

Approved 3-16-87
Date sh

MINUTES OF THE HOUSE COMMITTEE ON PUBLIC HEALTH AND WELFARE

The meeting was called to order by Vice-Chairman, Frank Buehler at
Chairperson

1:30 a.m./p.m. on March 4, 1987 in room 423-S of the Capitol.

All members were present except:

Chairman Littlejohn, Representative O'Neal, both excused.

Committee staff present:

Emalene Correll, Research
Bill Wolff, Research
Norman Furse, Revisor
Sue Hill, Committee Secretary

Conferees appearing before the committee:

Representative Nancy Brown
Robin Wells, Board of Directors/Support Services for Citizens with Autism, Inc.
Margene Dipaling, Ks. Planning Council on Developmental Disabilities
Kathleen Heiling, parent of a four year old son disabled by autism.
Ester Rhoades, parent of an autistic child.
Jeanette Springer, KANSAC Information and Referral
Donna Mouton, Ks. State Society for children/adults with Autism
Harold A. Kane, parent of an autistic child.
Sue Steele, Support Services for Citizens with Autism, Inc.
Representative Kathleen Sebelius
Gloria Olson, parent of autistic child
Ann Marshall-Levine, Ks. Neurological Institute(representing SRS)
Representative Gary Blumenthal
Representative Dorothy Flottman
John Kelly, Ks. Planning Council on Developmental Disabilities Services
Ken Schafermeyer, Kansas Pharmacists Association
Tom Hitchcock, Ks. Board of Pharmacy
Jerry Slaughter, Kansas Medical Society

Vice-Chairman called meeting to order when quorum was present, calling attention to HB 2413.

Rep. Flottman stated it had been suggested there were some technical points that need a second look, she moved that HB 2413 be reconsidered this date, seconded by Rep. Amos. motion carried.

Discussion ensued, i.e., Mr. Furse stated there are technical changes necessary. Line 32 on page one, and line 66, page 2 need the same terminology, "\$100 fee fixed by Secretary by Rules and Regulations". Rep. Amos moved to amend HB 2413 according to technical changes suggested by Mr. Furse, seconded by Rep. Harder, motion carried.

Rep. Weimer moved to pass HB 2413 favorably out of committee as amended, seconded by Rep. Green, motion carried.

Vice-Chairman called attention to HCR 5017, and began hearings.

Representative Brown gave hand-out, see (Attachment 1 and 1-A), for details. She stated she wished to have other conferees present make their statements since they were more qualified, and she would make a statement to summarize after they have concluded their comments.

Robin A. Wells stated she is a speech/language pathologist in Shawnee Mission Schools working with pre-school children with autism. Autism is a neurological dysfunction of the brain. It is the fourth most prevalent developmental disorder after mental retardation, epilepsy, and cerebral palsy, in that order. The disorder can be diagnosed by the time a child is 30 months of age, however unusual behaviors can be detected earlier. She explained different characteristics of autism. There are varying degrees of mental and communicative disabilities with autism. She explained symptoms, habits and mannerisms of the autistic. Each person needs an individual program developed for them specifically. (Attachment No. 2)

Unless specifically noted, the individual remarks recorded herein have not been transcribed verbatim. Individual remarks as reported herein have not been submitted to the individuals appearing before the committee for editing or corrections.

CONTINUATION SHEET

MINUTES OF THE HOUSE COMMITTEE ON PUBLIC HEALTH AND WELFARE

room 423-S, Statehouse, at 1:30 a/m./p.m. on March 4, 1987

Many have become highly educated, many are socially independent. There are 350,000 cases in the United States. Many are not unemployable. It is our problem to educate these people, and she urged for favorable passage of HCR 5017. She answered questions, i.e., yes, adequate trainers are more of a problem than diagnosing the autistic, though that too is still a problem in many areas. Yes, there are many new methods of treating and educating autistic individuals.

Kathleen Heling, gave (Attachment No.3), see for details. She detailed the long heart breaking efforts she and her husband experienced with their son Kevin. At the age of 6 months, he stopped developing mentally and they received no help from pediatrician. They began efforts to try to obtain a correct diagnosis and while going from facility to facility, and Dr. to Dr., their child was receiving no help at all. She began to research on her own, and feared Kevin was autistic. Only last Fall after hearing a physician well informed on autism speak, they then had Kevin re-evaluated and he is autistic. It is her hope that if HCR 5017 is passed it may help other parents from going through the trauma and frustration trying to get help and services for their son.

Ester Rhoades, an interested parent, stated Menninger Institute did a good diagnosis of recognizing that her son was autistic.

Margene Dipaling, gave hand-out of testimony, (see Attachment No.4), for details. She speaks in favor of HCR 5017 as a member of Ks. Planning Council on Developmental Disabilities, and for all parents in Kansas who have an autistic child whether these are children or adults, in regard to educational systems in Kansas. Many problems arise in the classroom because teachers are not trained to work with children who have autism. The teachers who are untrained look at the job of teaching the autistic as frustrating, physically wearing, and they soon become burned out. There is also stress on the families. Long term stress. Our current education system has trouble recognizing this as a serious problem. They give autism recognition only when problems involved get out of hand. She detailed the problems her son has had in school experiences. He has gone to many different schools, and has had over a long period of time only one teacher that has truly helped him. Now that teacher is no longer working with her son, he has regressed. Where is the training and support systems teachers need to help the autistic children/adults? This legislation is desperately needed. She answered questions, i.e., no, there is no specific program in Kansas that effectively trains teachers to work with autistic children. There is one classroom in Wichita for children with autism, ages 5-18. The educational system will have to take the problem of autism seriously. (This was a very emotional testimony.)

Jeanette Springer, gave hand-out, (see Attachment NO.5), for details. She detailed events of her son being diagnosed as autistic. He is now an adult and service programs are difficult to come by. She told of many schools he was in and out of, teaching him at home, learning lab at Kansas Newman College, full time to part time work programs, hospitalization at times. He now does volunteer work putting data into a computer on newborns for the "Pierre Program". One of the most important projects at the Mental Health Association in Wichita. He and they are proud of this accomplishment. She told of many letters and phone calls she receives, and noted one that is shown as an attachment this date.

Donna Mouton, (Attachment No.6), written testimony only.

Mr. Harold A. Kane, gave hand-out, (see Attachment No.7), for details. In 1968 their family doctor referred them to contact Childrens Rehabilitation Unit, (CRU) at Ks. Univ Medical Center to search for help for their son who is autistic. Then CRU referred the child to Help Educate Emotionally Distrubed, (HEED), a private school started by concerned parents of children needing help and education. He detailed the miles they had to drive weekly to keep their son in the HEED program. Other schools, and facilities followed. They are pleased that their son now is involved in Social Skills Training Project at Parsons State Hospital. He stressed the pressing need for early identification of autism and more specific programs for these children so identified. There are many who have not been so identified, and he noted the importance of item #1 on lines 59-60 of HCR 5017. At present there are no programs for autistic individuals after they finish the special education classes. He complimented those who have authored HCR 5017, and he urged for favorable support.

CONTINUATION SHEET

MINUTES OF THE HOUSE COMMITTEE ON PUBLIC HEALTH AND WELFARE,
room 423-S, Statehouse, at 1:30 a.m./p.m. on March 4, 1987

Hearings continue on HCR 5017:-

Sue Steel, gave hand-out, (see Attachment No.8), for details. She spoke to problems that adults with autism have in this state. She referred to P.L. 94-142, (the education of all handicapped children Act) as a salvation to parents of children with autism. Her printed testimony details her son's education and often he was subjected to the wrong type of programs. Presently there are programs in Shawnee Mission School District, and a few in Kansas City, Kansas have several children in their programs dealing with autism. Sad concerns from parents come when their young adult must move far from home in private or state institutions because of lack of support systems when they reach the age of 21. Simply stated, parents have had to recognize and accept the fact that autism is a developmental disability, but it seems policy makers/service providers have not. We are all asking why? She expressed her gratitude to sponsors of HCR 5017, and asked for its favorable support.

Ann Marshall-Levine, speaking for Dr. Gerald Hannah, the Mental Health and Retardation Services supports HCR 5017.

Rep. Nancy Brown at this point answered questions, i.e., yes, we are doing a better job in regard to screening and identifying these specific problems, but not good enough. There is more information needed, and the task force could provide more solid data.

Rep. Kathleen Sebelius introduced a conferee, Gloria Olson, the parent of a child with autism. (see Attachment No.9), for details. Her son Eric has been involved in many educational programs and has gained many skills that have helped him function in his family and community. They are concerned that as he approaches the age of 21 that he will be without services and a facility close to home. Current problems at Winfield State Hospital are of grave concern to them, and they hope for better things for their son.

Rep. Gary Blumenthal spoke of his brother who is autistic. He concurs with remarks made this date by those who deal with problems of obtaining education/services for their children. In earlier years there was no mandate for education and his brother therefore unable to obtain education/services until the age of 10. After being involved in several programs he was terminated because local community programs did not meet the needs of an autistic individual. He now is a client that has be re-entered into a state institution. He applauds those who have worked hard to bring HCR 5017 to this committee and he asked members consider it favorably. Line 55 indicates the members of the Task Force will serve without compensation and he felt this important. He then proudly showed members a photo of his brother Stevie taken with Governor Hayden.

