

Approved 4-8-87
Date

MINUTES OF THE SENATE COMMITTEE ON PUBLIC HEALTH AND WELFARE

The meeting was called to order by SENATOR ROY M. EHRLICH at
Chairperson

10:00 a.m. ~~p.m.~~ on March 31, 1987 in room 526-S of the Capitol.

All members were present except:

Committee staff present:

Emalene Correll, Legislative Research
Norman Furse, Revisor of Statutes Office
Clarene Wilms, Committee Secretary

Conferees appearing before the committee:

Mary Ellen Conlee, St. Francis Hospital, Wichita, Kansas
Dr. Robert Harder, Secretary, SRS
Representative Nancy Brown
Robin Wells, Support Services for Citizens with Autism, Inc.
Margene Dipaling, Kansas Planning Council on Developmental Disabilities
Sue Steele, Support Services for Citizens with Autism, Inc.

Others attending: see attached list

The minutes of March 23, 24, 25, 26 and 27 were presented for approval or correction. Senator Bond moved to accept the minutes as presented. Senator Anderson seconded the motion. The motion carried.

Mary Ellen Conlee appeared in support of SCR-1601. Ms. Conlee spoke to the committee reminding them of Dr. Charles Shields testimony given in support of SB-144 and also that of Dr. Robert Park, Wichita. In earlier testimony Dr. Shields noted that many doctors and anesthesiologists waive fees but hospitals need funds to provide care. Also, even without liver transplants, there were still costs for terminal hospital cases. Ms. Conlee stated it was felt that the fiscal note previously offered on liver transplants were too high.

Dr. Robert Harder opposed SCR-1601 requesting that the legislature not cover liver transplants. Dr. Harder stated that it does not appear to be in the interests of the state to fund high cost programs dealing with small numbers of recipients when much larger numbers are experiencing cuts in services due to present budget constraints. (attachment 1)

Representative Nancy Brown, co-sponsor of HCR-5017, stated that this resolution would establish a task force comprised of experts in the field, physicians, education professionals, and other appropriate individuals. Members would not be compensated nor paid expenses. Autism is a severely incapacitating, life-long developmental disability which impairs the way sensory input is assimilated, causing problems in communication, social behavior and irregularity in learning. (attachment 2)

Robin Wells spoke in favor of HCR-5017 and gave the committee background information concerning autism. Ms. Wells stated that not only individuals with autism suffer from the individual's disorder but families are also devastated. Information is needed in order to eventually provide services to aid citizens with autism in Kansas and help them obtain the most productive life possible. (attachment 3)

Margene Dipaling spoke to the committee in favor of HCR-5017. Ms. Dipaling stated that as a parent of an autistic boy, the most forward progress made by her son was from an instructor who had been educated and trained outside of Kansas. Ms. Dipaling stated that an early diagnosis allowed training programs to be implemented early thus avoiding many severe behavior problems. (attachment 4)

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 SENATE COMMITTEE ON PUBLIC HEALTH AND WELFARE,
room 526-S, Statehouse, at 10:00 a.m. ~~p.m.~~ on March 31, 1987.

Sue Steele spoke in support of HCR-5017. Ms. Steele stated that their organization, Support Services for Citizens with Autism, Inc., is regularly contacted for assistance in locating knowledgeable doctors, helpful medication, educational programs and residential, vocational, and respite care services. (attachment 5)

The meeting adjourned at 10:59 a.m. The committee will meet April 1, 1987.

SENATE
PUBLIC HEALTH AND WELFARE COMMITTEE

DATE March 31, 1987

(PLEASE PRINT)

NAME AND ADDRESS

ORGANIZATION

Mary Ellen Conlee

St Francis Regional Med Center

Marilyn Bracht

KINHI

Raymond Brown

visitor

Lynette M. Brown

visitor

Lee MacKael-Rubin

KNI-MH+RS

MARILYN PFLAUM - Topeka

KPNHAA

Donna Woodall - Andover

visitor

Diane Romaglia - Andover

visitor

Eric J. Swedlund - Andover

visitor

John Grove

KS Homes For Aging

Rent C. Hansen

SRS

Summary of Testimony on Senate Concurrent Resolution No. 1601
Liver Transplantation

The adoption of Senate Concurrent Resolution No. 1601 would require the Medical Assistance Program to cover liver transplantation for all eligible recipients.

Currently, the Medical Assistance Program does not reimburse for liver transplantation. This is because of exceedingly high costs with frequent complications making the cost even higher.

