

Approved 3-17-89
Date

MINUTES OF THE House COMMITTEE ON Appropriations

The meeting was called to order by Bill Buntin at
Chairperson

1:30 ~~am~~/p.m. on February 27, 1989 in room 514-S of the Capitol.

All members were present except: Representative Heinemann (excused)

Committee staff present: Ellen Piekalkiewicz, Paul West, Legislative Research
Jim Wilson, Revisor of Statutes
Sharon Schwartz, Administrative Aide
Sue Krische, Committee Secretary

Conferees appearing before the committee:

Ron Hein, Legislative Counsel for Unisys
Secretary Horace Edwards, KDOT
Jim Jones, Director of Operations, KDOT
Nick Roach, Division of Purchases, Department of Administration
Representative Darrel Webb
Representative Arthur Douville
Mike Oxford, Advisory Committee on Employment of the Handicapped,
Department of Human Resources
Lila Paslay, Association for Retarded Citizens of Kansas
Yo Bestgen, Kansas Association of Rehabilitation Facilities
Ben Coates, Director of Policy, SRS
Bill Wolff, Kansas Legislative Research Department
R. Douglas Sebelius, Norton County Attorney

Others attending: See attached list.

HB 2250 - An act relating to contracts for construction and repairs and purchases of materials and services by state agencies; concerning specifications; amending K.S.A. 1988 Supp. 75-3739 and repealing the existing section.

Representative Wisdom explained that HB 2250 relates to the acquisition of materials and services by state agencies. The bill provides that, except when the Director of Purchases makes a specific finding or determination that a prospective acquisition is a sole source, all specifications written for the acquisition of materials and services must be designed to insure that at least two potential bidders qualify. Representative Solbach suggested language should be added to allow the finding of a sole source to be made after the bids are let. He feels this would protect the state from possible lawsuits.

Ron Hein, Legislative Counsel for Unisys, appeared in support of the intent in HB 2250 and provided written testimony (Attachment 1). Mr. Hein stated the negotiated bid statute is being utilized by the Division of Purchasing without regard to the competitive bidding statutes. He believes the use of the competitive bid statutes in acquisition of computers would save the state money. He proposed an amendment to HB 2250 on Page 3, line 100 before the word "such" to insert "the functional requirements of."

Secretary Horace Edwards, Department of Transportation, appeared in opposition to HB 2250 stating the provision that the director of purchases make a determination of a sole source would appear to require purchasing to duplicate research already carried out by the agency over a period of years. Secretary Edwards stated KDOT has continued to purchase high intensity reflectorized sheeting for use in work zones due to the high incidence of injury and death nationally in work areas on roads and highways.

CONTINUATION SHEET

MINUTES OF THE House COMMITTEE ON Appropriations,

room 514-S, Statehouse, at 1:30 ~~am~~/p.m. on February 27, 1989

Jim Jones, Director of Operations, KDOT, expressed concern that HB 2250 may have the effect of requiring the Department to purchase a lower quality product than is desirable in the effort to write specifications to accomodate more than one bidder.

Nick Roach, Division of Purchases, Department of Administration, stated purchasing has no problem with HB 2250 as written, but suggested the addition in line 98 of the word "comparable." He noted transactions falling under this bill will take a little longer, though approximately 96% would not be affected by this bill. Mr. Roach concurs with Mr. Hein's amendment inserting the wording "the functional requirements of."

HB 2333 - An act establishing the self-sufficiency trust fund; authorizing the expenditures of moneys from such fund for certain purposes; providing for administration of such fund by the secretary of social and rehabilitation services.

Representative Darrel Webb explained that HB 2333 allows families, guardians or friends to establish a trust fund for a disabled individual without risking loss of other benefits such as supplemental security income or Medicaid eligibility. The self-sufficiency trust is designed to allow parents to supplement "active treatment" components of care either in Day Treatment or in residences. Representative Webb provided handouts explaining the self-sufficiency trust model in detail (Attachment 2). He noted the fiscal note for start-up of this program is \$92,000 for FY91.

Representative Arthur Douville testified in support of HB 2333 and pointed out that this is permissive legislation that would enhance what the state is trying to accomplish for its handicapped citizens.

Mike Oxford, Advisory Committee on Employment of the Handicapped, Department of Human Resources, testified in support of HB 2333 (Attachment 3). He stated HB 2333 removes disincentives, maintains current services without interruption, and allows for the provision of other needed services such as supported living arrangements, transportation, and private rehabilitation.

Lila Paslay, Association for Retarded Citizens of Kansas, expressed concern that setting up the self-sufficiency trust fund would be costly and she would not want to see it funded at the expense of current programs or other needed services for persons with mental retardation (Attachment 4).

Yo Bestgen, Kansas Association of Rehabilitation Facilities, appeared on HB 2333 and stated this proposal appears to have merit, but recommends that families and advocacy groups that could benefit from such a trust have input as to how this would effect their planning for family members (Attachment 5).

Ben Coates, Director of Policy, SRS, appeared on HB 2333 and provided written testimony (Attachment 6). He stated SRS has several basic concerns about the self-sufficiency trust program such as the lack of the charitable trust provision, staff intensive administration of the program by the state, and the possibility of this program competing with local efforts to develop endowments.

HB 2421 - Claims against the state

Bill Wolff, Kansas Legislative Research Department, reviewed the claims against the state in HB 2421 section by section for the Committee. A technical amendment will be made to correct the address of Bill Taylor in Section 4 (b).

CONTINUATION SHEET

MINUTES OF THE House COMMITTEE ON Appropriations

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Dr. Wolff explained that Section 7 authorizes payment for damages resulting from cars hitting chuckholes on I-35. Representative Moomaw made a motion to delete Section 7. Representative Shriver seconded. Motion carried.

During discussion of Section 13 (a) regarding utility bills for Osawatomie State Hospital, Dr. Wolff noted these services were provided in FY88. Since that fiscal year is closed, they are handled through the claims process rather than through the appropriations process. Representative Wisdom made a motion to delete Section 13 (a). Representative Gatlin seconded. Following further discussion, Representative Wisdom withdrew his motion with the permission of the second, Representative Gatlin. Chairman Buntin indicated he would look into this situation further.

R. Douglas Sebelius, Norton County Attorney, testified that the claim by the Norton County Sheriff's Department in Section 18 of HB 2421 arose as a result of the transition between the mental retardation hospital and correctional facility in Norton around October, 1987. During the transition and the start-up of the correctional facility, a number of inmates were housed and prosecuted by Norton County at significant expense to the county. In response to a question from Representative Hamm, Mr. Sebelius stated this is a one-time request for reimbursement to the county. Representative Shriver made a motion to delete Section 18 awarding \$12,175 to the Norton County Sheriff's Department from HB 2421. Representative Teagarden seconded. Motion failed.

By consensus of the Committee, Section 19 (c) will be amended to state payment for damages will be from the state park and resources authority general fees fund. Representative Teagarden moved to delete Section 20 directing payment of \$2,638.16 by the Board of Agriculture for an erroneous test for germination of soybeans. Representative Gatlin seconded. Staff advised that the Board of Agriculture discovered the error and notified other individuals but failed to notify this claimant. Representative Teagarden withdrew his motion with the consent of the second, Representative Gatlin.

Dr. Wolff submitted two additional claims for amendment into HB 2421: (1) Savin Corporation for untimely submitted invoices--\$666.77; and (2) Dr. Nora T. Quiason for physicians liability insurance--\$4,606.93. Representative Lowther moved that HB 2421 be amended by adding the claims for Savin Corporation, Stanford, Connecticut and Dr. Nora T. Quiason, Gladstone, Missouri and that the technical amendments necessary to the bill be approved. Representative Gatlin seconded. Motion carried. Representative Helgerson moved that HB 2421, as amended, be recommended favorably for passage. Representative Wisdom seconded. Motion carried.

Representative Helgerson moved that the minutes of February 15 and 16, 1989, be approved as presented. Representative Kline seconded. Motion carried.

The meeting was adjourned at 3:45 p.m.