Rep. Dorothy Flottman spoke of a nephew and his wife residing in Wisconsin who are both teachers in a private school and teach autistic children. She has visited this school on several occasions and has learned there is a desperate need for more programs to help autistic individuals.

John Kelly, Kansas Planning Council was unable to speak in person, but provided written testimony, (see Attachment No.10), for details.

Hearings closed on HCR 5017.

Vice-Chairman called attention to HB 2505, and hearings began.

Ken Schafermeyer, Ks. Pharmacists Association gave hand-out, (see Attachment No. 11), for details. Attachment indicates an opinion from Attorney General Stephan's office. There are currently pharmacies that are licensed by the state that are not being inspected because of current law. It is a matter of public policy that a State Regulatory Board inspect those licensees, and that is what we are requesting in HB 2505. He answered questions, i.e., yes, other Boards may have reciprocal agreements with other states, and the inspections would/could be done through these agreements. Drugs sent via mail order would be a good example of those pharmacies we would like to see inspected, he stated. We are currently aware of several mail order pharmacies that would fit into this category. No, I know of no court cases currently that speak to an interstate commerce problem in relation to licensing/inspection; yes every other state does have a Board that regulates pharmacists/pharmacies; no, I do not know if some are inferior to others, however all

CONTINUATION SHEET

MINUTES OF THE HOUSE COMMITTEE ON PUBLIC HEALTH AND WELFARE,
room 423-S, Statehouse, at 1:30 a/m./p.m. on March 4, 1987

Hearings continue on HB 2505:-

regulations and statutes in others states are not uniform; yes, some drugs are cheaper, some are not.

Tom Hitchcock, Ks. Board of Pharmacy provided hand-out, (see Attachment No.12), for details. Their Board supports favorable passage of HB 2505. It is the intention of the Board not to have their inspectors travel to out-of-state pharmacies, but to reach a mutual agreement with Boards in other states to have their inspectors perform said inspections on behalf of the Kansas Board. Results could be reported to the Kansas Board and handled no differently than in-state pharmacies. This is a good bill and will be an asset to the Board as well as health, safety, and welfare of Kansans, he said. Questions answered, i.e., yes, the Joint Committee on Rules and Regs reviewed statutes, they decided this was not statutes they felt needed to be changed. He said this bill was not asked to be introduced by the Board of Pharmacy.

Vice-Chairman called attention to HB 2412.

Jerry Slaughter stated he has prepared possible amendments to HB 2412, (see Attachment No.13) for details. It is not their intention to restrict smoking in grocery stores that include pharmacies. We recommend that section 4 of HB 2412 be deleted. Discussion ensued. At this point Chair deferred further discussion and action on HB 2412 until a later date.

Rep. Amos moved to pass HCR 5017 favorably out of committee, seconded by Rep. Shallenburger, motion carried.

Meeting adjourned 3:10 p.m.



TOPEKA

HOUSE OF
REPRESENTATIVES

NANCY BROWN
REPRESENTATIVE, 27TH DISTRICT
15429 OVERBROOK LANE
STANLEY, KANSAS 66224-9744

COMMITTEE ASSIGNMENTS
MEMBER: GOVERNMENTAL ORGANIZATION
INSURANCE
TRANSPORTATION

Testimony on
HCR RESOLUTION 5017 - ESTABLISHING TASK FORCE ON AUTISM
March 3, 1987

Mr. Chairman and Members of Public Health and Welfare:

As one of the co-sponsors of HCR 5017, I want thank you for the opportunity to testify on the proposed establishment of a task force on autism.

After introducing the resolution, several House members ask me to define autism. While there are several individuals providing testimony today who are better able to tell you about autism, let me at least set the stage.

Autism is a severely incapacitating, lifelong developmental disability. This disability, which usually appears during the first thirty months of life, is a disability that severely impairs the way sensory input is assimilated, causing problems in communication, social behavior and irregularity in learning. Autism has been found throughout the world in families of all racial, ethnic and social backgrounds, and is four times more common in males than females.

No psychosocial factors cause autism, but research has indicated that a variety of disorders such as meningitis or encephalitis can be involved as predisposing influences. Most autistic children look quite normal and are assumed to be normal at birth, and it may be several years before parents realize that their child is disabled in some way.

Autism is not a new problem. In fact, it is probably as old as the human race. However it is a problem which most people, other than parents and professionals, have little familiarity. (Statistics have indicated that autism occurs in about five of every 10,000 children.)

After learning more about autism through my relationships with the parents and members of KANSAC (Kansas Society for Children and Adults with Autism), I have concluded that autism is one of the most distressing disabilities that can affect a child and family. I feel this way, not only because it is a lifelong neurological disability with no known cure or even effective medical treatment, but because of its complexity and diversity. While there may be no "typical" autistic child - they do not have distinguishing features or characteristics - there are some common symptoms which are included in one of the attachments. (Attached is additional information which may help to further your understanding of this disability which is unlike any other.)

What happens to the autistic child and the family? There is little support for the young parents who learn that their bright, beautiful child has a disability they have never known. Furthermore it is crushing to learn there is no cure or treatment for their child's unpredictable behavior. And there are few places for them to take their child for help since they do not fit the definition or criteria for many support programs. Autistic children need skilled teaching, adults need places to live and work, and both young and old continue to fall "through the cracks" of the system throughout their lives. They do not fit into the category of mentally retarded or mentally ill, as indicated in the second page of the handout (note yellow sections).

attm #1 PHow 3-4-87

HCR 5017 was introduced to bridge the gap in the cracks. Because it has been a misunderstood population, there has been insufficient information to determine how to aid this group with their special needs. HCR 5017 was introduced to aid the parents, professionals, agency personnel, and the like, to insure the delivery of mandated services and to aid in the necessary support systems for the autistic individual and their family.

What does HCR 5017 do? It establishes a task force to consist of not more than 11 members composed of experts in the field, physicians, education professionals, and other appropriate individuals. These members will not be compensated, nor paid expenses, so there is no fiscal note. There will be some staff time necessary from the Office of the Secretary of Social and Rehabilitation Services. I understand from my conversations with Dr. Harder that they are willing and able to provide this needed support.

The task force is charged with specific requests which include the following:

- 1) Determine incidence and degree of severity of autism in Kansas and the geographic location of autistic persons in Kansas;
- 2) Identify support services, programs and resources available to persons who are autistic and their families;
- 3) Review training programs for education professionals working with autism, the effectiveness of current methods of diagnosis of autism, early childhood intervention strategies after diagnosis and current placement of autistic persons in schools, institutions and training programs; and
- 4) Develop findings and recommendations with respect to the diagnosis, treatment and services available in this state to persons with autism, to services available for the families of such persons and to such other matters relating thereto as the task force deems appropriate.

I have learned a great deal about autism through my association with many of the parents and professionals who live and work with autistic children and adults. I have been impressed with their patience, diligence, understanding and willingness to work within the system. However, they have learned that they do not fit the system. The Legislature, with very little investment, can work toward including them with the support and services they need. While the investment may be small, it will be immeasurable to the people, their families, and those who care for them. Thank you.

Janey Brown



National Society for Children and Adults with Autism

AUTISM FACT SHEET

What is autism?

Autism is a severely incapacitating, lifelong developmental disability that usually appears during the first three years of life.

Autism can occur by itself or in association with other disorders that affect the function of the brain such as viral infections, metabolic disturbances, epilepsy, etc.

Nothing psychological has been shown to cause autism; it is not a mental illness. Although some headway in research has been made, the etiology of this brain disorder is not yet completely understood.

How frequent is the occurrence of autism?

Autism is not as rare as one might think. It is the fourth most prevalent developmental disability after mental retardation, epilepsy, and cerebral palsy, in that order.

There are at least 350,000 cases of autism in the U.S., two-thirds of whom are adults. The disorder is four times more common in males than females.

What are some of the symptoms of autism?

- Slow development or lack of physical, social, and learning skills.
- Immature rhythms of speech, limited understanding of ideas, and use of words without attaching the usual meanings to them.
- Abnormal responses to sensations. Sight, hearing, touch, pain, smell, taste, balance, the way a child holds his body -- any one or a combination of these responses may be affected.
- Abnormal ways of relating to people, objects, and events.

*PAW
3-4-87
Autism 1.-A*

What is being done to assist individuals with autism?

The presence of an autistic person in a family can be overwhelming. Strong family support services are desirable, and special education or training for the autistic child or adult is usually necessary.

Although a cure for autism has not been found, it is generally regarded as treatable. Various methods including special education, speech therapy, vocational habilitation, and behavioral training have been utilized in working with autistic persons.



No single treatment is effective in all cases. Research and education are the main tools, made even more effective with Congressional passage in 1975 of the "Education for All Handicapped Children Act" (Public Law 94-142). This law guaranteed the right of all handicapped children "to a free and appropriate public education," resulting in increased specialized schooling for children and adolescents.