Kansas could expect to have an average of six liver transplantations per year if the Medicaid Program is expanded to cover this procedure. \$77,280 (the cost for one individual) multiplied by six is \$463,680 in all state funds if there were no complications. This amounts to \$1,035,000 if the state share is federally matched.

The Department could support coverage of liver transplantation for children and adolescents twenty-one years of age and under who are in the Early & Periodic Screening, Diagnostic & Treatment Program, and for whom the procedure is no longer experimental, if there was not such a tremendous shortage of funds for the rest of the Medical Assistance Program. Many needed services for some recipients are no longer covered. Other services are virtually unavailable because providers are discontinuing participation in the Medical Assistance Program.

Every individual having a transplant must take immunosuppressive drugs the rest of his or her life at a cost of \$3,808 annually in state funds and \$8,500 federal and state funds.

If liver transplantations were to be reimbursed, coverage should be confined to transplant centers that meet national criteria. One such center is at the University of Nebraska in Lincoln. These centers would have established criteria for determining which transplants should be approved and which ones should be denied. This is not a decision that can be made without the expertise of the surgeons and other physicians involved.

Because of the exorbitant cost of this procedure which is still fraught with problems and complications, the Legislature is encouraged to not cover liver transplants at this time, unless it is able to sufficiently fund other needed services of the Medical Assistance Program for Kansas elderly, disabled and poor.

LKK:plk
3-27-87

SP#1400
3-31-87
attachment 1

KANSAS MEDICAL ASSISTANCE PROGRAM COVERAGE FOR ORGAN TRANSPLANTS

The purpose of this testimony is to outline the Medical Assistance coverage in the State of Kansas for organ transplants.

Transplantation of organs began as early as 1950 with kidney transplants. However, it wasn't until 1982 and the advent of immunosuppressive drugs, particularly cyclosporine, that kidney transplants became accepted therapy for persons with life threatening organ failure. That year surgeons performed 103 heart transplants compared to 24 in 1976. The number of liver transplants jumped from 14 to 62 during the same period. Simultaneous with the technical developments in kidney transplantation and capitalizing on the advances in immunosuppressive drugs, the first heart and liver transplants were performed.

In contrast to patients with kidney failure, for whom dialysis is available to sustain life, no such practical artificial means of life support has been developed for patients with heart or liver failure. In addition, other problems such as the short time period the heart or liver could be preserved after removal from the cadaver donor and the more restrictive requirements for a suitable cadaver donor have slowed the widespread application of heart and liver transplantation. The even greater deterrent to the growth of the widespread use of transplant therapy however has been cost. Cost has been a major factor in the development of the current Social and Rehabilitation Services policies in Kansas regarding reimbursement for heart and liver transplants.

A report of the "Task Force on Organ Transplantation" in response to the National Organ Transplant Act (PL 98-507) concluded after a comprehensive study of organ donation and procurement procedures that the major constraint of heart and liver transplants has been cost, and this is the issue before us still today.

The State of Kansas does not provide reimbursement for heart or liver transplants through the Medical Assistance program.

Kansas is one of the nine remaining states that does not provide partial or full Medical Assistance reimbursement for liver transplants and one of the 17 states that does not provide any coverage for heart transplants. The reimbursement provided by many states is limited, provided only to designated transplant centers which meet explicit criteria of experience, logistic medical support and patient survival. Twelve of the states limit payment for hospital days to 12-60 days annually and many states provide no payment at all for related physician services.

Some states, such as Iowa have established a committee made up of citizens from all walks of life to make Medical Assistance coverage determinations for the citizens unable to cover the cost of organ transplants. Other states have established a fund specifically for coverage of transplantation for everyone needing assistance to cover the cost.

Coverage of the cost of transplants can exceed \$200,000 per case. Total care for one heart transplant patient for one year will range from \$170,000 to \$200,000. Of this cost, \$120,000 to \$150,000 will be spent during the hospitalization with the remaining \$8,000 to \$22,000 required for the continuing physician care and the immunosuppressive drug therapy. Total cost of liver transplants will range from \$230,000 to \$400,000. Of this total, \$80,000 to \$300,000 is for the period of hospitalization and \$8,000 to \$22,000 is needed for physician and drug costs for continuing care. High costs have been a major deterrent to the widespread application of transplant technology as a treatment for heart and liver failure.