GUEST LIST

COMMITTEE: HOUSE APPROPRIATIONS

DATE: 2-27-89

NAME (PLEASE PRINT)	ADDRESS	COMPANY/ORGANIZATION
Darrel Webb		State Rep
Arthur Dourille		State Rep
Lila Farley		ARC Kansas
Go Bestgen		RARF
Richard Snyder		Norton County
W. Hugh Shelton		Wata County
Nico Roach	Div. of Purchases	
Ruth Scott		KCC
Mike Orford	Topoka	KALERT
Mike Lechner	L.	"
Kathy Freeman	Topoka	MOP
David Goodell		SRS
Lewis Allen	Topoka	Ks Health Care Assn.
James Jones	Topoka	Ks Dept. of Trans.
WARREN W. SICK	Topoka	Ks. Dept of Trans
Mark Clark	TOPEKA	Ks. Dept of Income
Ron Bowles	Topoka	House Bill 2333
LINDA MCGILL	"	3M
JOHN C. BOTTENBERG	TOPEKA	3M
Kent Needham	Great Bend	Farmers Bank & Trust
LORA L. CRUMBINE	LENORA Ks.	
C. R. HAZARD	Topoka Ks	Future Heritage of Topoka
R. COMBS	TOPEKA	SRS
Chris Starfield	TOPEKA	SRS
Carolyn Muddendorf	Topoka	KSN A

TESTIMONY TO HOUSE APPROPRIATIONS COMMITTEE
ON BEHALF OF UNISYS CORPORATION
PRESENTED BY RONALD R. HEIN
RE: HB 2250
FEBRUARY 27, 1989

Mr. Chairman, members of the committee:

My name is Ron Hein and I am legislative counsel for Unisys. Unisys is the world's second largest computer company when measured by installed base. Unisys resulted from the merger of Sperry Corporation and Burroughs, which occurred in 1987.

Many of you may remember the major battle that the Sperry Corporation fought with the Director of the Division of Information Systems and Communications (DISC) in 1985. At that time, the Department Director was attempting to implement a single vendor philosophy in the area of computer acquisitions. That is, the Department wanted only computers manufactured by IBM, or the two minor computer companies that manufacture IBM clones, National Advanced Systems, and Amdahl.

The policy being espoused by DISC would have prohibited Sperry, Burroughs, DEC, NCR, Wang, Control Data, AT&T, Data General, Prime, and numerous other computer companies from bidding on state purchases of mainframe computer hardware. The Sperry Corporation refused to keep quiet in the face of this anti-competitive, discriminatory, and taxpayer-wasting proposal. After an intense legislative battle, and after the Diebold company hired, at a cost of \$125,000, concluded that the state of Kansas would be wasting millions of dollars to attempt to convert its personnel payroll system and central accounting system off of the Sperry equipment to an IBM computer, the policy was defeated, ultimately by vote of the finance council.

Diebold in fact recommended that the Sperry system be upgraded. However, since that time, there has been a consistent pattern of exclusionary bid specifications which are technically issued by the Division of Purchasing, but which, as a practical matter, are drafted by DISC. For instance, Prime Computer, which is a leading computer company in the area of computer assisted mass appraisal (CAMA) was prohibited from even bidding on the statewide reappraisal (CAMA) bid. Unisys, which processes more than 50% of the public assistance payments in the United States than any other computer company in the nation, was prohibited from bidding on the SRS FAMIS (Family Assisted Management Information Services) bid.

Although the legislature spoke on this subject in 1985, turning down the proposed single vendor philosophy, and instead mandating a competitive, non-discriminatory computer purchasing policy for the state of Kansas, over the years the bureaucrats have been able to do just the opposite. They are able to do so because the legislature does not take the time to look at the details of individual computer acquisitions.

HA
2-27-89
Attachment 1

I think the legislature would find it interesting that in 1980, Sperry system was bought in order to bring up KIPPS (Kansas Integrated Personnel Payroll System) and CASK (Central Accounting System of Kansas). In 1981, an IBM system was purchased to bring up KBITS (Kansas Business Integrated Tax System). By 1984, KIPPS and CASK were fully implemented and operational. After seven years, the KBITS project was finally terminated after millions of taxpayers' dollars were wasted. (I would call your attention to the legislative post audit study report on the KBITS disaster). During the entire seven years, the program was never implemented or operational. This is an unfortunate example of the extraordinary costs associated with a data processing purchases policy that places an exclusionary preference on product brand instead of product functionality.

Since then, several new mainframe computer systems have been purchased, all of them IBM, and many of them pursuant to bid specifications that prohibited other vendors from bidding.

Unisys supports the intent of HB 2250. However, in order to insure that the state of Kansas is getting the most competitive price possible, we would urge you to adopt the following amendment: On page 3, line 100, before the word such, insert the words: "the functional requirements of".

With this amendment, we truly believe that, at least in the area of computer acquisitions, the state of Kansas would be able to get better products at a lower price and save the taxpayers significant dollars while having a more efficient computer operation.

One last point needs to be stressed. The legislature has, somewhat unknowingly, authorized a process whereby competitive bidding can be disregarded completely, and the bids can be negotiated. I was in the legislature when the negotiated bid statute was enacted, and the intent behind it at that time was, in those instances where competitive bidding was not a reliable technique, there should be a process for "negotiating" the bid with responsible vendors. However, the Division of Purchasing has, in recent days, been utilizing the negotiated bidding statute as a means of totally disregarding the competitive bidding statutes, since the negotiated bidding statutes exempts such bid from all provisions of the competitive bidding statutes.

For instance, just recently, bids were to be taken on a statewide mini-computer contract. It was announced in advance that the competitive bidding statutes would not apply, and that the bid would be negotiated. Absolutely no criteria has been set down by the Division of Purchasing to indicate why the negotiated bidding was being utilized, what criteria would be utilized in arriving at the successful bidder, or what procedures would be followed by the Division of Purchasing. It is important to note that these mini-computer specifications were written by DISC.

In fact, it has been indicated that, although extensive specifications were drafted, that any and all specifications will, in the sole discretion of the state, be waived or waiveable. There is no protection against the arbitrary application of this process in which the personal preference of the negotiators outweighs the functional and financial merits of the non-IBM oriented bidders.

We would recommend to the legislature that you more closely examine what the bureaucrats in state government are doing with regard to computer acquisitions. The KCC recently spent two years drafting specifications in order to obtain a computer system that would meet their needs. After two years of labor intensive effort, at significant dollars, bids were opened to acquire the computer system. Three vendors bid, with the lowest bid being presented by DEC. Unisys had the second lowest bid, and IBM the highest bid. Subsequently, the negotiated bidding statute was "activated" by the Division of Purchasing, all bids were thrown out, and a final contract was negotiated directly with IBM. In the process, the specifications that were two years in the making were thrown out the window, including the most essential requirement of the original bid, that being that the hardware be capable of running a particular software system deemed by the KCC to be necessary for performing its job.

The net result today is that a computer has been purchased, the system is not operational, additional work needs to be done, and the state ended up spending more money than it would have had there been a level playing field in the bidding procedure.

After nearly five years of representing Unisys (or previously Sperry), I am well aware that when it comes to computers, members of the legislature feel ill at ease due to the complexity of computers. If the Division of Purchasing were to recommend that the state buy only Pontiacs and not permit Buick or Chevrolet or Ford or any other vendor or manufacturer to bid with regard to purchase of automobiles for the state motor pool, members of the legislature would come out of the woodwork in protest. However, when the Division of Purchasing and the Division of Information Systems and Communications does the same thing in the area of computers, there is a reluctance to cry foul, probably because, as individual legislators, you are afraid that you don't know enough about computer jargon or computer details. But that is exactly what is going on today, and the net effect is to cost the taxpayers of this state dollars.

We commend Rep. Wisdom for having the foresight to be aware of what is going on in this area, and to attempt to bring it to this committee's attention. We would be happy to provide additional information if the committee desires it at a later time.

Thank you very much for permitting me to testify this afternoon. I would be happy to yield to any questions.

NATIONAL FOUNDATION FOR THE HANDICAPPED

February 3, 1989

Mr. Ben Barrett
Legislative Research Department
State House, Room 545N
Topeka, Kansas 66612

Re: Self-Sufficiency Trust ©

Dear Mr. Barrett:

Pursuant to our telephone discussion of February 3rd, I am express mailing the enclosed materials regarding the Self-Sufficiency Trust.