Are there various ability levels with autism?

Individuals with autism show high and low abilities among and within the cognitive, motor, social, and communicative developmental pathways. Hence, even though some autistic people have distinct skills in music, art, mathematics, or in spatial concepts, they are still profoundly limited in other areas such as symbolic speech, interpersonal relations, and stereotypic behavior.

Extremely severe forms of autism (characterized by repetitive, self-injurious, aggressive, or other highly unusual behaviors) are present in only 2-3% of the autism population. This behavior may be difficult to change, posing a tremendous challenge to those who must manage, treat, and teach autistic people.

Is there a national voluntary agency for autism?

The National Society for Children and Adults with Autism (NSAC) is the only national agency dedicated exclusively to the education and welfare of people with autism.

Founded in 1965, NSAC has 200 chapters across the nation, the District of Columbia, and Puerto Rico. This network of local support groups for families is the lifeblood of the National Society.

NSAC provides legislative analyses and information and referral services to its constituency and the public. The Society operates the nation's most extensive clearinghouse for autism materials and information. It also coordinates and exchanges information with autism groups in many countries throughout the world.

NSAC is a private, nonprofit charitable organization with a 501(c)(3) tax-exempt status. NSAC participates in the Combined Federal Campaign, United Way, and Combined Health Appeal of America.

For further information, please contact: National Society for Children and Adults with Autism (NSAC), 1234 Massachusetts Avenue, N.W., Washington, D.C. 20005, (202) 783-0125.

Resolved:

That Legislators Hear From Us

State Legislatures across our country will be convening early in 1985. In most states, nowhere in their Mental Health/Mental Retardation Laws is autism mentioned, nor are services mandated for persons with autism and/or other developmental disabilities, with the exception of mental retardation.

Without a mandate from the state to serve persons with autism, usually autistic people "fall between the cracks" in nearly all the programs for handicapped citizens:

- Autistic, mentally retarded individuals are not usually accepted in programs for the mentally retarded because they are autistic - and have accompanying difficulties in understanding, communication, and/or behavior.
- Autistic, mentally retarded/behavior-disordered individuals are not eligible for the usual programs for behavior-disordered because they are mentally retarded.
- High functioning autistic individuals with normal I.Q.s are not usually able to be a part of programs for non-handicapped people because they have real deficits in social relatedness, and accompanying learning disabilities. They are not suitable for programs for behavior-disordered or they are perceptually handicapped and/or functionally retarded. At the same time, except for the top two percent, they cannot adequately and safely conduct their lives without guidance and supervision.

We can help legislators gain real perspective in understanding persons with autism, as we share with them facts such as these:

- Autism is one of the four major developmental disabilities, the other three being mental retardation, epilepsy, and cerebral palsy.
- Autism is a severe disorder of communication and behavior. It is a life-long disability, an organic disorder which affects the way the brain uses information. Persons with autism have extreme difficulty in learning language and social skills - and in relating to people.
- A minimum of one in every 1000 persons is autistic, or has autistic-like symptoms severe enough to prevent normal functioning.
- Eighty-five percent of people with autism are also mentally retarded; however, most of these, with extended training, can become good farm workers, competent employees of sheltered programs, or often even accomplished craftsmen.
- Of the upper 15%, only the top two

percent can eventually overcome the handicaps imposed by autism. The remaining 13% have normal I.Q.s and can often be trained to do highly skilled work in competitive employment; however, they need continuing help in self-care, language, self-direction, and independent living skills.

- Persons with autism and other developmental disabilities need life-long support services; but with no place in the service delivery system of the state to systematically serve them, they usually go unserved.

Several emphases are important as we approach legislators in 1985. It is important that we be specific about the following needs:

- 1) Statewide programs for the treatment of children and adults with autism and similar developmental disabilities, in which parents and professionals can work together to prepare persons with autism to live and work more effectively at home, at school, and in the community.
- 2) Statewide networks of public school classrooms to serve all ages and levels of persons with autism.
- 3) Statewide programs of Vocational Trainer/Worker Advocates experienced in working in the field of autism to work with Vocational Rehabilitation personnel and people with autism in job skill training, job placement, and on-the-job training.
- 4) State supported systems of creative residential placements for persons with autism, including:
 - Group homes
 - Supervised apartments
 - The possibility of farm communities, perhaps in conjunction with the state's University System, that will provide:
 - Vocational training to the wide spectrum of persons with autism, intensive social skills training, educational opportunities, and structured recreational/leisure-time experiences - as well as opportunities to move into community living and working situations
 - A research center for the better understanding of autism
 - A training center for professionals who plan to work in the field of autism or similar developmental disabilities, speech pathology, occupational therapy, recreation, social work, psychology, neurology, psychiatry, pediatrics, or other related

fields.

- 5) Case management personnel in Mental Health/Mental Retardation Centers within each state, trained in autism and other developmental disabilities, to identify and refer persons with autism or other developmental disabilities to experts in those fields - and to purchase services for them with state dollars.

In all our states, we have four main tasks:

- To serve as a support group for persons with autism and their families
- To heighten public awareness
- To serve as a source of information and referral
- And most of all, to broaden services for children and adults with autism

The group of autistic and developmentally disabled persons not being served is not large when compared to the mentally ill, mentally retarded, and alcohol/drug abusers now being served by our states. Nor are the dollars needed to serve them a large addition to the existing budgets of our states. But when each service, however small, has to be obtained through a Special Bill, often in the latter part of the Legislative Session, there often is not much money left; and what is obtained often appears much larger than it really is.

Legislators cannot help us unless they know our needs. However, many of them want nothing more than to serve the citizens of their state. They are ready to learn and willing to act if informed of the pressing needs of persons with autism. Let us resolve that they shall hear from us, in order that persons with autism may be better served.

Jo Anne Jeffries
Third V.P.; Chair
Government Affairs Committee



Diagnosing autism may be difficult because the condition is relatively rare and the clinical picture can vary so much from one child to another and from one time to another in the same child. Older children may have outgrown or overcome some of the characteristics while retaining others. It is important to get a good history when evaluating an older child. The information provided below may be useful to parents or professionals who need help in making a diagnosis. If you do not need it for yourself, pass it on to an agency or a professional who works with young children

AUTISM is a severely incapacitating lifelong developmental disability that typically appears during the first three years of life. It occurs in approximately *fifteen out of every 10,000 births* and is four times more common in boys than girls. It has been found throughout the world in families of all racial, ethnic and social backgrounds. No known factors in the psychological environment of a child have been shown to cause autism.

The symptoms are caused by physical disorders of the brain. They include:

- (1) Disturbances in the rate of appearance of physical, social and language skills.
- (2) Abnormal responses to sensations. Any one or a combination of senses or responses are affected: sight, hearing, touch, balance, smell, taste, reaction to pain, and the way a child holds his or her body.
- (3) Speech and language are absent or delayed, while specific thinking capabilities may be present.
- (4) Abnormal ways of relating to people, objects and events.

Autism occurs by itself or in association with other disorders which affect the function of the brain such as viral infections, metabolic disturbances, and epilepsy.