Serious debate on all levels of both the public and private sectors about the cost of organ transplantation has taken place. In light of the relentless increases in health care costs, is it reasonable to add additional expensive procedures to the therapeutic arsenal? Although the survival rate of heart or liver transplantation is fast becoming as high as survival in kidney transplantation, no federal funding has been created for heart or liver transplantation procedures such as for Medicare kidney dialysis for end stage renal disease. Federal financial support for liver transplantation is limited to well-defined categories of Medicare eligible pediatric patients. In practice this results in very few covered individuals because very few children are eligible for Medicare.

The Health Care Financing Administration just this month announced Medicare coverage of and restrictions on funding for heart transplantation to those performed in an approved center and only for those persons who have less than a 25 percent chance of surviving for six months without a new heart. A criteria for selection of heart transplant recipients must be developed by the facility performing the transplant. The facilities are selected by a panel of cardiology experts from a variety of specialties.

Considering the enormous costs of individual transplants and our current fiscal limitations, reimbursement for an expanded heart and liver transplantation program in Kansas requires choices. It is not simply a matter of expanding the program to include a new helpful and life enhancing service. Rather it becomes a matter of discontinuing certain services now being provided in order to free up funding to provide for the new service. A further restriction on the available options is that no limitation based on diagnosis or age can be imposed if federal funds are to be used. This means transplants cannot be provided only for the young or only for certain types of problems.

If Kansas had provided reimbursement for liver transplants in fiscal year 1985, we are aware of three transplants that would have been eligible for funding through the Medical Assistance program. Using the minimum figures from our estimated cost ranges for liver transplants of \$230,000 to \$400,000 for initial hospitalization and \$8,000 to \$22,000 for the continuing care, the minimum estimated cost of the three liver transplants would have been \$714,000. In contrast the following listing sets out the costs for fiscal year 1985 of certain preventive services that were actually covered during that year and the number of persons receiving these services.

<u>Home and Community Based Services</u>	<u>Dollars</u>	<u>Number of Recipients</u>
Non-Medical Attendant Care	\$352,313	942
Habilitation Services	355,000	124
Night Support Services	137,553	129
TOTAL	<u>\$844,866</u>	<u>1,195</u>

<u>Early, Periodic Screening and Diagnostic Treatment Programs *</u>	<u>Dollars</u>	<u>Number of Screens</u>
Medical Screens	\$617,466	17,852
Dental Screens	146,777	12,273
TOTAL	<u>\$764,243</u>	<u>30,125</u>

* The Early Periodic Screening and Diagnostic Treatment Program is mandatory for continued federal funding.

Source: HCBS - SRS Profile Reports
EPSDT - SRS Information Services Report

The discontinuance of any of these less dramatic preventive services would detract from the well being of a large number of individuals. Difficult as it is, the program is faced with the weighting of the choices. To date, the weighting has been in favor of the greatest amount of service to the largest number of persons rather than the high cost, but very visible transplantation procedures for the limited number of persons who would benefit.

LKK:plk
10-23-86

Liver Transplant Coverage by Kansas Medical Assistance Program

This document summarizes the effect of the following recommendations of the Interim Committee. These recommendations would have a profound effect on delivery of medical services for Kansas Medical Assistance MediKan recipients.

1. Reimbursement should be confined to transplant centers that meet national criteria, or in the absence of such criteria, develop policies that follow the recommendation of the Task Force on Organ Transplantation.

SRS concurs that coverage should be confined to transplant centers that meet national criteria. Criteria are available and these centers can easily be identified. One such center is located at the University of Nebraska in Lincoln, Nebraska. To our knowledge this is the only liver transplant center in the midwest. Criteria include such things as experience of the surgeon, number of transplants performed annually, and the coordination with a knowledgeable physician in the recipient's home community.

2. Liver transplantation be a covered service under Medicaid and MediKan.

Reimbursement has been the single deterrent of liver transplantation by third party payors nationally and certainly for the Kansas Medical Assistance Program. It is believed that reimbursement would be requested for six to twelve liver transplants annually if this became a covered service for all program recipients. The most conservative figures possible were given to the Committee studying proposal No. 26 by SRS. These projections assumed that six transplants would be requested for reimbursement annually.