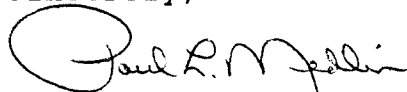
We are pleased to learn of the legislative interest and the impending introduction of SST legislation in your state. The National Foundation for the Handicapped is most willing to provide testimony before designated legislative committees upon request.

As we discussed, I do recommend that departmental and family/client advocacy organizations be exposed to the SST model in the pre-legislative process, in order to avoid internal discord due to the lack of understanding of the benefits of the program. We are available to provide an in-service at no fee, but do request reimbursement for out-of-pocket travel expenses.

I look forward to hearing from you regarding the status of SST legislation in Kansas. Copies of any draft legislation pending introduction would be greatly appreciated.

Thank you.

Sincerely,



Paul L. Medlin, As Agent
Senior Vice President
Corporate Development

Enclosures
PLM/lg

cc: James H. DeOre

HA
2-27-89
Attachment 2

The New York Times

NEW YORK, MONDAY, APRIL 4, 1988

Illinois Project Gives Families a New Way To Aid Disabled Kin

By KATHLEEN TELTSCH
Special to The New York Times

CHICAGO — Danny and Fay Moore have lived with anxiety since the births of their daughter and their son, both mentally retarded as a result of the genetic disorder Down's syndrome. The Moores shape their family life around providing special schooling and counseling for Stacey, 7 years old, and Aaron, 4, who are growing into adventurous, fun-loving children.

"Our concern is what happens to the children when we die," said Mr. Moore, a 36-year-old food service manager. "We're not wealthy people."

Some of the Moores' worries — and those of other families here in Illinois — have now eased with the beginning of an innovative trust fund to provide long-term care for the mentally or physically disabled.

The aim is to offer families a way to make a sound investment for their children's future, without affecting eligibility for government disability aid, impoverishing the family or adding a huge new burden on the state treasury.

It is an idea already being explored by other states to help millions of Americans who are mentally ill, physically incapacitated or developmentally disabled. Maine expects to enroll families in a program based on the Illinois model later this year.

The Illinois program, the Self Sufficiency Trust, is not intended as a substitute for Social Security disability or Medicaid benefits — what social workers sometimes refer to as the "sheets and eats" government services. Rather, it seeks to insure the extra care that would enhance the quality of life such as special therapy, transportation or recreation.

Avoiding a Catch-22

The concept of the Self Sufficiency Trust was developed by the National Foundation for the Handicapped, based in the Chicago suburb of Elmhurst. According to James H. DeOre, the group's executive director, the aim was to eliminate a Catch-22 situation that hampered relatives from bettering the lives of disabled family members. Many wanted to provide income or make bequests, but doing so risked a cutoff or reduction of government aid restricted to those with limited resources.

At least four million disabled Americans now receive Federal benefits, but the Federal Department of Health and Human Services has estimated that the country has 35 million disabled residents.

Illinois's Self Sufficiency Trust actually consists of three trust funds. Participating families will pool assets into a federally insured Private Trust Fund for investment. The interest earned on these investments will be transferred to a State Trust Fund, and spent on services for the disabled family members, beginning soon after enrollment

in the program. A Charitable Trust Fund is being set up for families not financially able to invest.

Developing a Care Plan

In joining the program, relatives or guardians and the trust's guidance counselors develop a life-care plan for the disabled family member. The program uses a computer data base in assessing the disabled participant's abilities and needs and in projecting the cost of current and future services.

The family then decides, in consultation with the program officials, what services are wanted for the disabled family member. The amount of the investment and whether it is immediate or delayed, lump sum or periodic, are determined in these negotiations. There is no minimum investment required, but families who want more services would have to invest more.

The services provided to the disabled family member are not regarded as "income" and thus do not affect eligibility for other government help.

Eight families are expected to be enrolled in the Private Trust Fund by mid-April and 50 families by the year's end, when assets in the Private Trust Fund are expected to reach \$10 million.

Charity Fund for Others

The Charitable Trust Fund will provide equivalent services for low-income or indigent disabled individuals who do not have financial support from relatives to enroll them in the Private Trust Fund. This fund is being built on contributions from foundations, corporations and private donors. In addition, when participants in the Private Trust Fund die, at least half the principal from the family contribution is turned over to the charity fund. The rest of the principal reverts to the family.

The legislation was sponsored in Illinois by Lee Daniels, a state legislator who has a handicapped 23-year-old daughter. The program was inaugurated at ceremonies March 29 when Dr. Dennis O'Connell, superintendent of a Chicago school district, contributed \$16,090 to the trust for his 25-year-old son, John.

Young Mr. O'Connell has Tourette's syndrome, a neurological disease afflicting 100,000 Americans and characterized by involuntary muscular spasms, verbal outbursts and intense restlessness. He works for a food distributor and receives Social Security disability aid. He now lives with his parents at home, but because of the trust program, in July he and 14 other handicapped residents will move into a new supervised housing complex.

The prospect of living on his own with friends is "exciting," he said.

The Moores also plan to create the maximum possible independence for their children when they grow up. They want them to live in some semi-supervised environment but to know "they still have family," Mr. Moore said.

Plans for More Group Homes

For now, the opportunities for placement in group residences are limited, and there is a waiting list. However, Mr. DeOre said the foundation was seeking grants and loans to develop at least four additional group homes.

Developing the trust so that a disabled participant's entitlement to government benefits will not be jeopardized involved satisfying a dozen agencies and working through a tangle of 3,000 pages of rules and regulations, said Ann Kiley, director of the Illinois Department of Mental Health and Developmental Disabilities.

The department helped pay for the foundation's development of the trust concept. A number of state agencies, including the Attorney General's office with its legal expertise, are supervising the operations.

An incidental benefit of the program is that the computer data base being used will give Illinois officials a more accurate picture of the state's disabled population and its needs, thereby allowing improved government assistance.

Illinois has been praised for pioneering the trust concept, but critics say the state lags behind many others in providing group residences for the mentally ill and mentally retarded.

'More Than the Bare Minimum'

Larry Russell, executive director of the National Alliance for Research on Schizophrenia and Depression, said five state agencies had been sued for failure to provide adequate care. The suit, brought by the Association for Retarded Citizens of Illinois, charges that 3,000 retarded adults are inappropriately "warehoused" and receiving inadequate care in nursing homes meant for elderly people.

Mr. Russell intends to enroll his 40-year-old son, Jon, in the trust program. He said the son now lived in a group home in Austin, Tex., because there was no such place for him in Illinois.

Harold Unger, a Chicago chemical engineer who is the trust program's secretary, said he and his wife, Dorothy, were preparing to enroll their 24-year-old daughter, Carol Ann, who has Down's syndrome. She works in a sheltered workshop operated by Ray Graham Association for the Handicapped and in her spare time enjoys playing the piano.

"We want a quality of life for her that will supply more than the bare minimum," said Mr. Unger. "That is what the Self Sufficiency Trust is all about."

News Summary

National

A trust fund to help the disabled in Illinois allows families to make investments to provide extra care for mentally and physically handicapped relatives without affecting eligibility for Federal aid. A1

2-2

Partnership offers help to disabled

A quiet revolution has begun in Illinois—an unusual private-public partnership that could help thousands of families provide long-term care for the mentally or physically disabled. It deserves continued support from the state and from the private sector.

The Self Sufficiency Trust program, inaugurated on March 29, offers families a way to invest for their children's future without affecting eligibility for government assistance, bankrupting the family or adding a huge new burden to the state treasury.

And it's not a program just for the wealthy. Too good to be true? An innovative program in Illinois? No, and yes.

Developed by the National Foundation for the Handicapped, based in Elmhurst, the new trust program could eliminate the barriers that restrict relatives of disabled people from giving them extra help.

In the past, many parents who wanted to provide additional income or make bequests to their disabled children could not. Doing so risked a cutoff or reduction of government aid. So only those people who did not need any government aid could afford to provide special services.

The new program creates three trust funds: a Private Trust Fund that pools assets from participating families; a State Trust Fund, which spends the investments from the Private Fund for services for the disabled family members; and a Charitable Trust Fund that is being built on contributions from corporations and private donors, to help those unable to participate in the Private Fund.

What does the program do? That depends on each disabled person's abilities and needs. It could assist in financing the cost of special schooling and counseling or any extra care, such as special therapy, transportation and recreation—all services that can build independence.