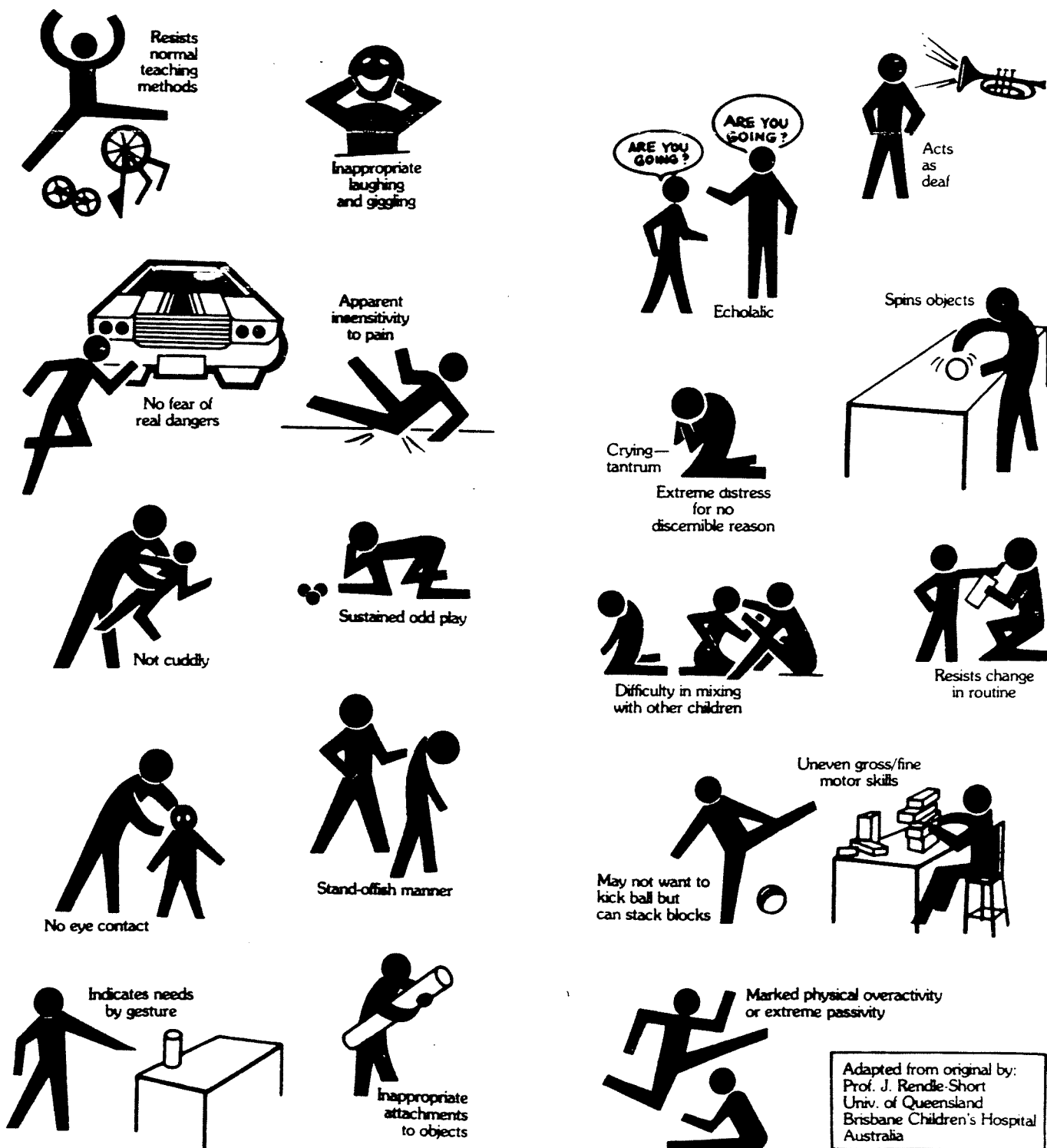
It is important to distinguish autism from retardation or mental disorders since diagnostic confusion may result in referral to inappropriate and ineffective treatment techniques.

The severe form of the syndrome may include extreme self-injurious, repetitive, highly unusual and aggressive behavior.

Special educational programs using behavioral methods have proved to be the most helpful treatment.

Autism is treatable—early diagnosis and intervention are vital to the future development of the child.

The accompanying chart visually portrays the more important signs and symptoms of autism. If a child exhibits seven or more of the symptoms listed above and in the chart and if the bizarre behavior is constant and inappropriate for the child's age, further evaluation is recommended.



Adapted from original by:
 Prof. J. Rendle-Short
 Univ. of Queensland
 Brisbane Children's Hospital
 Australia



**SUPPORT
SERVICES
FOR CITIZENS
WITH AUTISM, INC.**

6119 HALLET
SHAWNEE, KANSAS 66216
(913) 631-6237

A NON-PROFIT CORPORATION DEDICATED TO BUILDING A BETTER LIFE

BOARD OF DIRECTORS

M. SUE STEELE, CHAIR
THOMAS C. BOTTIGER
HAROLD A. KANE
MARY BETH NOLL, PH.D
LEE F. SUTLIFFE
ROBIN A. WELLS
MARK A. CORDER

DATE: March 4, 1987
TO: Public Health and Welfare Committee
FROM: Robin A. Wells
RE: House Concurrent Resolution #5017

Chairman Littlejohn, Vice-Chair Buehler and other respected committee members: Thank you for the opportunity of addressing you today concerning the proposed House Concurrent Resolution #5017. Prior to the decision making process regarding the necessity of forming a KANSAS TASK FORCE ON AUTISM, background information about this severely incapacitating life-long developmental disorder seems very appropriate.

Autism is a neurological dysfunction of the brain. It is the fourth most prevalent developmental disorder after mental retardation, epilepsy, and cerebral palsy, in that order. It occurs in approximately 15 out of every 10,000 births and is four times more common in boys than girls. The estimated number of cases in the United States is 350,000, two-thirds of whom are adults. Occurrence throughout the world is documented since no racial, ethnic or social link has been found.

3-4-87

ARM #2
PH+W

Autism, labeled in 1943 by Dr. Leo Kanner, can be diagnosed by the time a child is 30 months or three years of age. Some parents report unusual behaviors exhibited by their baby from birth while other infants seem to be developing normally, and then, around 12-24 months of age differences in behavior seem to be observed. No single cause has been found to be the contributory factor of autism although all psychological factors have been ruled out.

There are 19 known characteristics of autism and it is felt that if a child has at least seven of these characteristics, the diagnosis of autism should be strongly considered. Those 19 characteristics include 1) resists normal teaching methods, 2) inappropriate laughing or giggling, 3) acts as if deaf, 4) echolalic, 5) spins objects, 6) sustained odd play, 7) no eye contact, 8) no real fear of dangers, 9) apparent insensitivity to pain, 10) not cuddly, 11) indicates needs by gesture, 12) stand-offish manner, 13) marked physical overactivity or extreme passivity, 14) uneven gross/fine motor skills, 15) inappropriate attachment to objects, 16) difficulty mixing with other children, 17) resists change in routine, 18) extreme distress for no discernible reason, and 19) inconsistent ability/knowledge to do similar tasks.

Certain basic difficulties exist for the individual with autism. The disorder severely affects the way an individual receives sensory information, interferes with communication abilities, inhibits social interactions, causes difficulties in

learning rate and style, and often results in the individual exhibiting repetitive stereotypic behaviors which are socially inappropriate and vocationally interfering.

There are varying degrees of mental and communicative disabilities with autism. Each person disabled by the disorder must have an individualized educational plan developed addressing specific strengths and weaknesses so that maximum potential may be reached. While the majority of individuals with autism seem to function in a retarded range, 20% of individuals with autism are considered to be "high functioning". This "high functioning" label usually refers to those individuals who may be integrated into regular educational classrooms, who may attend college, who may have an advanced degree, and who may be socially and vocationally independent. It is felt that the earlier the intervention process begins, the better the prognosis will be.

In 1965, parents united nationally to form the organization known today as the National Society for Children and Adults with Autism. Their concerted effort has helped dispel the following myths which are 1) that autism is an emotional disturbance, 2) that autism is "caused" by the parents, 3) that individuals disabled by autism are uneducable, and 4) that individuals disabled by autism are unemployable.

Not only are individuals with autism themselves frustrated and puzzled by this unique disorder, but all those involved with program planning and care are equally dismayed. The effects on a

family may be devastating: from the initial diagnosis; to daily providing; to primary advocacy; to long term planning; and in some cases, to a possible decision of institutionalization. Those of us who live and work with individuals disabled by autism do not want to continue to see 95% of those adults in institutions as is currently the case. A TASK FORCE ON AUTISM would answer important questions regarding the status of the disorder in the state. With this information, services could be provided or modified to aid all citizens with autism in Kansas in obtaining the most productive life possible and in restoring their human dignity.

I urge you to support House Concurrent Resolution #5017.

March 4, 1987

To: Public Health and Welfare Committee
Representative Marvin Littlejohn, Chair

From: Kathleen P. Heiling
Lenexa, Kansas

Re: House Concurrent Resolution No. 5017

My name is Kathleen Heiling. I am the mother of a four-year-old son, Kevin, who is disabled by autism. I am here on behalf of my son and all persons with autism, to share with you my struggle to obtain a diagnosis for my child and the frustration I experienced at the hands of the medical community.

First, let me say that, prior to my son's disability, had I imagined having a handicapped child, I would have thought a diagnosis and treatment, in this day and age, would not be a problem. This is definitely not the case.

Kevin was a perfectly normal child until approximately eighteen months of age. At this time he was beginning to use a few simple words. Between eighteen months and twenty-four months, those words dropped out and no new words appeared. My concerns were dismissed by the pediatrician, who assured me that all kids develop on different timetables. I could not avoid my feelings that, over a period of six months, Kevin had stopped developing normally, and, in fact, was developing some abnormal behaviors. He began flapping his arms when excited and would become very upset at changes in routine.

Kevin's second birthday was the panic point for me. He was able to do very little of what development charts indicated a two-year-old should do. After receiving no help from our pediatrician, we visited a pediatric audiologist, just in case Kevin's speech delay was caused by a hearing problem.

atm #3
3-4-87
PNW

He informed us Kevin heard perfectly and that he was manipulating us and was jealous of his one-month-old brother. Even at the time, I felt this was ridiculous and the problem was something more serious.

We decided to take Kevin to a private speech therapist, and after five months of therapy, there still was no speech. We were instructed not to attend to Kevin's needs until he gave some approximation of a word.

