations of finding child care for special needs people.

A trip to the grocery store, Wal-Mart or the mall is energy-zapping. Kelli has some autistic characteristics in addition to her syndrome. She will refuse to get out of a car, or when she does get out, she puts her hands over her ears and refuses to move. It may take 10-15 minutes to get into a store. She speaks in a very loud tone of voice. When we eventually make it into where we are going, all eyes are upon us. If you do not notice us, you hear us! I try to engage people, especially small children, when they are staring at us to explain about "differences" in people and how hard it is for Kelli to learn things that are so easy for them. My son had his Senior Football Banquet Monday night. I had to have a special sitter for her; then when I returned home before she was completely asleep, had to calm her down once again enough to go back to bed. My son prefers to go to his friends houses because Kelli can have one of her tantrums in front of his friends. My sons' Christmas mornings have always been "trying" because all of the attention is focused on Kelli and trying to keep her patient and under control so her brothers can open their presents.

Kelli functions at about a 4-5 year old level, even though she is chronologically 26 years old. I still have to toilet her, brush her teeth, wash her hair, bath her, and dress her. Being four or five years old is okay—for about a year. But 20 years of being stuck there is not a pretty thing—not for me and probably not for Kelli.

I am 51 years old. I so want to see my sweet daughter in an environment that is good for her before a crisis arises. Unfortunately for me, I feel that a crisis in my family is right around the corner. Our family dog passed away on September 12. He was a Golden Retriever named Nick. A few weekends ago, Kelli, my son Ethan and I decided to go to the shelter to see if there was someone special for us. Kelli is very perceptive to my moods—I cannot express sadness or cry in front of her or she explodes into one of her episodes where she bites her arms, hits herself in the head and chest—blood literally flies. So we're at the shelter and I begin to get a bit teary thinking of old Nick. She immediately picked up on my mood and kept repeating, "Are you all right, are you all right, are you all right, are you all right?" We were in the car by then and the only thing that kept me from driving over the bridge was the thought that my son, Ethan was in the car. I am so tired.

One of Kelli's other bad habits is biting holes in her clothes. When she gets frustrated, she bites holes in her shirts. I cannot keep the child clothed. I have finally taken to mending the clothes as I cannot afford to keep replacing them. And the biting of her arms. I have tried everything—taking her to an ED to have splints made and wrapping them in ace bandages so she cannot bend her arms. She figured that out. Putting cups in the bottom of socks and duct taping the socks to the top of her arms—she bites through the socks. I've taped rulers to her arms so she cannot bend to get her arm in her mouth. If a police forensics team came through my house, they would swear a murder had occurred here because of the blood that is flung around when she is having one of her self-abusive episodes. I am so tired.

I would not want to be in your shoes—to have to decide whose problems are more dire or more important or more deserving than the others. All I know is that some of the best people I have met in my life have been because of my daughter. We are all in the same boat; we just haven't all arrived at the destination at the same time.

If you have questions, please ask. I could probably talk for hours on my life these past 26 years with Kelli. They have been years of my greatest joy and my greatest sorrow. Please consider my testimony when you are planning your funding requirements. Kelli (and her family) have come a long way. I would like to see a good future for Kelli and I know that can be accomplished in a residential setting. Thank you.

Testimony to Joint Committee on Children's Issues

By Mary Beth DeCock
Parent and Guardian of Steven DeCock
December 8, 2010

Chairman Lynn and members of the Committee, I appreciate the opportunity to speak to you today about the challenges facing young adults such as my son Steven and their families. Steven graduated from the classroom in 2009, and is currently on the waiting list for services. His cognitive level is about the same as a three year old.

Steven's experience in Kansas has been a positive one until graduation in 2009. The school system was excellent in preparing Steven for life after school. As a young adult, the system in place would have enabled him to go directly to day/work services in a smooth transition. It wasn't until we realized how long the waiting list was and how fast it was growing that we knew there was a problem. Our ideal situation would have been for him to graduate from high school with his sister, and go off "to work" as his sister went off to college. Instead, he watched her go on to a new phase of life, while he sits at home waiting.

As a single parent of four and sole guardian for Steven, I have often struggled to find care providers, lately relying on temporary help from my mother to fill in the gaps so that I can work to provide a roof over our heads. However, my mother is retirement age, with osteoporosis, and caring for Steven is too physically demanding for her to continue much longer. My own health has deteriorated in the past two years, and I fear for Steven's future. Within the next few years, I'll need to secure residential care for him, which will be another long wait.

Steven, like many others, would not qualify for work services. He is developmentally unable, as he would always need supervision, and that is only provided short term. His only alternative is day service, and that is not available to him until he comes up on the waiting list. Please keep in mind that the system we had took generations of advocates to create to make their adult transitioning a positive experience. We have made it outside of institutional settings. We are glad of the cost cutting efforts in eliminating institutions, but that doesn't mean our loved ones don't need assistance at all. I've hear of many families that have to make choices to quit work and go on assistance in order to care for our young adults. That just makes the families more stressed, isolated, and cut off from being a productive part of society. It goes against everything I believe in, but I am facing that choice myself in the next couple of years if Steven is still on the waiting list.

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There have been some changes in Steven since leaving school. He cries more, and is depressed often. He has mood swings, and his anxiety disorder has increased drastically, so that he repeats his schedule over and over to try to calm himself on what's happening next. His speech has worsened. When he was in school, he had summer school each year to keep him from losing ground. It is tragic to see how much of his abilities that took years to develop are slipping away from him. It breaks my heart when I see how his quality of life is declining so very fast.

I am only asking for services for Steven to be a productive adult with a supervised place to go to work with his peers and be safe. Wasn't Medicaid developed specifically for the categorically and medically needy such as himself? I know Kansas opted in to the program as well as providing for these adults in Article 7 of the Kansas Constitution, so why are there waiting lists? Please eliminate this hardship for these individuals. So many of these on the list need someone to speak for them. They cannot remain silent forever.

I know you all work hard for the good of Kansas residents, but please keep in mind Steven and the others represented here are your constituents, as well. Give him back his feeling of contribution to society, bring him into the fold. Don't let him be ostracized from the community. We've worked so hard for more years than you know to make him known and recognized as an individual in our community. Please consider our plea to end the waiting list for your most needy constituents.

Thank you.

December 8, 2010

To Whom It Concerns;

I understand that you will be involved in hearings today regarding the current "wait-list" for essential services for adults with disabilities living in Kansas. I also understand that these are very difficult financial times for our state that require very difficult decisions be made by all our legislators and decision makers. As a tax payer and citizen of our state I understand that I must be willing to make sacrifices and compromises in order to do what is best for state as a whole. I am willing to sacrifice and compromise and I understand that we must address our current deficit spending situation. I understand that these are times that require drastic cut backs and trimming of wasteful or unnecessary spending. I am smart enough to know that everybody wants something and not everybody is going to be able to get what they want.

That being said, I feel I must urge you to carefully consider the current situation faced by Kansas families that include a young adult with developmental disabilities. Waiting for five to seven years after they complete their high school education before they can begin receiving essential supports and services that allow them to function in the community is simply unacceptable. What an incredible waste of years of resources and educational programming and instruction designed to help these individuals maximize their potential. Let me explain why I feel so strongly about this.