Credit for the cooperative venture goes to the National Foundation for the Handicapped that developed the concept. Legislation sponsored by Rep. Lee A. Daniels (Elmhurst), the House Republican leader, was necessary to start up the trusts. And state agencies, particularly the Department of Mental Health and Developmental Disabilities and the attorney general's office, sorted through the rules and regulations to satisfy the dozen or so state and federal agencies involved.

If this kind of cooperation is possible, why can't it happen again to provide better residential care for the state's mentally ill and developmentally disabled?

Instead of settling for the bare minimum for disabled people, this new program allows families to supply more help. We hope this model program encourages other states to develop similar trust programs. It also should encourage Illinois lawmakers to develop other badly needed solutions to the state's own troubled programs.

Chicago Tribune

25¢ City and suburbs

Wednesday, March 30, 1988

Fund lets parents plan lifetime care for disabled child

By Constanza Montana

A Lombard family Tuesday became the first participants in a state-administered trust fund that allows parents to provide long-term care for their developmentally disabled children.

"The trust has enabled us to do long-range planning for John," said Dennis O'Connell, 50, superintendent of the Roselle Elementary School District and father of a developmentally disabled son. "I hope this allows other parents to provide for the special needs of their children" now as well as after the parents die, he said at a press

conference at the State of Illinois Building, 100 W. Randolph St.

Illinois became the first state to establish such a fund, called the self-sufficiency trust, nearly two years ago. Before the law was passed, government assistance was restricted to handicapped individuals with limited assets and income who were not beneficiaries of an estate. The fund, financed by contributions from families and private organizations, allows families to supplement government services without reducing state and federal aid for their disabled relatives.

The trust establishes two separate

pools of money, a private trust and a charitable fund. The private trust holds contributions from relatives of handicapped persons and guarantees lifetime care for the handicapped person.

The charitable trust is designed to help low-income disabled individuals.

It is supported by contributions from private donors and assets transferred from the private trust when the beneficiary dies.

For example, when John O'Connell dies, 50 percent of the principal invested by his family in the private trust will be transferred to the charitable fund. The other 50

percent will go to his heirs.

The Elmhurst-based National Foundation for the Handicapped, which developed the concept for the plan, has donated about \$20,000 to the fund, said Director James DeOre. "We duplicated John's program ... for a low-income person" or what it would cost to maintain for a lifetime a mildly handicapped individual in a residential setting beyond what government grants would provide.

"Hopefully what we see today is a beginning, the beginning of what parents, the families of disabled citizens and private sector assist-

ance and government can do one another to assist and our state," said Ann Kiley, director of the Illinois Department of Mental Health and Developmental Disabilities.

For John O'Connell, 25, the immediate gain is that he can stay in his parents' home and move to a supervised apartment complex for other disabled individuals. For parents, "the long-term benefit is to do with the financial security program provides for John when we're gone," Dennis O'Connell said. "Without this program would become the responsibility of the state."

Parents of handicapped children must do financial planning

This is the second of two columns by Grace W. Weinstein on financial planning for the handicapped.

Aaron Leaf, now 12 years old, was born both severely deformed and profoundly deaf. His parents, in learning to cope with the medical and emotional needs presented by his birth, learned to develop financial resources as well. His mother, Rianne Leaf, learned so well that she is now a financial planner with IDS Financial Services in Minneapolis, helping others facing similar problems.

Trusts established by parents are often suggested as a way to ensure a financially secure future for children who are disabled or chronically ill. The new Illinois Self-Sufficiency Trust described in my last column removes the uncertainty of private trusts and serves as a model for other states developing

similar programs.

But parents must also consider the present. If you are the parent or grandparent of a disabled child, these hints may help:

• A rule of thumb in financial planning is the need for cash reserves sufficient to cover three months' expenses. With a handicapped child, cash reserves should be much larger. The Leafs, for example, had to travel some distance for Aaron's treatment, incurring hotel and food costs as well as medical bills. They had to hire a registered nurse as a baby sitter, on the rare occasions when they both left the house.

• Both life and disability income insurance are critical. "There's usually only one breadwinner, because the other parent is caring for the child," Leaf points out. "If that parent dies or is unable to work, you must have some source



By Grace Weinstein

of income for the family." With life insurance, too, "you must look very carefully at how beneficiary designations are made; they must coincide with what you've done in your will." Leaving money outright to a handicapped child can make the child ineligible for needed Social Security and Medicaid benefits. It's often preferable to designate a trust to disburse insurance proceeds.

Because it will probably be impossible to buy life insurance on the disabled dependent, Leaf

recommends invoking the automatic child's rider on the parent's whole life insurance policies. It may be "gruesome to think about," she says, but a \$10,000 rider could provide enough cash for burial expenses.

• Health insurance, which most people have through their jobs, is clearly a necessity. If the insurance-carrying breadwinner in a family with a disabled dependent is even thinking about a job change, Leaf points out, it's vital "to be up-front about the child and find out ahead of time if the health plan will provide coverage." Don't make assumptions.

Where a previously healthy dependent suffers a disabling accident or illness as adulthood nears, remember that group health insurance often ends for children at age 19 or age 22. Check your coverage, before the designated

age cutoff, to see if the individual can be kept on the policy as a "dependent."

• Take advantage of the Internal Revenue Code, where you can deduct, for example, medical expenses longer deductible except to the extent that they exceed 7.5 percent of adjusted gross income. That's a pretty high figure for most families. Grouping medical procedures within a calendar year, however, perhaps by scheduling necessary surgery for January or December, can make it possible to claim some deductions. If you make structural changes to your house to accommodate a disabled person, such as by installing a wheelchair ramp, the cost is deductible. (Other improvements, such as a swimming pool,

■ PARENTS, Pa

Parents of handicapped children must do financial planning

■ PARENTS
Continued from Page C1

described for therapy, are deductible only to the extent that they don't improve the market value of the property.)

• A will is essential. Including a carefully thought-out designation of a guardian for the handicapped child. That child may have special needs, Leaf points out, and a guardian you've named for other children may be unwilling or unable to take the responsibility for a child with birth defects.

Tip for today: For more information about the Illinois Self-Sufficiency Trust, write to 340 W. Butterfield Rd., Elmhurst, Ill. 60126, or call (312) 941-3498.

"The Lifetime Book of Money Management," Grace W. Weinstein's comprehensive and useful financial resource for all ages and incomes, is available through her column. Send \$12.95 plus \$1.50 for postage and handling to "The Lifetime Book of Money Management," in care of this newspaper, P.O. Box 419150, Kansas City, Mo. 64141. Make checks payable to Andrews and McMeel.

2-4

ALAN E. NOURSE, M.D.

FAMILY DOCTOR



A woman writes that when she had a mammogram, the compression applied to her breasts was so painful she was left in tears—and black and blue. I've heard similar reports from other women, and I think there is no excuse for this. While a moderate amount of pressure to the breast is necessary to obtain a good low-radiation mammogram, the X ray should not be more than mildly uncomfortable. If you suffer real pain, report it at once to the facility's administrator—and also to the doctor who referred you.

ACCUTANE UPDATE & ALERT

In January 1986 I reported an FDA warning that women who were pregnant or became pregnant while taking the potent antiacne drug Accutane ran an extremely high risk of having a baby with major birth defects. Now that a number of birth deformities attributable to the drug have been reported, the FDA fears that the warning isn't being heeded. As we went to press, the agency was weighing new, tighter regulation of the drug.

Whether or not new regulations are enacted, doctors and patients can ensure safe use of Accutane. First, make sure the drug is really needed—Accutane is not for uncomplicated adolescent acne, but for cases of severe, disfiguring cystic acne that don't respond to other, safer treatments. Second, a woman who might possibly become pregnant should also use an

effective contraceptive, such as the Pill, for a month before starting Accutane (and should continue throughout treatment). The woman should have a pregnancy test immediately before starting the medication, and when she finishes treatment, she should ask her doctor how long to wait before trying to conceive, to be sure her body is free of the drug.

QUESTIONS FROM READERS

PAP ACCURACY

I'm 26 and very faithful about Pap smears, but lately I've been hearing that the reports themselves may not be accurate. How can I be sure that my results are correct?