During this time, I was questioning whether or not Kevin's behavior and speech problems were purposeful. In an effort to find out, we took Kevin to a behavioral psychologist at The University of Kansas Medical Center. He assured us Kevin's behavior was not willful, but offered no other explanation. He referred us to the Developmental Medicine Department of Children's Mercy Hospital. The doctor we saw there is one of approximately forty-eight developmental pediatricians in the country. Her initial exam indicated Kevin was mildly mentally retarded. When I informed her that Kevin had seemed fine at one point and seemed to lose skills, she recommended hospitalizing Kevin for a thorough medical and neurological testing. His CAT scan, EEG, bloodwork and genetic testing were all completely normal. When these results were presented to me, I asked for the first time about autism. I had been going to the library, bringing books home by the dozen, hoping I could find Kevin described in one, and find a diagnosis. In several books, autism was mentioned and Kevin seemed to have some of the characteristics. The doctor assured me that beyond doubt, Kevin was not autistic because he let people hold him and climbed into our laps during the exam. Also, she said, Kevin did not go about the room sniffing furniture. While relieved to hear her say this, I was more frustrated and confused, because I could not believe her diagnosis of mental retardation. I suspected learning disabilities, minimal brain dysfunction and processing problems, and even Tourette's Syndrome,

because of the motorical twitching associated with that disorder. I suspected many things except mental retardation.

I guess what prevented me from buying a mentally retarded diagnosis the most was Kevin's complete lack of speech and of social relationships with anyone but my husband and me, and a few adult relatives. Mentally retarded children, from everything I had read, would have the social abilities of children their own mental age. Thus, if Kevin were mildly retarded at age two-and-one-half, he should have the social awareness of a normal one-and-one-half-year-old child. This was not the case. His motor abilities would most likely be at a one-and-one-half-year-old level, as well. His were age-appropriate. He should have also been speaking at a one-and-one-half-year level, but he was not speaking at all. And, I wondered, are mentally retarded children this fussy and resistant to change?

We visited another pediatrician, who also felt Kevin was mentally handicapped. I began to look in to programs for special needs children, and to my dismay, none of the programs I observed seemed to have any children with behaviors like Kevin's. I finally found a program I felt was the best offered. Kevin remained at the school for a year, and while he enjoyed school, it became obvious to me that Kevin needed more structure and work with the interfering behaviors than was being offered.

Kevin was again evaluated by the doctor at Children's Mercy Hospital in April last year, and she still maintained he was mildly retarded. By this time, I was convinced in my mind, that Kevin was autistic. When I asked the doctor about Kevin's flapping, screaming, and lack of speech, she told me these were only "autistic-like" behaviors that sometimes manifested themselves in mentally retarded individuals.

Still uncomfortable with the diagnosis of retardation, I did not know what to do. I was tired of not knowing what was wrong with Kevin. For almost two years, I had been calling medical schools and universities, describing Kevin to anyone who would listen, and not once did anyone mention the possibility of autism. I had heard of a preschool at Kansas University Medical Center for autistic children. Kevin had a thorough intake evaluation there and again, we left without anyone suggesting autism, and again, we received a developmentally delayed diagnosis with "atypical" behavior. Kevin was deemed inappropriate for their program.

The turning point in my search came when I saw a newspaper article announcing National Autism Week. The article mentioned a local support and advocacy group, the JoWyCo Chapter of the National Society for Children and Adults with Autism. I contacted them and began attending meetings. I still had no diagnosis but the more I spoke with parents and educators at these meetings, I came to the conclusion myself that Kevin was autistic.

I inquired with the Shawnee Mission School District about preschool programs for autistic children and was assured a program was available. After thorough testing by many professionals and observation of possible placement classrooms, we agreed on a behavior-disordered setting for the current school year. He has made tremendous gains in the structured environment. His patience has improved greatly and the fussy behavior has diminished markedly. He has learned a few basic signs to indicate his needs, such as "drink", "eat", and "more".

Last fall my husband and I attended the annual convention of the Kansas Society for Autistic Children and Adults (KANSAC), and heard a doctor speak who was very well-informed on autism. In November, Kevin was seen by this doctor and my diagnosis was confirmed -- Kevin is autistic.

Kathleen P. Heiling
Page Five

One chapter of my story has been written - that of a diagnosis for my child. But much remains to be done and I am hopeful for a future when no parent has to go through what my family did to find out their child has autism.

I urge you to support House Concurrent Resolution No. 5017.



RESEARCH AND EDUCATION
FOR AUTISTIC CHILDREN

TO: The House Health and Welfare Committee
RE: House Concurrent Resolution #5017
FROM: Margene Dipaling

Martin Littlejohn, Chair
March 4, 1987

I am a member of the Kansas Planning Council on Developmental Disabilities. I am also the Director of the Kansas Society for Children and Adults with Autism. I do this as a volunteer. I do this as a volunteer because there is a need and there is not the money. Also, I do it as a volunteer because I am the parent of a 13 yr. old boy with autism. The reason I stay **is because of the very special people and their parents for which I advocate and work.**

I would like to speak for all the parents in this state who have an autistic child whether they still be youngsters or adults regarding the educational system in Kansas.

Many problems arise in the classroom due to one very fundamental problem. The teachers are not trained to work with children who have autism.

Ms. Wells gave you a look at what autism is. From her presentation you are able to see the difficulties unique to autism.

You can them understand why their training has to be specific to the handicap of autism.

You can also understand why teachers without specific training to teach and deal with the child with autism look at the job of teaching our children as frustrating and physically wearing. You can also understand why teachers burn out "quickly" when placed in classrooms with our children.

And maybe you can begin to understand how much stress this ultimately places on the family of the autistic child. It is long term stress. The "educational system" has trouble recognizing it as a serious problem. They give autism recognition at all only when the problems involved get completely out of hand.

3-4-87

PHYUW

Attm. #4

My son's experiences in school have been rocky at best.

When he was eleven, hardly a day went by when Jeffrey hadn't created some major problem that had to be related back to me. Finally, one day he yanked a little girl down to the ground by her hair. His teacher told the mother of the little girl and this mother threatened to sue the school district if Jeffrey (my son) wasn't taken out of her little girls class. Within two weeks he was in another classroom in another school. He did well in the new classroom for a year and a half. The new teacher taught him to use the computer and to play simple tunes on the piano. He even began reading and learning to spell. This teacher has gone to another classroom. He is not doing so well this year. He is in trouble a lot. The teacher that had done well with him for that year and a half was educated and trained in Iowa.

In all honesty there is not really a good reason to mention this about the teacher other than to say that it is ironic that one of our few good experiences with Jeffrey's education came from someone not trained in this state.

There is no specific program in Kansas that effectively trains its teachers to work with our children.

I had one mother from south east Kansas tell me why she teaches her high functioning autistic son at home. She won't let her son be "taught" in the public school system.

I have another mother happy just to have her autistic son sitting quietly in a chair 6 hrs. a day in school, doing nothing of any significance. In the past untrained teachers had trouble working with him. He would get hyperactive and physically aggressive. Later no one worked with him at all. He sat. He vegetated.

he was quiet. The mother thought she had to settle with him just being quiet. She was so tired of hearing the teacher go on and on about her child.

In Wichita there is one classroom for children with autism. Ages 5 through 18. All in one room.

My son is in a TMH classroom, Trainable Mentally Handicapped-Level 3. He is labeled under the category OHI. Other Health Impaired. I'm only a parent so maybe you can forgive me when I say being labeled "Other Health Impaired" doesn't signify much to me. And if someone says to me "oh don't worry about that label, he'll get an "individual education program," I have to look at them and the whole system in "Wonder"! Children with a label like that have to be virtually invisible in the system. With teachers untrained in autism I'm to believe that "other Health Impaired" helps somehow to define and address his problem.

I am in total sympathy of teachers placed in classrooms with our children. Where is the support and training they should be getting from the educational system?

There is a problem!

The educational system will have to take the problem of autism seriously when the state of Kansas begins addressing the issue. And the first step in doing so is with the passage of House Concurrent Resolution #5017.

Thank you!

March 4, 1987

FROM: Jeanette Springer
KANSAS Information and Referral
2004 Wellington Place
Wichita, KS 67203
(3166)262-0226

TO: Cahirman, Marvin Littlejohn
V. Chair, J. Frank Buehler
Committee members

HOUSE CONCURRENT RESOLUTION NO. 5017

My name is Jeanette Springer. I live in Wichita with my husband, Tom, my 91 year old parents, a semi-invalid sister and our 23 year old autistic son. An older son and daughter are now on their own.

I am grateful for the opportunity to speak to you today on the need for a task force on Autism in Kansas.

Our 3rd. child was born 23 years ago—a beautiful, perfect baby to look at and perfect to care for, but too good; so good in fact that I had a feeling his pediatrician should be consulted. I was an overanxious mother he told me at two weeks, one month, two months, three months and it wasn't until his second birthday check up that he agreed. He seemed shocked. We wanted something done and done RIGHT NOW. After 5 months wait to get him into the program at the Institute of Logopedics we started a 2 hour therapy session per week. Six months later he was much worse. We took him off program. It was expensive and wasn't working.

An article by Leo Kanner was given me by my mother. It described David as if he had sat in observation of him—rituals, no speech, ^{no} eye contact with a far away look out of them, yet physically beautiful without any interaction or seemingly any need for anyone. The library didn't have anything on this disorder. (That has been corrected.) Logopedics didn't believe there was such a thing as autism and diagnosed David as having "Aphasia".