First of all, I have worked as a special education teacher for over 30 years. My first 10 years were spent teaching students with mild to moderate disabilities. I spent a decade of dedicating each day to being the best teacher I could be and striving to help each student in my charge learn as much as they could in preparation for life after high school. My hope was that they would achieve successful integration into adult life and contribute positively to their communities. I hoped they would find a level of happiness and satisfaction that is (and should be) the expectation of every citizen, no matter what their "ability" level is. Eventually, I become very disillusioned and concerned about the number of students who graduated from high school and simply sat at home due to the lack of a "plan" that could help them secure supports and services they needed. I was thrilled when "Transition Planning" became part of the IDEA reauthorization and became a mandated (although still unfunded) service required by federal and state laws. I was thrilled when schools and communities began working collaboratively to ensure that transition programs and services were in place for young adults with disabilities as they made the transition from school to adult services. I jumped at the opportunity to become a "Transition Specialist" in 1988, when my district obtained a VI-B grant to promote effective transition services. I was so interested in the topic of successful transition planning and services that I decided to return to school and sought an advanced degree in Special Education with an emphasis in Transition. I eventually earned my master degree from the University of Kansas in 1996 and have since served on the Kansas and International Board of the Division of Career Education and Transition, a division of the Council for Exceptional Children (the major professional organization representing the educational needs of all children with disabilities). I have been employed as a vocational counselor and transition specialist in the Blue Valley School District since 1993. For many years I enjoyed the rewards of my career as I helped our students with disabilities make a "seamless" transition from school to adult services. I felt I had helped contribute to a process that was making a powerful and positive difference in the lives of the students I worked with and their families. Unfortunately, I have watched much of that powerful momentum swing back and I suddenly feel like I am back to where I started so many years ago. Once again, I am frustrated by a system that allows our young adults with disabilities to lose skills while they sit at home "waiting" for the resources that can change their lives.

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You see, the reality of that system is hitting way to close to home for me. Along the way, another huge life changing event occurred in my life. Special education became not only the way I earned my living, it became my life. I gave birth to my youngest daughter in November of 1991. That daughter, Emily RaeAnn Swenson, was born with significant disabilities. As an infant and toddler she suffered from extensive health issues (the diagnosis still uncertain). Her symptoms were extensive and varied and included a seizure disorder which resulted in subsequent brain damage due to lack of oxygen to her brain during several "status" seizures she experienced. Although many of Emily's health issues have resolved themselves over the years and she had been seizure free since the age of 4, she currently has several documented and ongoing conditions. In addition to her significant cognitive disabilities, Emily also has poor motor skills, vision problems, Attention Deficit Disorder, and Obsessive Compulsive Disorder. She has high anxiety and nervousness which causes her to perseverate and act out. The more anxious and frustrated she becomes, the more she acts out. She has not been diagnosed with Autism; however she displays a number of autistic characteristics and behaviors. Still, she is considered to be high functioning because she can independently handle most of her own self-care needs (eating, dressing, bathing etc.) and she can read at about a 2nd -3rd grade level, and she can count to 10 even though she has no concept of any practical math skills such as measurements, money or telling time. While attending school, she was friendly and cooperative and she thrived on the social interaction with typical peers.

She completed her traditional four years of high school in May 2010. Currently, she attends Blue Valley School District's ACCESS Program, a community-based program designed specifically for the needs of students age 18-21, with developmental disabilities. She works on things such as learning appropriate social skills, independent living skills and employability skills. For part of her instructional day she currently works as a volunteer at Oxford Animal Clinic where she socializes with the dogs, cleans kennels, washes laundry and performs other tasks in preparation for more independent work in the future. She is well liked by the staff and enjoys her time at Oxford immensely. She feels productive and accepted. She hopes she can improve her skill set enough that she can become more independent and perhaps even achieve part-time employment. At the present time, in order for Emily to perform the tasks successfully, she has the support of a full time job coach provided by the school district. It is a wonderful program and I am thrilled to be not only a Blue Valley School District employee, but also a Blue Valley parent. Since her birth, Emily has received top notch services through infant toddler programs and our public school system first in central KS, through both the Olathe and Blue Valley school districts. I can sincerely say that Emily has had an outstanding public school education and we have been thrilled with the gains she has made over the years. My ex-husband and I have also attempted to do whatever we have been able to do as parents to help Emily progress and reach her potential. We are grateful to all the wonderful professionals who have encouraged, supported and helped Emily (and us) since her birth.

Here is where our fear sits in. Soon Emily will age out of the public school system. She will exit her current school program in May of 2013, the year she turns 21. Just this month, we helped her put her name on the "wait-list" for the residential and day services that she will need once her public school education ends. (She has been on a wait list for "in-home supports" for the past several years also and as of this past funding cycle, her name has not come up for even those services). This year is the earliest she was eligible to be put on the waiting list for residential and/or day services as she can not even apply until she is within three years of exiting school services. Our understanding is that, as it stands now, she will have at least a five year wait (even more if funding issues aren't resolved soon) for these services once she completes her public school program. That means that she will not have the option of either residential placement or day services until she is at least 26-28 years old. During those five years of "waiting" what will she do? I am a single parent and simply don't have the option of staying at home with her. Her father lives in Kansas City, Missouri and is currently unemployed and has significant health issues of his own. Moving to the Missouri side would create a whole additional set of barriers and issues for Emily as she would lose her place on the "wait-lists" in Kansas, in addition to impacting her SSI and KS Medicaid. We do not have extended family members in the area that can assist or help us manage Emily. My mother, father, sister and brother have all passed away. Emily's has only a paternal grandmother still living and she is elderly and lives 4 hours away. Her sister has a family of her own to raise and take care of. She helps when and as she can but her time and resources are also limited. Her father and I serve as her co-guardians and even though we often find it difficult, we always attempt to work towards goals that will benefit Emily. One thing we both agree upon is how unacceptable a five to seven year "wait-list" for services is. We are both perplexed at how our society can allow this to happen. We both agree that it is wrong. We both feel helpless about what to do when we are soon faced with this reality.

While Emily "waits" for the funding that she needs to access adult services, the valuable skills she is learning and has worked so hard on will be forgotten. Many of her skills will be lost. By the time she receives funding, most likely she will no longer be nearly as employable or as socialized. Her loneliness and isolation will most likely lead to more frustration and more acting out. Her behavior will become more and more unmanageable. I am convinced that such a 'wait" time will most certainly lead to serious regression and loss of skills, not to mention create an unacceptable compromise to her health, well-being and safety. She simply is not functioning at a level where she should be left alone day after day. As she gets older and bigger, her behavior has become more and more difficult to manage and I am very concerned about what will happen to her if the day comes when I feel like I can no longer manage her behavior at home. Her father and step-mother share this concern when she stays with them on weekends. Again, we have consulted with behavior management specialists and she is also under the care of mental health specialists. Medications and behavior modification programs are helping us deal with these issues, still we are very concerned about the lack of options should we become unable to manage Emily at home in the future. I think you can get a picture of why we are so concerned for our daughter. She is our daughter. This is her life. This is our life. This is your community. This is your challenge.

And this is an all too familiar story. Not only do I face these fears each day as a parent, but also as a professional. I see far too many families who are faced with similar situations everyday. I watch as their young adults age out of the school program only to transition to nothing. I watch as working parents are forced with the decision of giving up their careers in order to stay at home and support their adult "children". I shake hands with our program graduates and wish them well, knowing that they face an all too uncertain future, where they will "WAIT" for years for the next phase of their lives to begin. I go home at night and wonder why I even have a job? Why am I employed as a transition specialist when there is nothing for our students to Transition into? What is the point? Why do I work so hard to help students gain skills just so they can sit at home and "wait"? What has happened to the progress we were making? Why are we going backwards again? Mostly, I wonder, what will happen to my daughter? What will Emily do? And Why? Why are we allowing this to happen? What if Emily were your child? What if this was your life?

Please help me understand. Please do something. Please carefully consider this situation and find a way to eliminate this complex issue in these difficult times. PLEASE!

Sincerely,

Randi R. Swenson, Transition Specialist (Blue Valley School District)
& Mother of Emily R. Swenson
913-681-0788 rraeswenson@gmail.com or rswenson@bluevalleyk12.org

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2107 Industrial Drive
McPherson, Kansas 67460

mcds
Multi Community Diversified Services, Inc.