One way is to tell your doctor you're worried. Ask him or her what lab reads your tests, what assurance you have that reports are accurate, and what measures are taken to assure that samples are adequate—or, example, does the lab tell the doctor when a given sample can't be properly read, so that it can be taken again? Sooner or later, uniform nationwide quality controls must be established for this important test, but meanwhile, direct pressure on doctors from their rightfully concerned patients—and on labs from physicians—can help improve standards immensely.

ADULTS AND STREP

Are strep throats as serious for adults as for children? Will the instant strep tests in doctors' offices be available for use at home?

Strep throats are always potentially dangerous. Adults may not end up with rheumatic fever as often as children do, but they can surely develop scarlet fever, throat abscesses, or septicemia (blood poisoning). As for the new "instant" strep tests, they may be on the market soon. But, while these tests are a fine office aid for doctors looking for the right antibiotic with which to treat a severe sore throat, what would you do with such a test at home? Ignore any

continued on page 32

FAMILY DOCTOR

continued

sore throat that wasn't positive for strep? You could be ignoring an equally dangerous staph infection or even diphtheria. I feel these tests are only as good as the doctor's advice you get with them—and attempting self-diagnosis of severe sore throats is just not a very smart idea.

PROJECT FOR THE DISABLED

The Illinois legislature has launched an innovative pilot project to help families provide long-term quality care for disabled family members without reducing eligibility for government aid.

Basically, Illinois families with physically or mentally disabled children can invest modest sums of money in a specially sheltered Self-Sufficiency Trust Fund. Income from the trust can then be spent for long-term care, sheltered homes, special therapy, and other services to provide higher quality of life for the disabled—more than the bare minimum, as one project leader described it. (A special Charitable Trust funded by foundations, corporations, and private donors will provide equivalent services for disabled individuals whose families are unable to contribute.) And unlike income from a private-savings plan, trust-fund help will not reduce a patient's entitlement to other government aid—a major benefit.

Just off the ground, this pioneering self-help program is already being studied by other states, including Maine, which are considering similar legislation. And Connecticut has enacted a similar plan for families with mentally retarded children.

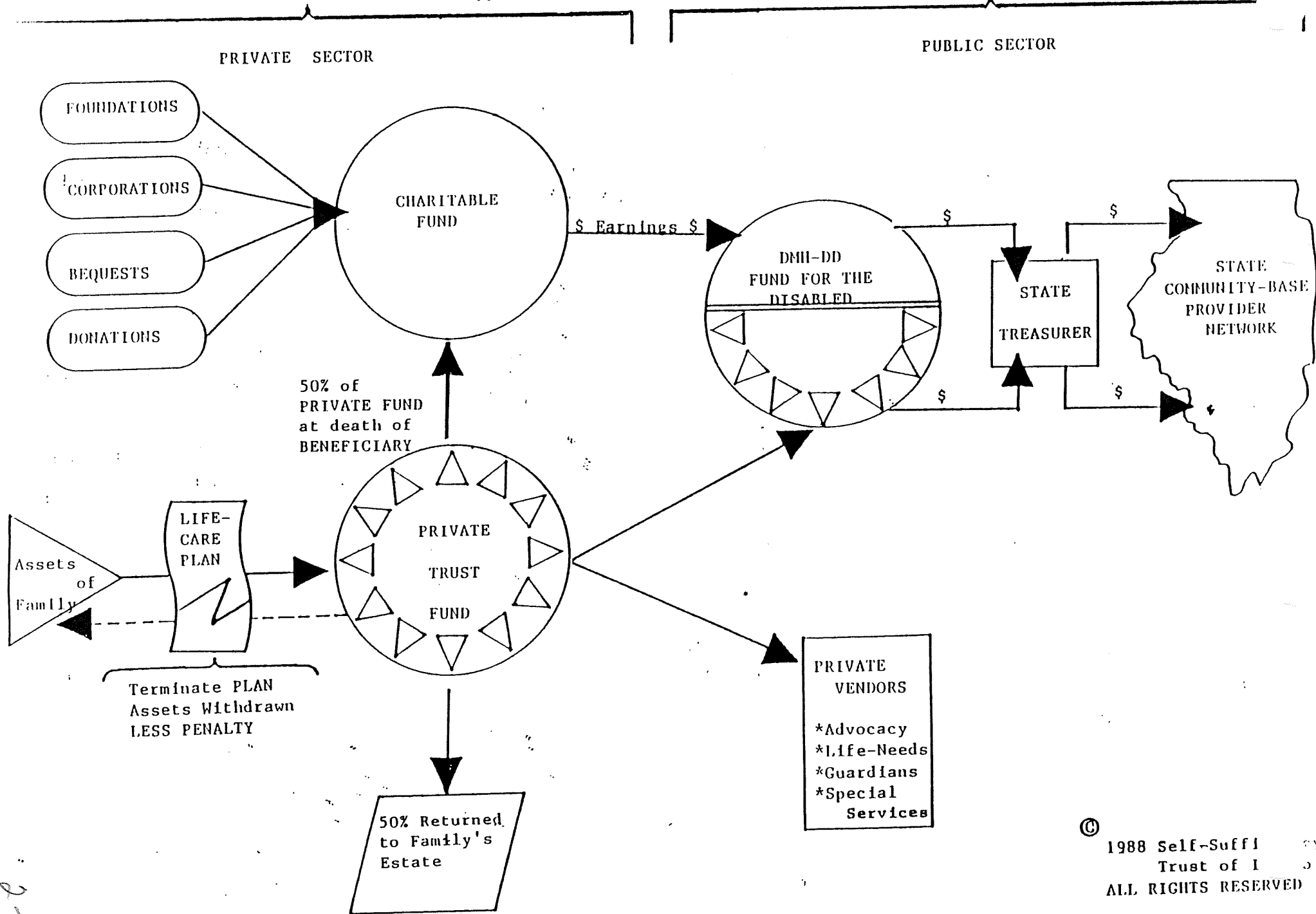
BABY'S SEX

Could you please tell me who determines the sex of a baby, the mother or the father?

The father—every time. A woman has two nearly identical "sex chromosomes" in each of her cells—an X and another X. This means that when she ovulates, every egg cell, which contains half her chromosomes, has an X chromosome. The man, on the other hand, has two different sex chromosomes in each cell—an X and a Y. His sperm cells, which carry half his chromosomes, contain either an X chromosome or a Y. If an X-bearing sperm fertilizes the X-bearing egg, the result will always be an XX baby—or a girl. If a Y-bearing sperm fertilizes the X-bearing egg, the result will be an XY baby—or a boy.

You may address questions on medical treatment or problems to Alan E. Nourse, M.D., GOOD HOUSEKEEPING, 959 Eighth Avenue, New York, N.Y. 10019. Only questions chosen for use in his column will be answered.

SELF-SUFFICIENCY TRUST
Supplemental Service Funding Process



9-8

SELF-SUFFICIENCY TRUST

PRIVATE SECTOR

PUBLIC SECTOR

- * Governed by a Volunteer Board of Trustees
 - Selected for individual commitment to and understanding of the needs of PEOPLE with DISABILITIES and THEIR FAMILIES.
 - Appointed by the National Foundation for the Handicapped.
- ** The Board of Trustees:
 - Set policy for the operating of the Private and Charitable Trust Funds.
 - Select and contract with Corporate Fiduciary Agent (Bank) to invest and manage all trust assets.
 - Select and contract with a Social Service Agent to complete all necessary intake processes, including the development of each Life-Care Plan.
 - Approve each Life-Care Plan and vote on participation of each family Trust/ Life-Care Plan.
 - Use discretionary trustee powers in cooperation with the Special Trustee to modify or approve expenditures within the guidelines of each Life-Care Plan.
- *** The Board of Trustees must comply with the TRUST and TRUSTEES ACT of Illinois (Ill. Rev. Stat. Ch. 17, Par. 1651-1690).