There wasn't a P.L. 94-142 back then, but I contacted the diagnostic center of the public schools. No, there were not any preschool programs for any type of child. I made a friend over the phone. Her name was Lorene Gurley. I later found out that she had a daughter who

PH & W
att #5
3-4-87

was mentally retarded. She was very supportive and related to my problems. She thought I should go visit Lilac Lane, a preschool for the mentally retarded. They said that he just didn't fit there. He was normal looking and advised me that he needed normal peers to model from.

Our out of town trips in search of help starts here and I will give you a thumb nail sketch. Mayo Clinic in Rochester, MN., Menningers in Topeka. We were heartbroken and the future looked bleak for our little boy who would soon be school age and couldn't communicate, but looked so "normal". Next we went to try the patterning program we had heard was so controversial. It worked. He had a very time consuming, intensive program we followed every day, but it was worth it for him. He was reading, cursive writing, counting (which we didn't teach, but found this was a splinter skill he had). Philadelphia

By age 5 (He was small for his age) he was accepted at the neighborhood preschool. No interaction with other children, but liked parallel play. Attended regular kindergarten the following year. The following two years he attended a small class for the emotionally disturbed, but it became a rule that if the student couldn't be mainstreamed full time, there would not be a class for him. Next a few months of private school for L.D. students (until the teacher closed the school to go to a monastery back east) and then Mrs. Gurley suggested Holy Family. He lasted in the class for the L.D. students just two days. He hid in the closet in a wagon. A staff from the school district, which included Mrs. Gurley, came to the staffing. Nothing was available and so Mrs. Gurley was authorized to attend a training school for autistic in St. Louis that I had just found out about. The Judevine Center. A class in Wichita would take years and we didn't have that kind of time to wait. We moved to Texas and then to California for the next two years. Texas had a nice class for the physically impaired children. Just 6 pupils and 1 aid and teacher, California had him in a resource room full time. I was called numerous times to pick him up because of bizarre behaviors, so when they wanted him to attend a class down the mountain, I didn't agree to it. Back to Wichita and though the autistic class was in operation by that time, it was full. Dr. Pete Fanning did find room in the L.D. class at Logopedics until the following year when there was room in the class at Dodge School. All went well the first year.

The second year was not so good because the class had too large of an age span and David was regressing at a rapid rate. P.L. 94-142 was in

effect now and it was a battle to take him out of school. We did win the battle and I taught him at home and then he was enrolled in the Learning Lab at Kansas Newman College. At 18 he felt he should be getting vocational training so we were enrolled at Starky. The public school provided David with a private aid and he was a great worker. When he graduated, he lost his beloved aid. A full time work program with no one to pace or buffer him from the world proved to be more than he could handle in an environment not geared for his impairment and he went out of control. He lasted there only a few short months and then was hospitalized for a while as medication was started. He had never before had to have drugs.

He attended 6 months of day program and he was ready to try again. In order to keep him busy we started swimming lessons at W.S.U., piano lessons and a private communications disorder specialist comes once a week to work with him. He seemed to be doing so well that a friend of mine, Linda Weir Enegren, suggested that I have him do volunteer work. We now work two mornings a week at the Mental Health Association. He is an office assistant it says on his application. He puts data into the computer on newborns for the "Pierre Program". One of the most important projects they have, I am told.

Please note the letter I have enclosed. I receive letters and phone calls from all over our nation such as this one. The fact that I wish to point out from my talk in retrospect is--although persons with autism have areas of mental retardation, it is the AUTISM which requires the necessity for understanding and special consideration of environment and supervision. Notice this mother is asking me the same questions that I asked when our son was very small. Where are the answers today for yesterdays questions of 23 years ago? A task force might find the answers for us all. They are expensive to educate and I believe their education should be cost effective, so once again, on behalf of my family and all Kansas families who have members with autism, I ask for your support of Resolution No. 5017.

Thank you.

Ks. State Society for Children &
Adults with Autism
449 S. Bleckley
Wichita, Ks. 67218

Donna Morton
Po Mrs. John W. Miller
209 N. Leonard
Girard, Ks. 66743

Dear Ks. Society,

I am the mother of a 5 yr. old boy with autism. I am currently living in Louisiana and am a member of the local society ASAC (Acadian Society for Children & Adults with Autism). My son is placed in an autistic class. He has undergone extensive testing which included seeing a Child Psychiatrist & a Pediatrician Neurologist. After all the testing was completed; the diagnosis of autism was reached.

I will be moving to Kansas in the very near future with my son. We will be living in the Girard, Ks. area (near Pittsburg, Ks.) I have learned there are autistic classes at Parsons State Hospital. I wish to know of any other classes for autistic children in the Southeast Ks. area and also the local society that covers that area of Ks.

Please send me the address of the local society at my mother's address which is at top of the page.
I appreciate your help very much.

Thank you.

Sincerely,

Donna Morton

att.m #6
3-4-87
PH & W

To: Public Health and Welfare Committee
Representative Marvin Littlejohn, Chairman

From: Harold A. Kane
3121 North 84th Terrace
Kansas City, Kansas 66109

Re: House Concurrent Resolution No. 5017

Mr. Chairman and members of the Committee:

My youngest son was born in 1962 and is Autistic. In the early 70s Autism was not diagnosed as quickly as it would be today.

In 1968 our family Doctor referred us to the Childrens Rehabilitation Unit at the Kansas University Medical Center because of severe behavior Problems with our son. C.R.U. in turn referred us to H.E.E.D. a private school started by a group of parents because there wasn't any other available program. H.E.E.D. stands for Help Educate Emotionally Disturbed. My son attended H.E.E.D. school from 1968 to 1971. The first half of this period the school was 15 miles from our home which meant a 30 mile round trip twice a day for a total of 300 miles weekly. The last half of this period the school was moved to 25 miles away which meant a 50 mile round trip twice a day or 500 miles a week. Thank God for Public Law 94/142.

From 1971 to 1975 our son was a student at C.R.U./K.U.M.C. as he was past the age limit for H.E.E.D.

In 1975 CRU/KUMC ended the Emotionally Disturbed program and our son was transferred to a Personal and Social Adjustment program in the K.C.K. school system. He was in this class for a little over a year.

In the fall of 1976, because of increasing violent behavior he was admitted to Rainbow Mental Health Center as an inpatient. After a ten month period, he returned home and attended Rainbow as a day patient. In January 1978 he was accepted in a new program in the schools called S.P.A., Severe Personal Adjustment. This lasted three years and he then moved to a new Work Activity Program, where he stayed until June 1982.

Because of Extreme Violent Behavior at home, he was sent to Ossawatimie State Hospital where he remained from June 1982 until October at which time we brought him home because of concerns we had about the side-effects of the medication he was receiving.

In April 1983, our son was admitted to Parsons State Hospital and Training Center where he still resides. In February of this year, 1987, he

PH + W attm #7

3-4-87

was referred to the Social Skills Training Project which is designed for the research and treatment of Chronically Abberent Behavior, primarily aggression and self-injurious behavior. This program is operated by the Kansas University Research Team at the Hospital. To date there has been a big improvement in his behavior and we hope and pray for continued success.

At the present time the Wyandotte County Special Education Co-op provides programs from preschool to age 21. The pressing need is for early identification of Autism and MORE specific programs for these children so identified. I have been a member of the Wyandotte Co/Op Special Education Advisory Board since the beginning and I am sure we have many Autistic students who have not been identified as such. This points out the importance of item #1 lines 59 and 60 of the resolution.

At the present time there are NO programs for Autistic Individuals after they finish the Special Education classes. There is a Sheltered Workshop and a Group Home for Mentally Retarded People but because of aggressive and or other behaviors most Autistic individuals would not be accepted in either of these programs.

All of the items listed in this resolution are of critical importance to Autistic individuals and I would like to thank the people who drew up this Resolution as they have been very thorough in their research on this matter. I urge all members of the committee to support this Resolution.

Thank you for your time and attention.

Sincerely,

Harold A. Kane



**SUPPORT
SERVICES
FOR CITIZENS
WITH AUTISM, INC.**

6119 HALLET
SHAWNEE, KANSAS 66216
(913) 631-6237

A NON-PROFIT CORPORATION DEDICATED TO BUILDING A BETTER LIFE

BOARD OF DIRECTORS

March 4, 1987

M. SUE STEELE, CHAIR
THOMAS C. BOTTIGER
HAROLD A. KANE
MARY BETH NOLL, PH.D
LEE F. SUTLIFFE
ROBIN A. WELLS
MARK A. CORDER

To: Public Health and Welfare Committee
Representative Marvin Littlejohn, Chair

From: Sue Steele
Shawnee, Kansas

Re: House Concurrent Resolution No. 5017

My name is Sue Steele and I am the mother of a 23 yr. old man disabled by autism. I speak to you as a parent and as chair of the Board of Directors of Support Services for Citizens with Autism, Inc.