Phone: 620-241-6693
Fax: 620-241-6699
McPherson Industries: 620-241-6797
Fax: 620-241-7610

December 8, 2010

To: Senator Julia Lynn, Chair
Members of Joint Committee on Children's Issues

From: Colin McKenney, President/CEO
Multi Community Diversified Services, Inc.

RE: Developmental Disabilities Support Waiver

Good afternoon, Madam Chair and members of the Committee.

Service options for children through the Medicaid waiver program for people with developmental disabilities are very limited. While a number of options are made available for adults, far less consideration seems to have taken place for school-age children living with their families. Because of this, our system is an example of one size fits all when it comes to support services for children.

Regardless of the type of disability or disabilities a young person has, almost all will be pointed toward in-home support services when they become eligible for the developmental disabilities waiver. In most instances, in-home support services mean funding for an individual to provide support services in a child's home. For some children with disabilities, that type of service creates an opportunity for individualized time to work on acquisition of skills or to provide intensive care if needed. In those instances, having a designated support worker to spend one-on-one time is quite a blessing.

Unfortunately for many children with qualifying disabilities, receiving one-on-one supervision from a support worker in the home is not the primary need. Receiving in-home supports may be one of the needs, but having access to specialized therapies or equipment that are not otherwise funded by Medicaid, a local school district, or the family's insurance may be a far greater need in the effort to minimize the limiting effect a child's disabilities create throughout his or her life.

With that idea in mind, a group of disability stakeholders created and distributed a survey to families of children with developmental disabilities across Kansas. The goal of the survey was to determine if families had opinions about ways the system could be modified to better meet the needs of their

Colin McKenney, CEO/President
Board of Directors: Carlton Spencer, Chairman; Larry Schmidt, Vice Chairman;
Jean Anderson, Secretary/Treasurer; Members: Dr. Jerry Leopold, Ken Sims, Dawn Jennings

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children. With more than 350 responses from all over the state, it became clear that many families do have a strong interest in exploring other service options for their children:

- Of 367 responses, 283 indicated they would strongly consider a new waiver option that allows more flexibility to purchase needed support services, therapies, equipment or supplies.
- The top five priorities families indicated they would like to pursue with available funding included specialized therapies, specialized education, teaching materials, specialized childcare, and transportation services.
- Fifty-six percent of responses indicated a willingness to explore a flexible service option, even if the total annual funding offered for services is less than it would be for the traditional waiver program.

While the level of support decreased when the question referenced the concept of decreasing funding, I believe the number of families who indicated a willingness to consider less funding and more flexibility is remarkable. That question likely came across to many families that completed the survey as an introduction to yet another way to cut funding for programs. Despite that perception, well over half of the responses went out on a limb and agreed to consider the idea.

Although a support waiver would create an opportunity to save funding, that isn't a leading consideration for creating the waiver. The idea is simply to create an option for families to consider that provides a standardized annual allocation amount for them to work with. If the need for hourly support services in the home is not the highest priority, it may very well make more sense to opt for a standardized allocation that offers the flexibility to choose a variety of program options that may cost less than the annual program total offered through the traditional waiver program.

As indicated, the ability to choose the new support waiver would be one option for families. If a family is currently receiving services through the developmental disabilities waiver program and wishes to switch to the new program, that decision would be left up to the family. If a day comes when many families are offered funding for their children who are on the waiting list, a good number of them might opt for the support waiver as an alternative to our current waiver. An additional benefit of the support waiver might be the ability to stretch the dollars to a greater degree to assist more families. The allocation process simply spends the available dollars on service plans until no dollars remain, so more expensive service plans exhaust available dollars quicker. If some families select a service option that costs less than the current program, it stands to reason that the savings could be made available to the next individual waiting for services.

I hope that you will agree that the concept our committee has been working on for the past few years represents an idea with a great deal of potential. We have explored the feasibility of the program, solicited input from families of children with disabilities, and outlined service categories to meet the needs of as many of them as possible. At this point in the learning process most interested individuals ask what must yet be accomplished to make this service option a reality. The short answer is that most of the technical work remains to be done. Discussion needs to move forward with representatives of Medicaid, which would likely be followed by a significant allocation of the time of state staff members to turn our outline into a detailed Medicaid waiver application.

Because this is a time of reduced staffing in state departments without a correlating reduction in work to be done, finding time to move new programs like this forward becomes a real challenge. Our plan is to continue to make progress as time allows, with a strong hope of having a new program to offer to families and children by the beginning of fiscal 2013.

I would be happy to answer any questions you may have about this concept.

Sean has made tremendous progress over the past sixteen years. He can communicate and socialize with familiar individuals at school, home and at the YMCA. He struggles to communicate when he is in new situations and with new people. We have investigated many devices to help him communicate in the community. The most versatile and user friendly device we have found is the iPad. As a family with a young man in college and a soldier who has been out of the country 7 of the last 15 years, funds to purchase the iPad are not readily available. As the device is needed in the community, it is not something the school is responsible to provide. If we were able to utilize the waiver funds to meet Sean's needs in the community, it would help him with his struggle to communicate!

Imagine sitting in your living room when you smell smoke. You run to the kitchen to see a 17 year old standing three feet from the flames on the stove top. He just stands there and whispers 'fire'. Now imagine waking up at 5 a.m. to smell something burning. The smell leads you to the 17 year old's room. The iron is lying on the floor next to his favorite shirt and an iron shaped black mark on the floor. These are just two of the situations we faced this summer. Sean has no concept of danger. He was trying to be 'like everyone else'. He wanted to cook a pizza on the stove top. He wanted to iron his shirt. The carpet, shirt and potholders can be replaced. Add those cost on top of 'Sean proofing' yet again. With each new skill come unintended consequences. I cheer because he wanted to iron a shirt. I cry because I know my adult son still requires the house to be childproofed. Many of the items needed to keep Sean safe are costly. With a flexible waiver we would be able to find ways/things that would keep Sean safe and allow him to learn independent living skills. At this point we are forced to lock items away. We are not teaching him.

Something else that must be taken into consideration is the considerable amount of money necessary to meet Sean's medical and disability related needs. When we lived in Junction City, Sean spent a month in Children's Mercy for pancreatitis. He has had three surgeries for epilepsy in Omaha, Nebraska. We have had to repair numerous holes in the wall where he hit his head. We've replaced microwaves, DVD players, bathroom tile, beds, DVD and MP3 players… no matter how much you make, when you are raising a child with developmental disabilities you incur tremendous costs.

Our family is not alone! There are many Kansas families whose child/youth receive the DD waiver, yet the supports are limited or non-existent. "Tony's" family paid more than $100 a month for the parent participant fee. They were unable to find personal care attendants. Frustrated by the lack of services and the cost, they elected to remove Tony from the waiver services. Tony will turn 18 in February. He is on the bottom of the waiting list, will graduate and move to the adult world with no services. There are many other Tonys going without services.

I have the privilege of working for Families Together, Inc. Families Together is the Parent Training and Information Center serving Kansas families which include a child/youth who has a disability. Over the past ten years, I have brain stormed ways to find PCAs with numerous parents and case managers. I have also helped families to search for funding for assistive technology devices, accessible clothing items, items to help ensure their child's safety at home, etc. ... With a more flexible waiver, many of these needs could be addressed and would not require additional funding. On behalf of Sean and all of the parents I've helped, I hope that you will respond to the need for more flexibility in our waiver system.

Thank you for your time and for believing in ALL Kansas Kids.

Leia Holley
824 S 135th
Bonner Springs, KS
(913) 422-1260

22-2

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Thank you for your time and for believing in ALL Kansas Kids.