- * 1986 passed into law of Public Act 94-1373 creating a mechanism to receive private trust assets to expand, enhance and supplement services for disabled eligible for services under the Illinois Department of Mental Health and Developmental Disabilities.
 - Established Chapter 91 1/2 Sections 5-118 and 5-119 of the "Mental Health and Developmental Disabilities Code".
 - Empowers the State Treasurer as ex-officio and custodian of the public sector fund.
 - Provides for the Comptroller to direct payments from each account within the "fund" upon receipt of certified vouchers approved by the Director of DMH-DD.
 - Requires DMH-DD to adopt rules and regulations for the administration of the public sector "fund".
 - Monies shall be spent pursuant to existing department rules governing expenditures for services and based upon the individual trust agreements (Life-Care Plan) for each eligible Beneficiary.
 - If Director determines monies cannot be expended pursuant to department rules or service availability, funds and accrued interest will be returned to the beneficiary's Private Trust Fund.
- ** The receipt of monies from the Self-Sufficiency Trust (Private Fund) will not in any way reduce, impair or diminish the benefits each beneficiary would otherwise be entitled to under law.
- *** Establishes a "Fund" for the Disabled to accept monies from any source which, subject to appropriations, will be used for services to low-income disabled eligible for DMH-DD services.

2-7

NATIONAL FOUNDATION FOR THE HANDICAPPED

Self-Sufficiency Trust

An Abstract

The Self-Sufficiency Trust ("SST") is a supplementation concept.

All providers supplement state payments for services using dollars from United Ways, philanthropy, parent tuition etc. The SST operates in a similar way.

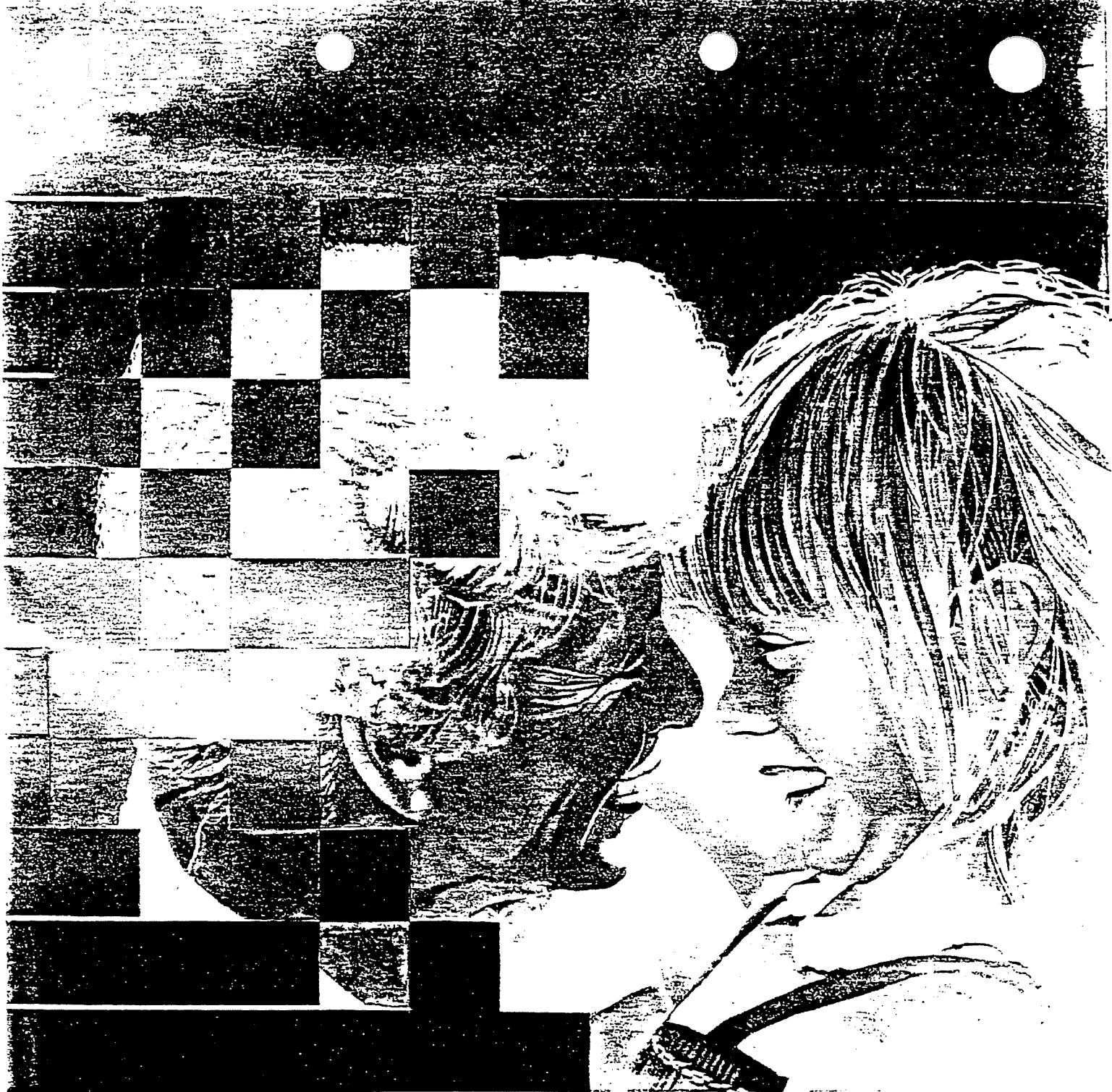
The SST was designed to permit supplementation by parents who were trapped in the current two-tiered system of treatment created by state funding short-falls.

Currently, the two-tiered system is made up of those people fortunate enough to be in services, and those who cannot obtain them. In addition, even for those in services, not all of their needs are addressed.

Those waiting to be served are deprived of the rights of employment, housing, and access to care if they attempt to supplement these services. Some advocacy groups have threatened to seek class action redress against this current two-tiered system.

The SST was designed to allow parents to supplement "active treatment" components of care either in Day Treatment, or in residences. In addition to the supplementation of their own child, others not in the Trust benefit, as do future non-trust persons as well, through the 50% residual at the death of the handicapped person which is transferred to the Charitable Fund.

The application of financial technology (i.e., trusts) to the needs of the chronically disabled permits a more effective long term matching of dollars against need. The use of IRA's as a hedge against the potential reduction of Social Security is one example of this type of mechanism.



by *Paul Medlin*

When parents and families with children who are disabled ponder the future, they face concerns that parents of non-disabled children do not. They must provide a life-care legacy that will not render their disabled dependent vulnerable after the parent's death. Innovative research and development in nontraditional estate and future care planning has begun to replace the usual "catch 22" situations faced by these families with effective measures to

assure the protective legacy their dependents need. The Self-Sufficiency Trust model removes the complications that have traditionally stymied effective estate planning efforts by parents; it includes the personalized life-care monitoring and guardianship services that significantly reduce future vulnerability.

Conceived in Illinois, the Self-Sufficiency Trust evolved from the research of the National Foundation for the Handicapped under the direction of Mr. James

The Self-Sufficiency Trust

Innovation in Life-Care Planning for the Disabled

H. DeOre, with funding in part from the Illinois Department of Mental Health. In September 1986, the Self-Sufficiency Trust was enacted into law (P.A. 84-1373) by unanimous vote of the Illinois Legislature.

The Trust model was seen as an "estate planning" option that would avoid conflict with existing rules that penalize families for providing direct services to their disabled dependents eligible for federal assistance under the Supplemental Security Income and Medicaid programs. Further, the Trust would encourage the flow of money from private sources, focusing on expanded supplemental services to the disabled. This new private-public initiative encourages parents, state government, and service providers to work together to plan now for a secure future for the disabled.

The Self-Sufficiency Trust model includes private and public trust components. It is governed by a volunteer Board of Trustees that works first with the family co-trustees to control the Private Fund to which families may contribute the assets (money, securities, property) designated by private trusts for life-care services of named disabled beneficiaries. Secondly, the Board of Trustees controls the Charitable Trust which accepts residual and donated assets for use in providing service to low-income and indigent persons with disabilities who are unable to participate in a private trust.

Further, the Board of Trustees controls the disbursement of funds as defined in each "life-care plan" of the named dis-

abled beneficiaries, and ensures that necessary supplemental services are provided each beneficiary. Finally, the Board of Trustees works with the Illinois Department of Mental Health and Developmental Disabilities to ensure that the repository of donations from the Charitable Fund are used to expand existing governmental supported services to benefit people with disabilities where the greatest need exists.

What Are SST Life-Care Plans?