Since we had two children my husband and I knew something was wrong with our son Andy when he was only a few months old. His doctor was not alarmed, but it soon became apparent. There was inappropriate social behavior, abnormal eating and sleeping habits and most importantly, no language. The first nine years of his life was spent going from doctor to doctor seeking help and being told he was probably mentally retarded, brain damaged or a simple "no" diagnosis. At the same time, we searched for educational programs. He was rejected by programs serving the mentally retarded because of his acting out behavior. Consequently, he spent much of his young life at home without services. Twice he was accepted to a day program for the mentally retarded but only for a few hours of custodial type care. We tried medication and megavitamin therapy. None of these treatments helped. His behavior continued to become aggressive. My husband and I took turns going with the other children to school activities, etc., while the other remained at home with Andy. Andy was finally diagnosed autistic at the age of 10. After becoming educated on autism, my husband and I were satisfied and almost relieved with the diagnosis.

Att # 8

PH & W.

3-4-87

However, it was most frustrating to find programs for individuals with autism were non-existent. Through the efforts of our parent support group and the passage of P.L.94-142 (the Education of All Handicapped Children Act), the school district in Lubbock, Texas developed a program specifically for children with autism. We were pleased with Andy's slow progress the next 9 years after moving to Shawnee Mission. We worked closely with his dedicated teachers, trying to keep abreast of new ideas and techniques of how to teach him a way to communicate and functional living and social skills. We found the more Andy learned to communicate the aggressive behavior decreased. In fact, he is very delightful today. The next disappointing time in Andy's life was when he turned 21 and he was to leave the school district. We thought we had prepared him to function in a sheltered workshop setting. After a 4½ day evaluation, he was rejected from the only workshop in the county. Due to the characteristics of his disability, we felt Andy was not given a fair evaluation. My husband and I appealed the decision and Andy was given a 2 week evaluation. He was accepted, but only to a year long waiting list. I volunteered for three months until staff of a part time program was comfortable working with him. He is now being served by the sheltered workshop but only as a client in a program isolated from the workshop area. This program does not provide the essential on-the-job training he needs due to the nature of his disability. Andy continues to live in our home.

Life for Andy has not been easy. Life for my husband and me and our other three children was far from normal. We did the best we could at the time. We try not to look back but to the future and continue to help Andy learn new skills so he can live a more normal life. I only bring up the past to this committee today to make you aware that parents seem to be facing the same problems some 20 years later.

I am a charter member of the Kansas Society for Children and Adults with Autism (KANSAC) and I organized the local JowyCo Chapter. For 10 years, members of our organization have worked very hard to improve services for individuals with autism. We educate the public on autism through the newspapers, TV and radio and by speaking to universities and civic organizations. We have conducted many conferences and workshops offering updated

facts about the disability, including new educational and vocational techniques. Yet, parents contacting us for assistance are still looking for knowledgeable doctors, helpful medication, educational programs and residential, vocational, and respite care services. It is very frustrating to tell them that the majority of these services do not exist. There has been a slight improvement in educational programs, but there still seems to be a lack of the other services. The really sad concerns come from parents who had to move their young adult to private or state institutions, far from home, because of the lack of support when they reached the age of 21.

Support Services for Citizens with Autism, Inc. is a group of concerned parents supported by concerned professionals. It was certified as a corporation by the State in 1985. Our purpose is to develop appropriate services that are lacking. We are in the process of developing the first group home in Kansas. We hope to provide vocational training and job opportunities for adults with autism. It appears we cannot accomplish this alone -- we need help. Already we have encountered many obstacles. The largest being the lack of knowledge about autism by state and local service providers and policy makers in all areas of service.

Simply stated, parents have had to recognize and accept the fact that autism is a developmental disability, but it seems the policy makers and service providers have not. We ask why?

I am grateful to Representatives Brown, Blumenthal, Douville, Flottman, Pottorff, and Vancrum for sponsoring House Concurrent Resolution No. 5017. The resolution perfectly describes the needs. The outcome of the task force will be most beneficial to those trying to improve services for individuals disabled by autism.

In closing, I ask this committee for help by supporting and recommending the passage of House Concurrent Resolution No. 5017. Thank you very much.

3215 West 11th.
Topeka, KS 66604
March 2, 1987

Honorable Kathleen Sebelius
Kansas State House
Topeka, Kansas

Dear Representative Sebelius:

I am writing to express my support for House Concurrent Resolution No. 5017 which would establish a task force on autism. Unfortunately, due to conflicting work responsibilities, I cannot be at the hearing on March 4. I will try to arrange my schedule to come to future hearings or any other meetings related to this issue.

As you know, I have a 16 year old son with autism and mental retardation. (I am enclosing a picture of him.) Eric Olson has been in educational programs since the age of three and has gained many skills that have helped him function in his family and the community. He continues to have many limitations, however, and adolescence has brought some new problems which are fairly typical of people with autism. For example, he goes through endless routines and has many compulsions which interfere with his daily activities. He also becomes very upset by even the slightest deviations in routine. These characteristics quite likely could make his adjustment in a sheltered workshop or group home impossible unless the staff were willing and able to understand and work with these behaviors.

I have been a working mother throughout most of Eric's life and our family has been able to cope despite some very stressful times. As Eric approaches age 21, I wonder what will happen to him---and the rest of the family. Must I quit a job which is badly needed for income as well as personal satisfaction to stay at home all day with Eric? Should my husband do that instead? Should we hire a "baby sitter" to be with him so that he can eat and watch T.V. all day? Will he, like so many adults with autism, be rejected by one program after another because they don't know how to work with these people and are not mandated to learn how?

The thought which terrifies me (especially given the recent stories about Winfield State Hospital) is that Eric will one day end up in a state institution. That would cost the state of Kansas so much more in so many ways than would community based programs for people with autism.

I appreciate your interest in Eric and other people with autism.

Sincerely,

Gloria Olson
Gloria Olson

aHm. #9

3-4-87

P#8 W



KANSAS PLANNING COUNCIL

on DEVELOPMENTAL DISABILITIES SERVICES

Fifth Floor North
State Office Building
Topeka, Kansas 66612
VOICE-TTY
(913) 296-2608

JOHN KELLY
Executive Secretary

March 4, 1987

Testimony in Support of House Concurrent Resolution 5017
Regarding the Establishment of a Task Force
on Autism

Presented to House Committee on Public Health & Welfare

Thank you Representative Buehler and members of the House Committee on Public Health and Welfare for the opportunity to share with you the Council's position concerning the establishment of a task force that would assist citizens with autism to achieve greater independence.

The Kansas Planning Council on Developmental Disabilities was created by K.S.A. 74-5501 - 5506 in response to Federal legislation. The Council's mission is to improve the quality of life, maximize the developmental potential, and assure the participation of citizens with developmental disabilities in the privileges and freedoms available to all Kansans.

The Council is composed of 15 members, one-half of whom are either developmentally disabled themselves or are parents or guardians of persons developmentally disabled. We therefore have an understanding (and are honored to count as one of our members, the current President of the Kansas Society for Adults and Children with Autism) of the many issues facing persons with autism and members of their families.

Presently, there does not, in this state, exist demographic information identifying the location, severity and numbers of persons with this developmental disability. This information is pulled from national prevalency rates which may or may not be correct when applied to Kansas.

PH+W
QHM # 10
3-4-87

estimony
HCR 5017
March 4, 1987

HCR 5017 would not only identify the numbers of persons which is critical to the establishment of programs but would review and comment on the effectiveness of current programs and develop recommendations. All of which needs to be in the hands of persons with autism and their family to use in determining an effective course of action.

We support the intent of this bill and encourage you to move this issue with a favorable recommendation.

John Kelly
Executive Secretary
296-1608



RECEIVED

OCT 08 '86

K.P.H.A.

STATE OF KANSAS

OFFICE OF THE ATTORNEY GENERAL

2ND FLOOR, KANSAS JUDICIAL CENTER, TOPEKA 66612

ROBERT T. STEPHAN
ATTORNEY GENERAL

MAIN PHONE: (913) 296-2215
CONSUMER PROTECTION: 296-3751
ANTITRUST: 296-5299

July 20, 1984

ATTORNEY GENERAL OPINION NO. 84- 71

Lynn E. Ebel
Attorney, Kansas Board of Pharmacy
Davis, Davis, McGuire & Thompson
P.O. Box 69
400 Shawnee Street
Leavenworth, Kansas 66048

Re: Public Health -- Examination and Registration of
Pharmacists -- Registration of Out of State Pharmacists
Doing Business in Kansas

Synopsis: The requirements of the Kansas Pharmacy Act, K.S.A.
65-1601 et seq extend to all persons within or without
the state who deliver prescription drugs in Kansas.
Cited herein: K.S.A. 65-1636, K.S.A. 1983 Supp.
65-1626, 65-1631, 65-1643.

* * *

Dear Ms. Ebel:

As counsel for the Kansas Board of Pharmacy, you request our opinion
regarding the authority of the board to require out of state pharmacies
doing business in Kansas to hold Kansas pharmacy licenses and be subject
to the board's regulations.