Leia Holley
824 S 135th
Bonner Springs, KS
(913) 422-1260

22-2

Looking For Adventure?

Want To Have Some REAL Fun?

Looking for fun and adventure while
"working" for a cool guy! ME: Sean!
Qualifications: Must like to have fun, be patient,
be creative, like to go new places and meet new people?
Hours: Evenings (after school) and some weekends

Manager's (Mom) note:

Sean is an amazing 12-year-old. He is looking for a buddy, someone who will basically be a big brother/sister.

He loves swimming, eating pizza, playing on the computer, going to new places and to school and watching Wheel of Fortune. Sean has overcome many challenges and found some great people who help him learn. He loves to be with people. What makes Sean unique is he has a form of autism.

Sean has always been a part of his community and school. He needs a new friend to take him places and do the things he likes to do.

If you are up for the challenge and a truly life changing/enriching experience give me a call. Sean will show you the world from a new perspective!

(20-30 hours per week at $8/hour plus some perks.)
(913) 422-1260 Home (after 3 p.m.) and
Work (913) 287-1970.
Leia Holley, Sean's mom,

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MAKE A

Difference

TESTIMONY BEFORE THE JOINT COMMITTEE ON CHILDREN'S ISSUES

December 8, 2010

Madam Chair 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 the staff of the Interagency Coordinating Council for Early Childhood Developmental Services. We are an advisory group based in state and federal law. Our area of emphasis is young children (aged birth through five years) with or at risk of developmental delay/disability.

Today, I would like to address the Infant-Toddler Services Program, also known as Part C of IDEA or *tiny-k*. The 37 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 multi-disciplinary team that determines which child is eligible, what services and interventions are needed, where these interventions will be provided, and by whom they will be provided.

There are no waiting lists with this program. Federal law requires that every eligible child aged birth to three years be identified. Once a child is identified, the law requires that all those supports and services deemed necessary by the child's team then be provided

We wish to note that the Governor made a cut to the *tiny-k* program, a part of the KDHE budget in November of 2009. The impact of this cut was absorbed entirely at the state agency level, limiting the negative effect on direct services to the children and families. The *tiny-k* system has historically been and continues to be under funded. One of the beautiful features of this system is its diverse and varied funding pattern. The down side to this diversity is in tough economic times, we suffer funding cuts from multiple sources. In addition to the Governor's November cut to Part C, recent reductions in special education, Medicaid, and Community Developmental Disabilities Organization (CDDO) funding have adversely impacted the tiny-k program and the services they provide. All of these reductions, in addition to negatively impacting services, also potentially put at risk the federal grant funds received by Kansas for Part C services.

Our local service programs continually need to pursue various funding sources to provide these vital early intervention services. 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. More importantly, we risk losing local networks and providers because they can simply no longer continue to subsidize 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 later in life. Data indicates that one in four children served by *tiny-k* needs no further special education services at

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age three years. 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.

We clearly understand that the state faces a budget crisis of historic proportions. Policy-makers are facing difficult choices at every turn. IF Kansas is to continue being eligible for the federal Part C grant, federal law requires us to "*maintain our efforts*" and to not use federal funds to supplant state resources. We want to make sure that Kansas is eligible for any future federal Part C grants, in order to continue this highly valued and vital service to vulnerable young Kansans and their families.

The Council has similar concerns about the state's support of special education, maintenance of effort, and the possible impact upon services for children aged 3-5 years of age.

Thank you again, for your past support of this critically important program.

I would be happy to stand for questions.

21. Northwest KS Educational Service Center
703 West Second Street
Oakley KS 67748
'hy Kersenbrock-Ostmeyer
ail:kko@nkesc.org
5) 672-3125 x111 Fax:(785) 672-3175
www.nkesc.org
Area Served: Cheyenne, Decatur, Graham, Gove, Logan, Rawlins, Sheridan, Sherman, Thomas, Trego, Wallace, 1/4 of Lane

22. Osage County ICC Infant-Toddler Services
1318 N. Topeka Avenue
Lyndon KS 66451
Ruth Jones E-mail: rjones@three-lakes.org
(785) 828-3113 Fax: (785) 828-3671
Area Served: Osage, west-half of Franklin

23.Ottawa-Wellsville Infant-Toddler Program
416 S Main Street
Ottawa KS 66067
Sarah Walters E-mail: sarah.walters@greenbush.org
(785) 242-0910 Fax: (785) 229-8119
www.greenbush.org About us/special education/tiny k
Area Served: Part of Franklin (boundaries of USD289 and USD290)

24. Parents and Children Together, Inc.
PO Box 573 (150 Plaza Drive)
Liberal KS 67905-0573
Jan Nondorf E-mail: pact@swko.net
(620) 624-2222 Fax: (620) 624-3181
Area Served: Seward

25. Pottawatomie/Wabaunsee Infant-Toddler
Special Services Cooperative, USD #320
510 E Hwy 24
Wamego KS 66547
Anna Nippert E-mail: nipperta@usd320.com
(785)456-7366 Fax: (785) 456-6292
www.usd320.com/programs/specialed/infant_toddler.aspx
Area Served: Part of Pottawatomie and part of Wabaunsee (USD 320, 321, 323, 329, 330)

26. Prairie Band Potawatomi Nation
15380 K Road
Mayetta KS 66509
Melinda Feldkamp
E-mail: FeldKamp_Melinda@pbpnation.org
(785) 966-2707 Fax: (785) 966-2514
Area Served: Prairie Band Potawatomi Reservation

27. REACH *tiny-k* Infant Toddler Services
800 Main Place, Suite 304
Winfield KS 67156
Nancy Juhlin E-mail:nancy.juhlin@greenbush.org
(620) 229-8304 Fax: (620) 221-4452
www.greenbush.org
Area Served: Cowley

28. Reno County Infant Toddler Network
303 East Bigger
Hutchinson KS 67501
KaAnn Graham E-mail: grahamka@usd308.com
(620) 615-5850 Fax: (620) 615-5871
Area Served: Six Reno Co School Districts

29. Infant Toddler Services Network of Riley County
PO Box 471 (2600 Kimball Avenue)
Manhattan KS 66505
Lona Foust E-mail: lonaf@manhattan.k12.ks.us
(785) 776-6363 Fax: (785) 776-6363
www.infant-toddler.org
Area Served: Riley, excluding the military base; USD383 & 384 area in Pottawatomie Co.

30. Russell Child Development Center
Children & Families Network
714 Ballinger
Garden City KS 67846
Jill Reagle E-mail: jreagle@rcdc4kids.org
(620) 275-0291 Fax: (620) 275-0364
www.rcdc4kids.org
Area Served: Finney, Grant, Greeley, Hamilton, Haskell, Kearny, Lane, Morton, Scott, Stanton, Stevens, Wichita

31. Salina Regional Health Center
Infant-Child Development
501 S Santa Fe Suite 210
Salina KS 67401
Joyce Trower E-mail: joycetr@srhc.com
(785) 452-6050 Fax: (785) 452-6056
www.srhc.com/Services/rehab/icd.html
Area Served: Ellsworth, Ottawa, Saline

32. Sedgwick County Early Childhood Coordinating Council
Rainbows United, Inc.
2258 N. Lakeway Circle
Wichita KS 67205
Lee "Paco" Price E-mail: lprice@rui.org
(316) 945-7117 Fax: (316) 945-7447
www.RainbowsUnited.org
Area Served: Sedgwick

33. Shawnee County Infant-Toddler Services
TARC
2701 SW Randolph Ave
Topeka KS 66611
Kathy Johnson E-mail: kjohnson@tarcinc.org
(785) 232-0597 or (785) 633-7645
Referrals: (785) 233-7374
Fax: (785) 232-2097
Area Served: Shawnee