The cost of providing six liver transplantations in FY 1988 is projected to be:

	<u>State</u>	<u>Federal</u>	<u>Total</u>
Surgeon	\$ 67,200	\$ 82,800	\$ 150,000
Hospital	107,520	132,480	240,000
Assistant Surgeons	29,568	36,432	66,000
Anesthesiology & Other Physicians	40,320	49,680	90,000
Immunosuppressive Drugs	22,848	28,152	51,000
Other Drugs	40,320	49,680	90,000
Laboratory & Radiology	67,200	82,800	150,000
Medical Evaluation - Post Operative	48,384	59,616	108,000
Other Costs	40,320	49,680	90,000
Total	<u>\$463,680</u>	<u>\$571,320</u>	<u>\$1,035,000</u>

The costs listed above are for routine, uneventful, and successful liver transplants. These figures do not reflect any costs associated with complications during surgery, complications after surgery, or rejection of the donor organ. In some specific cases the additional costs resulting from these complications have been known to run as high as \$1,000,000 per case.

3. A separate budget request be presented to the 1987 Legislature that covers liver transplantation only, and in future budgets, the cost of transplantation be set out separately in medical assistance budgets.

A separate line item in the budget could be established for those parts of transplantation services that can be clearly identified such as the surgical procedure, some drugs and follow-up care if that diagnosis is given and not the diagnosis for the secondary condition resulting from the transplantation. Drugs, except the immunosuppressant which is still specific for transplantation, could not be identified. It would not be possible to track all reimbursement for services resulting from transplantation.

4. The Secretary of SRS adopt rules and regulations setting out specific diseases on conditions that are medically acceptable as criteria for transplantation.

SRS does not concur with the recommendation that SRS set out regulations specifying the disease or conditions for which transplantation will be covered. The physicians who have the expertise from their knowledge and experience must make those decisions. This is one of the reasons why only centers that meet the national criteria are used. Part of that criteria is the experience of the physicians. To set diseases and conditions out in regulations would be far more limiting than is appropriate. If a new disease was identified for which a liver transplantation was the treatment of choice, payment would be denied because it was not included in a regulation. These regulations can only be changed annually.

The criteria utilized by the University of Nebraska and other nationally certified transplant centers in determining the disease or condition for which transplants will be covered are medically sound and defensible are:

1. Life threatening liver disease with no other form of treatment.
2. Contraindications are malignancy and active sepsis.
3. Must have psychiatric evaluation of both recipient and family to determine compliance with regime established.

Further more, and most important, to have such requirements would immediately eliminate federal participation in reimbursement. The code of federal regulation 42 440.240 states "The plan must provide that the services available to any categorically needy recipient under the plan are not less in amount, duration, and scope than those services available to a medically needy recipient, and (b) the plan must provide that the services available to any individual in the following groups are equal in amount, duration and scope for all recipients within the group; (1) the categorically needy, (2) a covered medically needy group.

5. SRS investigate the possibility of purchasing drugs most often prescribed for recipients of organ transplants in bulk.

The federal supreme court ruling known as the Portland Decision would not allow SRS to make special purchases for private citizens. It states that non-profit institutions cannot compete against for profit individuals. For Social and Rehabilitation Services, purchase of drugs in large amounts would require the storage of the drugs and that a method of maintaining inventory records and security be established so that only Medical Assistance recipients get the drugs. Except for immunosuppressive therapy there would be no way of knowing the amount needed, nor could the drugs be identified as being used for transplantation only. To purchase the immunosuppressants in bulk would not be cost efficient. Since there is only one drug in this category bidding, the method utilized for bulk purchase, would only have one bidder which could drive up the cost. Finally when the medication is extremely expensive it should be issued in amounts that eliminate waste. It would not seem to be the wisest decision to attempt bulk purchase of drugs used in transplantations.

In conclusion the Kansas Regulation states that experimental and pioneering procedures will not be covered. Therefore, we would recommend at this time that coverage be limited to participants in the Early and Periodic Screening Diagnostic and Treatment program so that liver transplantation can be limited to children and adolescents for whom this is not considered an experimental procedure. The code of Federal Regulations 42 440.250 (b) allows different limitations then for other recipients not in this program. The Early and Periodic Screening, Diagnosis and Treatment Program is limited to those twenty-one years of age and under.

If the Medical Assistance budget is adequately funded SRS would support the one million dollar plus budget for liver transplantation coverage as long as the policies for coverage and reimbursement can be handled as other procedures in the program and there are no special requirements.

LKK:plk
3-27-87
Exec. Proposal 26



TOPEKA

HOUSE OF
REPRESENTATIVES

COMMITTEE ASSIGNMENTS
MEMBER: GOVERNMENTAL ORGANIZATION
INSURANCE
TRANSPORTATION

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

Testimony on

HCR 5017 - Establishing Task Force on Autism

Mr. Chairman and Members of the Senate Public Health and Welfare Committee:

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

After introducing the resolution, several House members asked 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, life-long 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 life-long 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 of the existing 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 one of the handouts.