Each "private trust" within the Self-Sufficiency Trust is operationally based upon the individual "Life-Care Plans" developed by the parents or family and the knowledgeable trust staff. The Life-Care Plan becomes the document that governs the administration and disbursement of each "private" trust fund and identifies those supplemental services that the family or parent desires for their disabled dependent. Identifying future needs and costs is difficult. Therefore, a computerized data-base that assesses present need, projects changing future service needs, and correlates present and future costs of those services helps each family to plan realistically, based on their capacity to fund supplemental service needs through estate planning. Principal assets are individually calculated that will provide a flow of interest income sufficient to fund present and/or future supplemental service needs.

Initiation of private trusts will vary for families, depending on the assets required to fund their plan. Some families may establish a trust within the Self-Sufficiency Trust while they are living by depositing assets in a private trust at one time or over several years. Others may make provisions to deposit their disabled heir's share of the parent's estate into a Self-Sufficiency Trust via a trust clause in their will. Some may choose a combination, but regardless of the funding ap-

proach taken, families will have carefully constructed a "life-care plan," defined the supplemental services desired, and initiated estate planning for the benefit of their disabled dependent.

What Role Does Parent/Grantor Play in SST?

Upon the establishment of a Self-Sufficiency Trust account, the donor or grantor of the private trust may serve as co-trustee or may designate someone else. The co-trustee retains the right to disapprove or delay implementation of the disabled beneficiary's "life-care plan." Until disbursement for services is made from each representative beneficiary's Self-Sufficiency Private Trust Fund account, the grantor (parent or other) may withdraw from participation and recover his or her original contribution minus a penalty based on the number of years of participation in the SST Private Fund. The SST Private Trusts are considered irrevocable, meaning that the original intent of the grantor of the trust cannot be changed.

Additionally, the Self-Sufficiency Trust model provides that at least 50% of the principal remaining in the Private Trust at the death of the disabled beneficiary be left to the Charitable (Remainder) Trust, with the balance returned to the heirs of the Trust grantor. These residual assets, combined with private donations, allow the Board of Trustees to service the indigent.

How Are Funds Disbursed?

Once the individual SST Private Trust is established and funded, the disbursements that benefit each disabled beneficiary may be completed in one of two ways. First, monies (interest) may be "donated" by design in the Life-Care Plan to a counterpart SST State Fund operated by the

Paul Medlin is involved in setting up the Self-Sufficiency Trust nationwide. For additional information about SST call (312) 941-3498, or write The National Foundation for the Handicapped, 340 W. Butterfield Rd., Elmhurst, IL 60126.

Department of Mental Health and controlled by the State Treasurer. This "donation" process transfers the assets required to purchase the needed supplemental services to an individual account maintained for each beneficiary entitled to benefits from that government department. Vouchers are then processed via the state treasurer to pay for the desired supplemental service. While many find this step in the process unsettling, it has the distinct advantages of preserving public entitlements and avoiding invasion of the trust. Disbursements by the Department of Mental Health via the state treasurer are made to regular service providers.

Monies deposited for this purpose may not revert back to a private trust or charitable trust account, unless it is determined by that department that the funds cannot be used to purchase the services for which they were designated in the agreement. At that point, funds may be returned.

The second disbursement process involves direct payments to private vendors, human service providers, advocates, or successor guardians who are monitoring the welfare and condition of the beneficiary. This service provision sets the Self-Sufficiency Trust apart from generic trusts devoid of life-care monitoring. Families may build into the life-care plan a personalized, non-profit organization or group to look out for the best interests of each disabled beneficiary and to act as either an "advisor" to the Board of Trustees, ensuring that Trust assets are meeting valid needs, or purchasing quality services. They may also seek a successor guardian to assume legal consent authority at some point in the future. The peace of mind that is desired by all families with dependents who are disabled is offered, not as an option, but as a major component of the Self-Sufficiency Trust model.

So far we have discussed the Self-Sufficiency Trust from the standpoint of its mechanics as a "pooled-income" trust. What does it contribute to the overall improvement of services for our nation's disabled? What makes it desirable to families with dependents who are disabled? How is it unique in its approach to estate planning?

Historically, government and the private sector have joined together to carry out the mandate of services to people with disabilities. Using its resources, each state has developed a system of services to fulfill

its mandated responsibilities. The Self-Sufficiency Trust concept evolved from the realistic acknowledgement that a state's capacity to provide these needed services is diminished by increased demand, the changing economic climate, and national policies. The SST embodies the search for alternative service capabilities and the generation of resources necessary to provide them in the future.

The Self-Sufficiency Trust research found that most states face the following problems:

- Fluctuations in tax revenues have an impact upon services provided to people with disabilities. It is unreasonable to expect state tax revenues to support the increasing needs of the population.
- Unmet housing needs unfairly affect a segment of the disabled population.
- Increased life spans intensify chronic housing shortages.
- Reduced Federal program support further increases the stress on state treasuries.
- Deinstitutionalization places heavier demand on the private provider networks to supply services and housing to the disabled.
- Fluctuations in governmental grants place severe strain on the capacity to continue these services and to survive funding shortfalls.

All these factors add to the uncertainty of future services for the disabled and hinder effective estate planning by families that might supplement their disabled dependent's future care needs. Estate planning for the disabled had to be more than a trust that could withstand invasion. Rather, it had to address the real situations that could negatively effect future services and their funding. The Self-Sufficiency Trust combined private (family) concern with public (state) financing needs into a legislatively-based mechanism that seeks to resolve problems confronting the service delivery system as a whole.

The Self-Sufficiency Trust has been enacted into law in Illinois and Maine. To date, an additional ten states have expressed interest. The potential benefit of a nationwide Trust network is, of course, economy of scale, resulting in trust management savings, larger principal investment and return, and most importantly, increased private sector (parent and family) voice in services and financing of those services for the disabled. However, several advantages accrue to each state in which it is enacted:

- New sources of private funding to expand services for disabled people.
- A computerized data collection system to identify type, scope, and time projection of need-specified services (i.e., residential) with which to plan future services for disabled people.
- Potentially reduced dependence upon federal support, which carries with it red tape and the expense of obtaining those federal funds.
- Private-public partnership which actively involves each in working toward improved/expanded services for disabled people.

For families, several major advantages are incorporated into the SST model. Several years and close to a million dollars of research have carefully evolved into a trust which encompasses the "state of the art" in estate planning for the disabled. Disincentives have been eliminated, specifically in the areas of safeguarding public entitlement benefits.

Medicaid Eligibility

The Health Care Financing Authority (HCFA) of the Department of Health and Human Services have ruled that neither principal nor interest held in a SST Private Trust will be counted in determining Medicaid eligibility. Many families fear the loss of the medical benefits or related state support of residential care if they contribute assets to their disabled adult children, or that assets they wish to set aside for future needs will have to be spent down before their children will become eligible again. Under this ruling, parents may establish a Self-Sufficiency Trust without affecting their disabled son or daughter's eligibility.

Similarly, the Council General's Office of the Social Security Administration for Region V (Illinois and upper Mid-West) has determined that SST principal and interest will not be counted as resources in determining eligibility under the Supplemental Security Income (SSI) program.

For most persons with disabilities who depend upon public entitlement support, these rulings will ensure that parental estate planning efforts become supplemental to, and not replacement of, public benefits. Additionally families participating in a Self-Sufficiency Trust will not face the requirement of spending down or exhausting private assets in order to regain eligibility for public benefits. ways

Orientation

STATE OF ILLINOIS
PUBLIC ACT 84-1373



Question & Answer 5/20/88

2012

THE SELF-SUFFICIENCY TRUST ©

What is the Self-Sufficiency Trust?

As a private sector initiative, the National Foundation for the Handicapped and James H. DeOre developed the Self-Sufficiency Trust concept. This concept permits individuals with disabilities and their families potential access to, and the potential capability for developing services and programs to supplement current state and federal benefits.

This plan was also conceived to assist states, hard-pressed due to limited resources, with a potential means for developing a new income stream for expansion of badly needed services.

What disabled groups are covered by the Self-Sufficiency Trust?

The Self-Sufficiency Trust serves the developmentally disabled, the chronically mentally ill and the physically handicapped.

Why was the Self-Sufficiency Trust copyrighted?