34. Southeast KS Birth to Three Program
SEKESC
2601 Gabriel
Parsons KS 67357
Nancy Juhlin E-mail: nancy.juhlin@greenbush.org
800-362-0390x1765 (cell) or 620-724-3541
Fax: (620) 221-4452
www.greenbush.org About us/special education/tiny k
Area Served: Allen, Bourbon, Chautauqua, Cherokee, Crawford, Elk, Labette, Montgomery, Neosho, Wilson, and Woodson

35. Sumner County ICC
Futures Unlimited, Inc.
2410 North A
Wellington KS 67152
Ginny Butts E-mail:ginnyb@futures-unlimited.org
(620) 326-8906 x224 or 888-326-8906
Fax: (620) 326-7796
www.futures-unlimited.org.
Area Served: Sumner

36. Sunflower Early Education Center
1312 Patton Road
Great Bend KS 67530
Cathy Estes E-mail: cestes@sunflowerdiv.com
(620) 792-4087 or (800) 692-4087
Fax: (620) 792-4685
www.sunflowerdiv.com/EarlyEducation.htm
Area Served: Barton, Pawnee, Rice, Rush, Stafford

37. Wyandotte County Infant-Toddler Services
4911 State Ave
Kansas City KS 66102
Scott Kedrowski E-mail: skedrowski@wcits.org
(913) 287-8851 x147 Fax: (913) 287-5431
www.childrenstlc.org/WyCoITS.html
Area Served: Wyandotte

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KANSAS INFANT-TODDLER SERVICES
KANSAS DEPT HEALTH & ENVIRONMENT
1000 SW JACKSON SUITE 220
TOPEKA, KS 66612-1274 (785) 296-6135
(800) 332-6262 FAX: (785) 296-8626
www.ksits.org
09/2010

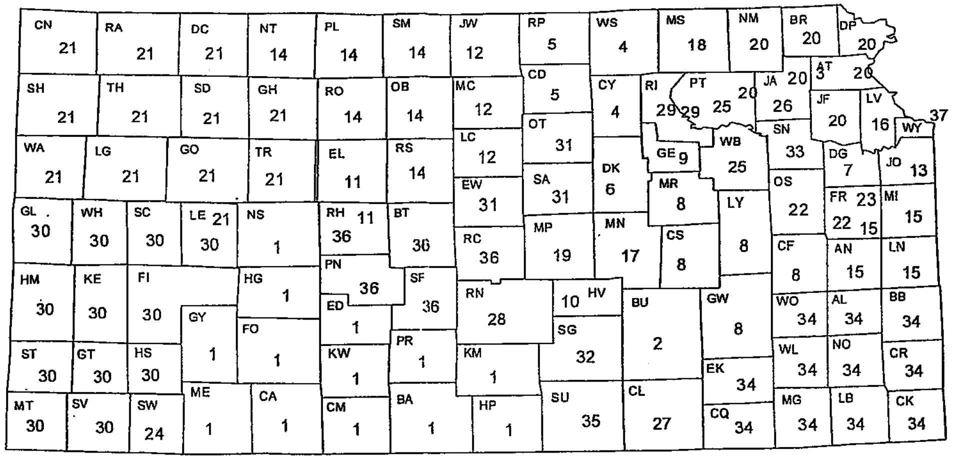
23-3

KANSAS INFANT-TODDLER SERVICES

Community Networks 2010-2011

tiny-k
Early Intervention Services

Kansas Community Early Intervention Networks - SFY2011
KDHE Infant-Toddler Services, 785-296-6135



1. **Arrowhead West, Inc.**
401 Edgemore
Dodge City KS 67801
Erica DeAnda-Soltero Email: erica@arrowheadwest.org
(620) 225-5177 Toll free: 1-888-500-1804
Fax: (620) 227-2072 www.arrowheadwest.org
Area Served: Barber, Clark, Comanche, Edwards, Ford, Gray, Harper, Hodgeman, Kingman, Kiowa, Meade, Ness and Pratt

2. **Butler County Infant Toddler Services**
- Bright Beginnings
409 N Main Street
El Dorado KS 67042-2039
Susan Harsh Email: sharsh@rui.org
(316) 320-1342 or (800) 650-9260 Fax: (316) 320-1216
www.RainbowsUnited.org
Area Served: Butler

3. **Atchison City Infant Toddler Program**
-Early Childhood Committee of Dream Team
Atchison Hospital Association
Rehabilitation Services
800 Raven Hill Road
Atchison KS 66002
Joyce Allen Email: jallen@atchhosp.org
(913) 360-5550 Fax: (913) 674-2015
http://atchisoncountydreamteam.org/default.aspx
Area Served: City of Atchison

4. **Clay-Washington Infant Toddler**
PO Box 219 (412 Park Street)
Greenleaf KS 66943
Sally Henry E-mail: ehenry@bluevalley.net
(785) 747-7903 Fax: (785) 747-2606
Area Served: Clay and Washington

5. **Cloud-Republic Infant-Toddler Services**
1502 Lincoln St
Concordia KS 66901
Nancy Jefferson E-mail: nancyj@occk.com
(785) 243-1977 FAX: (785) 243-4524
www.occk.com
Area Served: Cloud and Republic

6. **Infant Toddler Services, Dickinson County**
300 N Cedar Ste. 221
Abilene, KS 67410
Jean Gobber E-mail: jgobber@occk.com
(785) 263-2208 FAX: (785) 263-3795
www.occk.com
Area Served: Dickinson

7. **tiny-k Early Intervention (Douglas County)**
2619 W 6th Street Ste B
Lawrence KS 66049
Dena Bracciano E-mail:tinykdena@sunflower.com
(785) 843-3059 Fax: (785) 843-3562
www.douglascountytinyk.org
Area Served: Douglas

8. **Flint Hills tiny-k Services**
1700 W. 7th Ave
Emporia KS 66801
Judy Stanley E-mail: jstanley@usd253.org
(620) 341-2260 Fax: (620) 341-2233
Area Served: Chase, Coffey, Lyon, Morris, Greenwood; USD417 in Wabaunsee Co

9. **Geary County Infant-Toddler Services**
USD #475, Geary County Schools
123 N. Eisenhower
Junction City KS 66441
Stacey Mayberry
E-mail:staceymayberry@usd475.org
(785) 717-4130 Fax: (785) 717-4217
Area Served: Geary and USD 475 including Fort Riley

10. **Harvey County Infant Toddler Program**
Cooper Early Education Center
816 Oak
Newton KS 67114
Mary Beasley E-mail: mbeasley@newton.k12.ks.us
(316) 284-6510 Fax: (316) 284-6513
www.newton.k12.ks.us/sch/eecc/index.html
Area Served: Harvey

11. **Hays Interagency Coordinating Council**
Hays Area Children's Center, Inc.
94 Lewis Drive
Hays KS 67601
Doug Greer E-mail: doug@hacc.info
(785) 625-3257 Fax: (785) 625-8557
www.hacc.info
Area Served: Ellis, Rush

12. **Jewell/Lincoln/Mitchell Counties ICC**
PO Box 583 (1720B N. Hersey)
Beloit KS 67420
Jill Klos E-mail: jklos@usd273.org
(785) 738-3055 Fax: (785) 738-2945
Area Served: Jewell, Lincoln, and Mitchell

13. **Johnson County Infant-Toddler Services**
6400 Glenwood Ste 205
Overland Park KS 66202
Amy Owens E-mail: amy.owens@itsjc.org
(913) 432-2900 Fax: (913) 432-2901
www.itsjc.org
Area Served: Johnson

14. **Kid-Link/DSNWK**
509 Main
Stockton, KS 67669
Laura Kolb E-mail: laura_kolb@notes1.dsnwk.org
(785) 425-6766 Fax: (785) 425-6052
www.dsnwk.org/KidLink.html
Area Served: Norton, Osborne, Phillips, Rooks, Russell, Smith