SPH/llw
3-31-87
attachment 2

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 those associated with the autistic, to insure 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 eleven members comprised 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!

Nancy Brown

NSAC 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.

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

■■■

DEFINITION OF AUTISM AND ITS SYMPTOMS

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.

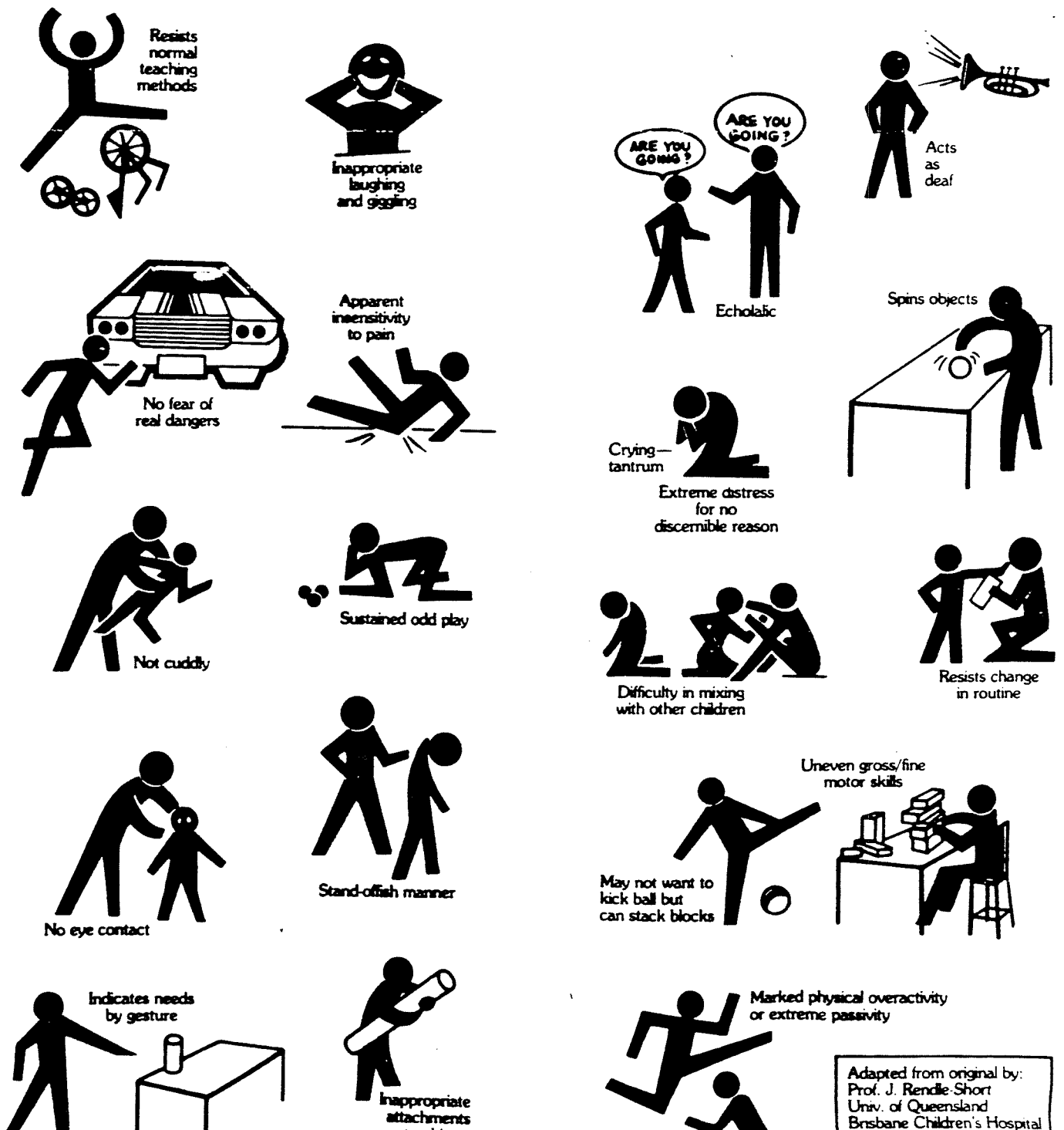
It is important to distinguish autism from retardation or mental disorders since diagnostic confusion may result in referral to inappropriate and ineffective treatment techniques.