K.S.A. 65-1636 is contained in the Kansas Pharmacy Act; K.S.A. 65-1625
et seq., and provides:

attm #11
3-4-87
PH & WS

Lynn E. Ebel

Page Two

"Except as otherwise provided in this act, the sale and distribution of drugs shall be limited to pharmacies operating under registrations as required by this act and the actual sale or distribution of drugs shall be made by a registered pharmacist or other person acting under his or her immediate personal direction and supervision."

K.S.A. 1983 Supp. 65-1626(i) states that to "distribute means to deliver . . . any drug." Subsection (g) states that to "dispense means to deliver prescription medication to the ultimate user pursuant to the lawful order of a practitioner."

The term pharmacy is defined at K.S.A. 1983 Supp. 65-1626(s) as "premises, laboratory, area or other place (1) where drugs are offered for sale, where the profession of pharmacy is practiced and where prescriptions are compounded and dispensed . . ."

As noted above, only pharmacies operating under the direction of a registered pharmacist may distribute drugs in Kansas under K.S.A. 65-1636. K.S.A. 1983 Supp. 65-1643(f) provides that it is unlawful for "any person operating a store or place of business to sell, offer for sale or distribute any drugs to the public without first having obtained a registration or permit from the board . . ."

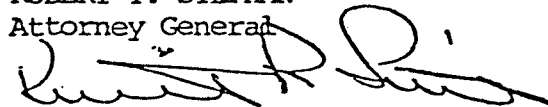
In none of the foregoing statutes is there any language of limitation which suggests that only Kansas residents are subject to the board's control. Rather, Kansas statutes provide for the registration on a reciprocal basis of out of state pharmacists without examination. K.S.A. 1983 Supp. 65-1631(d). We therefore conclude that the language of the Kansas Pharmacy Act does not suggest that its provisions are limited to pharmacies within this state.

A consideration of the purpose of the act also suggests that there was no intent to limit the application of the act. The state's interest in establishing and maintaining high standards in the dispensation of prescription drugs is clear. See, e.g., State ex rel. v. Fadely, 180 Kan. 652, 665 (1957). We therefore conclude that both the language and purpose of the Kansas Pharmacy Act require that out of state pharmacies doing business in Kansas hold a Kansas pharmacy license and be subject to all Kansas regulations.

Very truly yours,



ROBERT T. STEPHAN
Attorney General



Kenneth R. Smith
Assistant Attorney General

RTS:JEF:KRS:may

Kansas State Board of Pharmacy

900 Jackson, Room 513

XX
XXXXXXXXXXXX

TOPEKA, KANSAS XXXXXXXX 66612

PHONE (913) 296-4056

STATE OF KANSAS



Mike Hayden
XXXXXXXXXX
GOVERNOR

HOUSE BILL 2505

HOUSE PUBLIC HEALTH AND WELFARE COMMITTEE

Mr. Chairman, members of the Committee, my name is Tom Hitchcock, and I serve as the Executive Secretary of the Kansas State Board of Pharmacy. I appear before you today on behalf of the Board to speak in favor of the passage of House Bill 2505.

From the Attorney General's Opinion #84-71, it was concluded that both the language and purpose of the Kansas Pharmacy Act require that out-of-state pharmacies doing business in Kansas hold a Kansas pharmacy license and be subject to all Kansas regulations. To license, without authority to inspect out-of-state pharmacies, does not protect the public health and welfare. House Bill 2505 will give the Board of Pharmacy authority to have their agents participate in such inspections.

The Board's intention would not be to have their inspectors travel to out-of-state pharmacies to conduct such inspections, but rather reach a mutual agreement with the Board in that state to have their inspectors perform the inspection on behalf of the Kansas Board. Results could be reported to the Kansas Board and would be handled no different than in-state pharmacies.

House Bill 2505 is a good bill and will be an asset to the Board as well as the health, safety, and welfare of Kansas citizens.

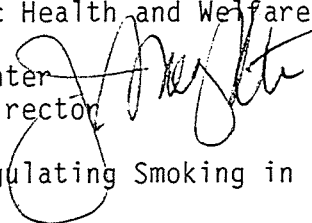
3-4-87
attm. #12
PHTW



KANSAS MEDICAL SOCIETY

1300 Topeka Avenue · Topeka, Kansas 66612 · (913) 235-2383

March 4, 1987

TO: House Public Health, and Welfare Committee
FROM: Jerry Slaughter 
Executive Director
SUBJECT: HB 2412; Regulating Smoking in Public Places

The Kansas Medical Society is grateful for the opportunity to present our views on HB 2412 earlier this week, and would again like to thank the committee for introducing the bill at our request.

During the hearing, the question of prohibiting smoking in various health care institutions was raised, and it was pointed out that it would create a hardship in certain circumstances. One example is patients in substance abuse treatment facilities and psychiatric care units. Another example is grocery stores that include pharmacies. For the purposes of the law, the whole grocery store is considered to be a pharmacy, and under section 4 of HB 2412, smoking would be prohibited completely.

It was never our intention to create problems in these areas, so we would recommend that section 4 be deleted entirely, and health care institutions be treated like any other public place. That would give flexibility to hospital administrators and others to regulate smoking in a manner that did not affect patient care areas.

We believe this amendment will take care of the concerns expressed by some of the conferees on Monday, and should strengthen the bill. Thank you for giving our comments your consideration.

JS:nb

PH & CW
attm #13
3-4-87

HOUSE BILL No. 2412

By Committee on Public Health and Welfare

2-18

0017 AN ACT regulating the smoking of tobacco products in public
0018 places and at public meetings; prohibiting the use of tobacco
0019 products in health care institutions; declaring certain acts to
0020 be misdemeanors and prescribing penalties for violations;
0021 repealing K.S.A. 21-4008.

0022 *Be it enacted by the Legislature of the State of Kansas:*

0023 Section 1. As used in this act: (a) "Public place" means
0024 enclosed indoor areas open to the public or used by the general
0025 public including but not limited to: Restaurants, retail stores,
0026 public means of mass transportation, passenger elevators, health
0027 care institutions, educational facilities, libraries, courtrooms,
0028 state, county or municipal buildings, restrooms, grocery stores,
0029 school buses, museums, theaters, auditoriums, arenas, recrea-
0030 tional facilities and state buildings.

0031 (b) "Public meeting" includes all meetings open to the pub-
0032 lic.

0033 (c) "Smoking" means possession of a lighted cigarette, cigar,
0034 pipe or any other lighted smoking equipment.

0035 (d) "Health care institution" means any office of a health care
0036 provider as defined by K.S.A. 40-3401 and amendments thereto,
0037 any medical care facility as defined by K.S.A. 65-425 and
0038 amendments thereto, psychiatric hospitals, institutions for the
0039 mentally retarded and any other place where health care services
0040 are provided to the public.

0041 Sec. 2. (a) No person shall smoke in a public place or at a
0042 public meeting except in designated smoking areas.

0043 (b) Smoking areas may be designated by proprietors or other
0044 persons in charge of public places, except in health care institu-
0045 tions; passenger elevators, school buses, public means of mass

delete

0046 transportation and any other place in which smoking is prohib-
0047 ited by the fire marshal or by other law, ordinance or regulation.

0048 (c) Where smoking areas are designated, existing physical
0049 barriers and ventilation systems shall be used to minimize the
0050 toxic effect of smoke in adjacent nonsmoking areas.

0051 Sec. 3. In each room or area in which smoking is prohibited
0052 by this act, the proprietor or other person in charge of the
0053 premises shall post or cause to be posted in a conspicuous place
0054 signs clearly stating that smoking is prohibited by state law. The
0055 person in charge of the premises shall also post or cause to be
0056 posted in any room or area designated as a smoking area, signs
0057 stating that smoking is permitted in such room or area. The
0058 proprietor or person in charge of the public place shall have the
0059 authority to establish the percentage of area in the public place
0060 which shall be posted and designated as a smoking area.

0061 Sec. 4. ~~Smoking is hereby prohibited in all health care insti-~~
0062 ~~tutions.~~—

0063 Sec. 5. Any person found guilty of smoking in violation of
0064 this act is guilty of a misdemeanor punishable by a fine of not
0065 more than \$20 for each violation. Any person found guilty of
0066 failing to post signs as required by this act, is guilty of a mis-
0067 demeanor punishable by a fine of not more than \$50. All such
0068 fines shall be retained by the county conducting the prosecution.
0069 In addition, the department of health and environment, or local
0070 department of health, may institute an action in any court of
0071 competent jurisdiction to enjoin repeated violations of this act.

0072 Sec. 6. Nothing in this act shall prevent any city or county
0073 from regulating smoking within its boundaries, so long as such
0074 regulation is at least as stringent as that imposed by this act. In
0075 such cases the more stringent local regulation shall control to the
0076 extent of any inconsistency between such regulation and this act.

0077 Sec. 7. If any provision of this act or the application thereof
0078 to any person, thing or circumstance is held invalid, such inva-
0079 lidity shall not affect the provisions of application of this act that
0080 can be given effect without the invalid provision or application,
0081 and to this end the provisions of the act are declared to be
0082 severable.

delete