15. **Lakemary Center Infant Toddler Services**
501 S Hospital Dr. Suite 400
Paola KS 66071
Liz Stone E-mail: lstone@lakemaryctr.org
(913) 294-4343 Fax: (913) 294-4485
www.lakemaryctr.org
Area Served: Anderson, Linn, Miami, Franklin C
Central Heights School District

16. **Leavenworth County Infant-Toddler Services**
1276 Eisenhower Road.
Leavenworth, KS 66048
Danielle Nichols E-mail: dnichols@lvits.org
(913) 250-1111 Fax: (913) 250-1115
Area Served: Leavenworth

17. **Marion County Early Intervention Services**
1500 E Lawrence
Marion KS 66861
Debbi Darrow E-mail: ddarrow@mcsec.org
(620) 382-2858 Fax: (620) 382-2063
Toll free: (877) 878-4519 x111
http://mcsec.org/ech.htm
Area Served: Marion

18. **Marshall County Infant-Toddler Services**
1017 Broadway Suite 8
Marysville KS 66508
Mary Caffrey/Michelle Luppen
(785) 562-5502 Fax: (785) 629-6388
E-mail: mcits1@yahoo.com
Area Served: Marshall

19. **MCKIDS (McPherson County, KS, Infant Development Services)**
1106 Hospital Drive
McPherson KS 67460
Nancy Kessinger
E-mail:nkessinger@mcphersoncountyks.us
(620) 241-9595 Fax: (620) 241-1760
http://www.mcphersoncountyks.us/
Area Served: McPherson

20. **Northeast Kansas Infant Toddler Services**
Northeast KS Education Service Center
PO Box 320 (601 Woodson)
Lecompton KS 66050
Rachel Raydo E-mail: rachelraydo@gmail.com
Kris Pedersen E-mail: kpedersen@ku.edu
(785) 887-6004 x 3 Fax: (785) 887-6096
Toll free: 866-987-6004
www.keystonelearning.org
Area Served: Atchison (except city of), Brown, Doniphan, Jackson, Jefferson, Nemaha, USD322 in Pottawatomie Co; USD 343 in Douglas Co

AREAS SERVED are counties
unless otherwise noted.

RAINBOWS

UNITED, INC.

bringing potential to life

December 8, 2010

TO: Joint Committee on Children's Issues

FR: Deb Voth, President, Rainbows United, Inc.

RE: *tiny-k* and Developmental Disabilities Services for Kansas Children

Good afternoon. I'm Deb Voth, President of Rainbows United in Wichita. It is a privilege to be here with you today on behalf of the over 3,400 children, birth through age 21 and their families who will be served through Rainbows United this year.

As we begin the legislative session this year, I acknowledge the difficult financial environment of our great State. I know you will face many challenging decisions and tense conversations, and I applaud your willingness to serve your fellow citizens. Thank you for lending your time and expertise to create an environment that fosters a future of prosperity for *all* Kansans.

Today, my comments relate to your fellow citizens who have *no* voice in this year's legislative process. These Kansans will not call your office, e-mail you their interests, contribute to any campaign, or cast a single vote. With such a large portion of the State's budget allocated for education and social services, I encourage you to carve out some special time during the session ahead to listen to families whose children are impacted by these vital programs. You will gain invaluable knowledge and a unique perspective when you hear first-hand the challenges faced daily by families raising a child with special needs. You will gain a new sensitivity regarding the extra time, increased financial strain and stress families face as they try to make the best decisions possible for their children. Helping families cope early on and learn to grow in understanding of their loved one and their needs, is a critical step in the success of the child's progress and overall growth.

Kansas' network of *tiny-k* providers – like Rainbows United – are the first link families encounter in their new role as parents of children with special needs. *Tiny-k* networks provide essential early intervention for children with special needs or with a disability ages birth to 3. Services like speech therapy, occupational therapy, physical therapy, hearing and vision service and much more are provided to all eligible children and their families at no cost, and most are delivered in the comfortable and convenient location of the family's home Rainbows United is fortunate to provide these services in both Sedgwick and Butler Counties. In Fiscal Year 2010 we served over 1,030 children birth to age three and our staff made an average of 1,360 visits each month through this program. As a *tiny-k* provider, we have struggled like other networks to maintain the requirements of the state and federal government when the funding has not kept pace with the need for services. Let me explain.

In Fiscal Year 2010, $2 million in Federal stimulus funds helped fill the gap for Kansas *tiny-k* providers created by the State's reduction in Special Education Categorical Aid and allowed young children with special needs to continue receiving services. These funds run out in June 2011. Without restoring those dollars there is no more room in already meager operating budgets to deliver these critical and timely services to children and their families without your support for additional funding. Because of *tiny-k* providers' agreement with the State and Federal governments, we are required to serve all eligible children in need of these interventions, regardless of the dollars you and your colleagues allocate to the program.

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In most businesses, you can cut back on the number of products you manufacture when there is less money coming in. Under our *tiny-k* contract, we must continue to provide early intervention services to every child who qualifies regardless of a decrease in funding. And, we can have NO waiting lists for *tiny-k* services.

Unfortunately, I can speak firsthand about providing services to children without the sufficient funding. You may recall, last year Rainbows United found itself in a very vulnerable situation when it was discovered that our funding levels were misrepresented and we were providing services without the funding to support operations. Today, we KNOW our true revenues and costs, and our financials are accurate. But I am still concerned about the ongoing financial viability of the *tiny-k* program when networks are being asked to take on the financial risk of serving more children with less money, a risk most businesses would never assume.

At Rainbows, we have made extremely difficult decisions as part of our restructuring process. Some of our more high profile cost saving measures have included consolidated facilities, downsizing staff by 45 percent, and eliminating a majority of our services for typically-developing children. In addition, we are continually monitoring our operations to contain costs. Overall, we have cut our operating budget by 40 percent! We have not given raises for two years and just this week I told staff we are cutting benefits and increasing the employee's share of higher health insurance premiums.

You will recall from Doug Bowman's comments that in order to receive Federal funds designated for *tiny-k* or Part C – the Federal name - that Kansas must demonstrate maintenance of effort. We risk this in Kansas. We all know that when funding gets as tight as it is, accountability of funds increases.

You have also heard from the caring and committed professionals who represent our State's developmental disabilities industry. Please be reminded the Medicaid waiver for developmental disabilities in Kansas does not provide funding for supports for anyone under the age of 5. Children are elgible for the developmental disability waiver at age 5, but the waiting list is over 4,000 individuals. Currently, families wait over four years for funding to help them continue to care for their child in their home. In Sedgwick County, as reported in SRS's November report on DD services, the waiting list has 1069 individuals on it. Of these 464 are families with children who have disabilities. Families can struggle enough without the added burden of not being able to secure appropriate care for their child so they can work, go to school, take care of their other children, and try to maintain somewhat of a typical family life.

This last year, family support funding, which is the main funding source for items used for day-to-day living, was greatly reduced and funding for respite care was totally eliminated. Items like diapers for teenagers, formula for children, supplements that give additional nutrition are all essential to the health and well-being of children and their families. In Sedgwick County alone, the family support funding that was cut by the State dropped from funding 250 families to just 85 for 2010. Just think of that – a 66 percent cut in funding to families who were <u>at most</u> getting $2,500/year to help support their child in their home and the community.