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



**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

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TO: Public Health and Welfare Committee
Senator Roy Ehrlich, Chair
FROM: Robin A. Wells
Overland Park, Kansas
RE: House Concurrent Resolution #5017
DATE: March 31, 1987

Chairman Ehrlich, Vice-Chair Bond 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 disability 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.

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 the 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 to address 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 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.



RESEARCH AND EDUCATION
FOR AUTISTIC CHILDREN

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

March 31, 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. I get gratification from my work because of the very special people for whom I advocate and their parents.

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 then 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 this child 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 only when the problems involved get completely out of hand.

*SP4KW
3-31-87
attachment*

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 wasn't taken out of her little girl's class. Within a couple of 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.

I am only mentioning this about the teacher because 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 southeast 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.

I think this is a good place in my presentation to say that it is extremely important that children with autism be diagnosed early, so that training programs could be implemented early. This is a program of intervention. Many severe behaviors could be avoided if correct training programs were being used early in an autistic child's life.

If there was early diagnosis and an educational system enlightened in the area of autism it would alleviate many of the behavior problems in the classroom. I could envision more mainstreaming of these children. And the beginning of success stories in the classroom with the autistic child.

Public Law 94-142 guarantees children with handicapping conditions the right to a "free appropriate" public education.

For a time I had to supplement Jeffrey's public education with private speech lessons, because he was not getting a specific speech program through the school, although it was written into his individual education program. I had to hire a psychologist to come into my home to work on behavior modification with my son. For my son to get appropriate training and education it did not come Free!

Public Law 94-142 designates the school the lead agency for identifying children's needs and coordinating Individual Education Program.

The Kansas Education System has not educated itself about Autism. How then can we expect them to identify our children's needs. It can not. It has to virtually play a guessing game with each autistic child it is supposed to teach. Too often the teacher learns off the child rather than the child getting quality training from the teacher.

Public Law 94-142 was a necessary step in gaining access to appropriate education for the handicapped. But PL 94-142 is as good as the expertise in the educational system.

The attitude of the Kansas educational system would appear to be that there is not a significant problem here. I believe we are making a case to the contrary. There is a problem. A very real problem. One in which families across Kansas and I are faced with on a daily basis.

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

JM



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To: Public Health and Welfare Committee
Senator Roy Ehrlich, Chair

From: Sue Steele
Shawnee, Kansas

Date: March 31, 1987

Re: House Concurrent Resolution No. 5017

Senator Ehrlich and other committee members, I want to thank for giving me this opportunity to speak in support of House Concurrent Resolution 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.

Prior to the passage of P. L. 94-142 (the Education of All Handicapped Children Act of 1975) many children, including my son, spent the majority of their young lives at home with no services or were inappropriately placed in institutions. Further, many were misdiagnosed. (My son was 10 yrs. old when he was given the autism label) Parents spent an enormous amount of time and money searching for doctors and/or educational programs that could help their children. It is very sad to think that half of their educational years were wasted. I only bring up the past to this committee today to make you aware that parents in Kansas seem to be facing the same problems some 20 years later.

Local chapter members of the Kansas Society for Children and Adults with Autism 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. Research to find the cause and cure of autism continues. While there are a number of treatments being used to help individuals with autism, experts in the field agree education is the treatment of choice. As pointed out earlier, subsequent to the passage of P. L. 94-142, most of our children are now being served in some type of special education program. There has been an inconsistent improvement in educational programs across the state.

Another major problem is a lack of extended community services for the adult. There are no vocational or residential services specifically designed to serve individuals with autism when they reach the age of 21 and are no longer served by the school district. A few adults are being served in sheltered workshops with untrained staff and the majority are once again, sitting at home with no services or inappropriately placed in institutions.

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 a small community-based home for adults with autism, the first in Kansas. We will provide vocational training and job opportunities. 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 in our state. The prevailing attitude that individuals with autism cannot learn or will never be able to hold a job is changing. We have available to us now the technology to enable us to change the alarming statistic that 95% of persons with autism will end up living in institutions. The

medical, educational, and other service providers must be made aware of these updated facts.

The outcome of lines 57 through 72 of the resolution will be most beneficial to those who are trying to improve services for individuals disabled by autism. I might point out lines 55 and 56 state "that members of the task force on autism shall serve without compensation or expenses".

I am grateful to Representative Brown, Blumenthal, Douville, Flottman, Pottorff, and Vancrum for sponsoring House Concurrent Resolution 5017 and I am sincerely thankful to Senator Bond for his additional support. In closing, I ask this committee for help by supporting and recommending the passage of House Concurrent Resolution 5017. Thank you very much.