In 1995, our State made a promise of appropriate community supports to families of children with disabilities by endorsing the philosophy that individuals are most successful in their home communities rather than institutions. Today, that promise is empty for many Kansas families who look to agencies that have the ability, expertise and desire, but no resources to help. But by working together, we CAN make appropriate, cost-effective, and dignified supports a priority for children with disabilities and their families right now. My colleagues and I look forward to working with you in the months to ahead to solve this seemingly insurmountable challenge. While many in our State – providers and families included – are driven by fear, it is my desire that together we can all be driven instead by hope. Hope that our promise to children and families will not be forgotten, but embraced. Thank you.

Our daughter Colbie Clair Robinson was born at 28 weeks and weighed 2lbs 14oz, and was 14 1/2 inches long. Luckily she was only on a ventilator for a day. Her second sonogram at 20 days showed a PVL brain bleed, the result of being extremely premature and anemic. We spent six weeks in the hospital before we were able to bring her home after making her goal of weighing five pounds. My wife and I were extremely nervous about this situation after watching teams of skilled physicians and nurses observe Colbie twenty-four hours a day. What were WE supposed to do if something happened to her! We felt so unprepared for what was happening.

After being at home with Colbie for three months alone, Rainbows United had set up appointments in our home to grace her with services like Physical Therapy, Occupational Therapy, Speech Therapy, Social Workers, and Nutritionists. Strangers to us at the time, they were given the task of helping Colbie develop as a normal little girl. Rainbows United was extremely beneficial to my family by informing and educating us as to the care of Colbie, as well as showing us resources in the community that would enhance her growth.

With her third birthday coming up in February, we are very happy to say that Colbie has definitely shown progress in all of her faculties. Although Colbie can only say a few words and is to receive her wheelchair in the next week, she continues to learn and work hard for the Rainbows Team. She enjoys playing barbies with her sister, shopping with her mother and having her daddy give her rides on my back.

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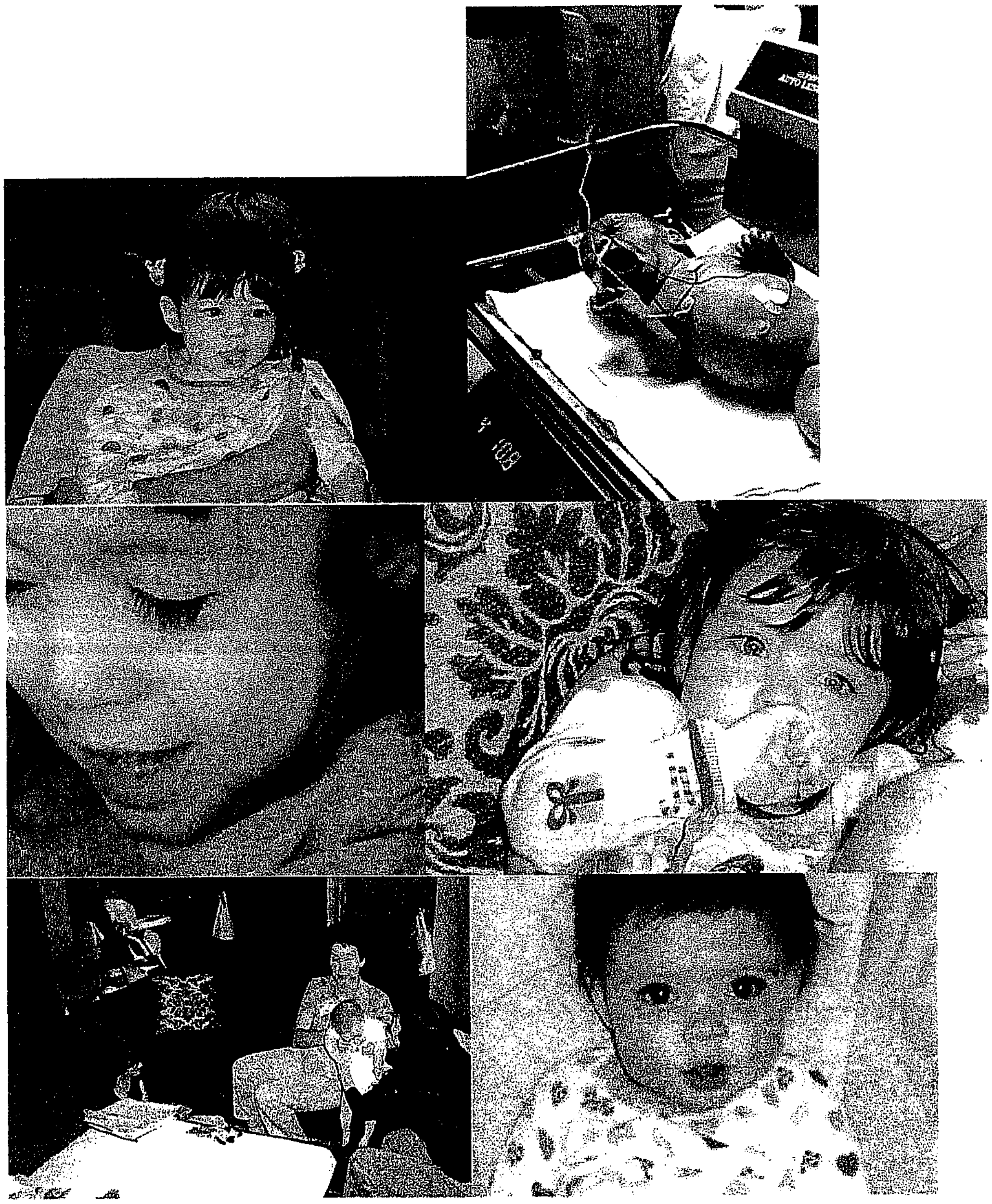
We no longer see the Rainbows team as strangers, but as people who love and care for our daughter. They have been with us through the rough times of having a handicapped daughter and always have the patience to support my family. I have to say thanks to Ellen, Sarah, Jana, Melissa, Dawna and the entire Rainbows United staff. We will have to say goodbye to them in February but I can only hope that they continue the tradition of caring for children like my daughter Colbie.



25-2

KANSAS LEGISLATIVE RESEARCH DEPARTMENT

68-West–Statehouse, 300 SW 10th Ave.
Topeka, Kansas 66612-1504
(785) 296-3181 ◆ FAX (785) 296-3824

kslegres@klrd.ks.gov http://www.kslegislature.org/klrd

November 2, 2010

To: Legislative Budget Committee and Governor Mark Parkinson

From: Kansas Legislative Research Department and Kansas Division of the Budget

Re: Human Services Consensus Caseload Estimates for FY 2011 and FY 2012

The Division of the Budget, Department of Social and Rehabilitation Services, Kansas Health Policy Authority, Department on Aging, Juvenile Justice Authority, and the Legislative Research Department, met on October 28, 2010, to revise the estimates on human services caseload expenditures for FY 2011 and to make initial estimates for FY 2012. The caseload estimates include expenditures for Nursing Facilities, Regular Medical Assistance, Temporary Assistance to Families, General Assistance, the Reintegration/Foster Care Contracts, psychiatric residential treatment facilities, and out of home placements. A chart summarizing the estimates for FY 2011 and FY 2012 is included at the end of this memorandum. The estimate for FY 2011 is increased by $49.3 million from the State General Fund and $98.0 million from all funding sources. The new estimate for FY 2012 then increases by $248.8 million from the State General Fund, and $78.7 million from all funding sources. **The combined increase for FY 2011 and FY 2012 is an all funds increase of $176.7 million and a State General Fund increase of $298.1 million.**

The estimates include Medical Assistance expenditures by both the Kansas Health Policy Authority (KHPA) and the Department of Social and Rehabilitation Services (SRS). Most health care services for persons who qualify for Medicaid, MediKan, and other state health insurance programs were transferred to the KHPA on July 1, 2006, as directed in 2005 Senate Bill 272. Certain mental health services, addiction treatment services, and services for persons with disabilities that are a part of the Regular Medical Assistance Program remain in the budget of SRS.

FY 2011

For FY 2011, the estimate is an all funds increase of $98.0 million and a State General Fund increase of $49.3 million as compared to the budget approved by the 2010 Legislature. The amount approved for Medicaid programs by the 2010 Legislature assumed the full extension of the American Recovery and Reinvestment Act (ARRA) for all of FY 2011. The original Act authorized enhanced federal match until December 2010. The actual extension passed by Congress reduces the across-the-board federal match increase from 6.2 percentage points under the original act to 3.2 percentage points from January 1, 2011-March 31, 2011 and 1.2 percentage points from April 1, 2011-June 30, 2011. The portion of the State General Fund increase in FY 2011 totaling $43.0 million, is attributable to the lower than originally anticipated funding from the American Recovery and Reinvestment Act (ARRA) funding. The decrease in anticipated federal match rate also impacts Medicaid programs not included in the caseload process. The total amount of reduced federal funds due to the reduced ARRA funding totals $53.9 million.

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The remaining State General Fund increase totaling $6.3 million is attributable to caseload growth above the approved amount for FY 2011. The all funds increase is due largely to increased estimates for Mental Health expenditures, regular medical expenditures and nursing facilities expenditures, partially offset by a decrease in out of home placements and Psychiatric Residential Treatment Facilities. The SRS Mental Health increase of $13.4 million in all funds and $5.8 million State General Fund increase in FY 2011 reflects an increase in beneficiaries and an increase in the payment rates for both the Prepaid Ambulatory Health Plan (PAHP) and the Psychiatric Residential Treatment Facilities. Expenditures for the regular medical program have increased by $8.4 million from all funding sources, including $30.5 million from the State General Fund. Estimates of Nursing Facilities expenditures increased by $72.0 million, including $10.1 million from the State General Fund, attributable to increased estimated cost per person and the addition of $64.1 million from all funding sources to account for funds generated by the nursing facility provider assessment.

FY 2012

The FY 2012 initial estimate is $2.4 billion, including $1.0 billion from the State General Fund. The estimate is an all funds increase of $78.7 million and a State General Fund increase of $248.8 million as compared to the revised FY 2011 estimate. The portion of expenditures anticipated to be funded by the federal government for the Medicaid program have decreased due to the end of the American Recovery and Reinvestment Act (ARRA) funding at the end of June 2011. The increased amount of State General Fund required for matching in FY 2012 for caseload expenditures is estimated to be $175.6 million. The total amount of funding needed to replace federal funds for caseload and non-caseload programs as a result of the elimination of ARRA enhanced Medicaid funding totals $216.0 million in FY 2012. The base Medicaid matching rate for federal contribution, excluding ARRA funding, was reduced by 1.6 percent between FY 2011 and FY 2012. The estimated impact of this reduction in FY 2012 is $35.3 million for caseload expenditures. The impact of the base federal match rate on non-caseload items is estimated to be increased State General Fund expenditures of $9.1 million in FY 2012. The remaining increases reflect caseload growth, for both increased individuals and cost increases, totaling $94.9 million from all funding sources and $37.9 million from the State General Fund in FY 2012.

Regular Medical expenses for KHPA were increased by $168.3 million from the State General Fund and $65.4 million from all funds due to estimated increases in caseloads and higher per person expenditures. This estimate includes a decrease in fee fund expenditures for the state match and a corresponding increase of State General Fund expenditures attributable to decreased fee fund revenue projections for the Kansas Health Policy Authority for FY 2012. The fee fund revenue projection does include an assumption of continued revenue from the health care cost containment contract in FY 2012 at a lower amount than FY 2011.

Nursing Facility expenditures were decreased by $7.8 million all funds, but increased by $43.0 million from the State General Fund, due to increased cost per person, partially offset by a decreased estimate for the second year of the provider assessment expenditures. Caseloads for Temporary Assistance for Families have increased by $3.0 million, from all funding sources, due to increased estimates regarding the numbers of persons accessing services. The SRS Mental Health increase of $9.7 million in all funds and the $28.0 million State General Fund increase in FY 2012 generally is tied to estimated increases in beneficiaries and cost per person for the Prepaid Ambulatory Health Plan (PAHP). In addition, the estimate for the foster care contract is estimated to increase by $5.5 million from all funding sources, due to an estimated increase in the number of children receiving services and an increased cost per child.

Human Services
November 2, 2010
Consensus Caseloads Estimates

Program		FY 2011 Approved	November Revised FY 2011	Difference from Approved	November Estimate FY 2012	Diff. From FY 2011 Estimate
Nursing Facilities	SGF	$ 112,857,112	$ 123,000,000	$ 10,142,888	$ 166,000,000	$ 43,000,000
	AF	373,700,000	445,706,642	72,006,642	437,900,247	(7,806,395)
Targeted Case Management (Aging)	SGF	$ 1,532,869	$ 1,634,935	$ 102,066	$ 2,200,000	$ 565,065
	AF	5,092,093	5,072,712	(19,381)	5,169,173	96,461
Psychiatric Residential Treatment Facilities (PRTFs) (JJA)	SGF	$ 2,439,439	$ 2,151,953	$ (287,486)	$ 2,979,200	$ 827,247
	AF	7,816,022	6,676,862	(1,139,160)	7,000,000	323,138
Out of Home Placements (JJA)	SGF	$ 20,892,477	$ 17,843,651	$ (3,048,826)	$ 19,000,000	$ 1,156,349
	AF	23,718,873	21,622,100	(2,096,773)	22,000,000	377,900
Nursing Facilities for Mental Health (NFMH)	SGF	$ 14,000,000	$ 14,000,000	$ 0	$ 14,500,000	$ 500,000
	AF	16,258,274	18,562,101	2,303,827	18,742,269	180,168
Temporary Assistance for Families	SGF	$ 29,821,028	$ 29,821,028	$ 0	$ 29,821,028	$ 0
	AF	54,039,150	54,500,000	460,850	57,500,000	3,000,000
General Assistance	SGF	$ 3,024,000	$ 3,024,000	$ 0	$ 3,200,000	$ 176,000
	AF	3,024,000	3,024,000	0	3,200,000	176,000
Reintegration/ Foster Care	SGF	$ 86,586,575	$ 91,000,000	$ 4,413,425	$ 91,000,000	$ 0
	AF	136,165,704	139,000,000	2,834,296	144,450,000	5,450,000
Regular Medical (KHPA)	SGF	$ 351,204,882	$ 381,731,500	$ 30,526,618	$ 550,000,000	$ 168,268,500
	AF	1,336,228,635	1,344,600,000	8,371,365	1,410,000,000	65,400,000
Mental Health (SRS)	SGF	$ 74,181,170	$ 80,000,000	$ 5,818,830	$ 108,000,000	$ 28,000,000
	AF	241,920,135	255,300,000	13,379,865	265,000,000	9,700,000
Community Supports and Services (SRS)	SGF	$ 9,955,014	$ 10,979,652	$ 1,024,638	$ 14,600,000	$ 3,620,348
	AF	32,837,496	34,066,560	1,229,064	34,304,511	237,951
AAPS/PIHP* (SRS)	SGF	$ 5,729,724	$ 6,300,000	$ 570,276	$ 9,000,000	$ 2,700,000
	AF	18,900,000	19,547,006	647,006	21,146,617	1,599,611
TOTAL	**SGF**	**$ 712,224,290**	**$ 761,486,719**	**$ 49,262,429**	**$ 1,010,300,228**	**$ 248,813,509**
	AF	**2,249,700,382**	**2,347,677,983**	**97,977,601**	**2,426,412,817**	**78,734,834**

SGF – State General Fund
AF – All Funds
* Addiction and Prevention Services (AAPS)/Prepaid Inpatient Health Plan (PIHP)