The National Foundation realized there was a possibility for individuals and groups to use the concept without fully appreciating the requirements involved. To avoid any problems associated with this type of activity, and due to the significance and seriousness of the public trust invested in this concept, the National Foundation has chosen to copyright the materials which describe the development, the installation, the servicing, as well as the operations of the Trust. The National Foundation for the Handicapped charges each state \$1,000 per year, once it has an established and operating Self-Sufficiency Trust. This fee is used by the National Foundation for the Handicapped for charitable purposes.

What is the role of the National Foundation in developing the Self-Sufficiency Trust?

The National Foundation for the Handicapped provides each state with the technical assistance for developing its Self-Sufficiency Trust. In addition, the National Foundation for the Handicapped can provide to each Trust grants and/or low-interest loans for cash flow purposes. For example, in the State of Illinois, the National Foundation for the Handicapped made a grant to establish staff for the Self-Sufficiency Trust.

What steps are involved in establishing the Self-Sufficiency Trust?

The actual mechanisms for establishing a Self-Sufficiency Trust may vary from state to state according to state law. Through the legislative process of enacting a state law in each state, the basis for the Self-Sufficiency Trust is established.

Under the model legislation, a private charitable 501(c)(3) organization establishes the Self-Sufficiency Trust, and appoints a board of directors. This board is comprised of members of the private and public sector. The Trust document provides the structure and guidelines for its operations.

The National Foundation for the Handicapped, through an agreement with the charitable 501(c)(3) organization, provides for the initial organization of the Trust. Subsequently, the National Foundation for the Handicapped enters into a contractual relationship to provide technical assistance, training and service to the Trust in each state.

What are the regulatory requirements in each state for the Self-Sufficiency Trust?

The regulatory requirements will vary from state to state. Each state must go through a review of its law and trust structure by the Social Security Administration, by the Health Care Financing Administration (HCFA) and any other regulatory bodies within the state that will be affected by implementation of the Self-Sufficiency Trust.

How long does it take to develop a Self-Sufficiency Trust in a state?

There are three stages of the Self-Sufficiency Trust Project: development, installation and maintenance.

In the development stage, the organizational structure is created by state law, the trust documents are executed and the Trust Board of Trustees are appointed.

The second stage, the installation stage, includes education of parents, providers and professionals, training staff, setting up of operations and appropriate interviewing of families.

The third stage includes operation, maintenance and service of the Trust.

What are some of the services of the Trust?

The Trust can provide the opportunity for families to plan for the future care and funding of services for the disabled population.

For the state, the Trust can function as a state-wide case management organization, endeavoring to locate services for families at no charge for this service. Secondly, the Trust develops for each state information on persons who are not currently in services, particularly in the area of special education. Through its database Disabled Population Profile System, the Trust links clinical service needs of each individual with a disability with potential state reimbursement services in the future. Dollar amounts identified for these services can then be used by the state legislature and administration as a precise planning tool, so that estimates for future costs can be made for budgeting purposes.

Third is the actual negotiation for service provision by the Trust. These may be in the areas of respite care, housing, day treatment services, guardianship and advocacy care.

What about provisions for low-income families?

The Trust has specifically designed a program to meet the needs of low-income families. First, low-income families are encouraged to financially participate in the Trust, specifically through life insurance policies, where the Trust may help to match a family's participation.

Secondly, for those low-income families where financial participation is not possible, individuals are identified to the state by the Trust as needing services.

Third, funds generated by families who are in the Trust, must also provide services for low-income families with individuals with disabilities.

Fourth, a percentage of a family's contribution to the Trust will be retained upon termination of their contract and transferred to the Charitable Fund to make grants for low-income families. At the death of the individual with a disability, 50% of the principal is distributed to the Charitable Fund to make grants for low-income families. The remaining 50% flows back to the heirs of the donor.

And fifth, by bringing new resources into the system, the state has the opportunity of expanding services for low-income families.

What are the fees to families?

There are no direct fees to families active in the Trust. In Illinois the Trust currently anticipates a 1.4% cost for operations, which will be retained by the Trust for its earnings. This compares to an average Trust cost of 1.5% to 2.0% throughout Illinois.

Can the Trust help with the current growing housing shortage for the disabled?

The Trust database will facilitate in the identification of needed housing and potential residents allowing the state, providers, and parents to develop new housing with small group homes, condominiums, and integrated apartment environments. Also, the Trust database will identify parents who could join together to purchase a home for their disabled relatives who have similar needs.

In both these instances, a local provider would participate as necessary and appropriate in providing needed care and securing required licenses.

Parents of young children with disabilities may want to use this second concept of capital purchasing for investment purposes to achieve future care and service objectives for their son or daughter.

Can the Trust financially participate in the operating costs of the house?

Trust dollars may only be used to provide rehabilitation, training for employment, special assistance in the workplace, necessary help with personal care and other special help in coping with handicaps.

What are some additional advantages of the Self-Sufficiency Trust?

One advantage of the Self-Sufficiency Trust is that it functions on behalf of the family. This benefit of broadened advocacy on behalf of the family is of particular advantage to the individual with a disability once the parent or guardian has passed away.

Families who have relatives at various provider organizations may consider leaving their money to those organizations to continue care or services after the parent or guardian has passed away.

Unfortunately, many providers have limited service capability, and because of health needs or for other reasons, the individual with a disability may not actually live out his or her life within the purview of a certain provider. The trust in encouraging parent planning may facilitate the provision of quality care even if the individual with a disability leaves a provider.

One of the primary programs needed by adult, mentally or physically disabled individuals is the training for continued education, employment or special work places so the individual can enjoy a more full and productive life.

Programs such as sheltered workshops, job and career training programs and supportive employment programs are utilized by individuals with disabilities to access employment and productivity. The Self-Sufficiency Trust provides the family with the opportunity to plan for and financially participate in these services and through the Trust provider mechanism, to ensure their availability and accessibility.

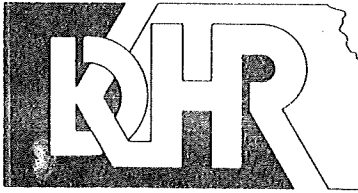
One of the most critical aspects of service includes the need for emergency in-home care. Often the serious illness of a spouse and/or sudden trauma in a family situation creates a substantial burden on the other parent. He or she is not only confronted with the problem relating to the spouse, but must also cope with the individual with a disability living at home. Through the Trust, families can make provisions and plan for such emergency respite care to preclude the burden of accessing this care at an unexpected time, and to realize the peace of mind that such care makes available.

For additional information call (312) 941-3498.

SELF-SUFFICIENCY TRUST

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The National Foundation for the Handicapped
1850 K Street N.W., Suite 500,
Washington, D.C. 20006, (202) 778-8117
340 W. Butterfield Road
Elmhurst, IL 60126 (312) 832-9700

Transcript Manual #3
Revised 5-20-88

**ADVISORY COMMITTEE ON EMPLOYMENT
OF THE HANDICAPPED**

1430 S.W. Topeka Boulevard, Topeka, Kansas 66612-1877
913-296-1722 (Voice) • 913-296-5044 (TDD) • 561-1722 (KANS-A-N)

Mike Hayden, Governor

Dennis R. Taylor, Secretary

February 27, 1989

TESTIMONY IN SUPPORT OF HOUSE BILL 2333
Presented by Mike Oxford, Legislative Liaison

Thank you for the opportunity to appear before you.

Our committee supports House Bill 2333. It would allow families, guardians or friends to establish a trust fund for a disabled individual without risking loss of other benefits such as Supplemental Security Income (SSI) which carries automatic eligibility for Medicaid as well.

Currently, any money a person receives must be counted as income under existing SSI regulations. A person is allowed to earn up to \$65.00 per month without impacting on cash benefits, however. Furthermore, all other resources must be exhausted before eligibility kicks in. This causes the rapid depletion of what is, often times, a lifetime of savings. Any income a person receives below this cap is subtracted from the cash benefits which would have otherwise been received. This results in a substantial disincentive to people trying to provide for the future of friends and family members with disabilities.

House Bill 2333 removes disincentives, maintains current services without interruption and allows for the provision of other needed services such as supported living arrangements, transportation, private rehabilitation and so on. This means that the scope of services for individuals can be increased and at little or no cost to the state.

I ask that you report House Bill 2333 favorable for passage.
Thank you again for your time.

ws:a:h2333

HA
2-27-89
Attachment 3



Hope through understanding

ROBERT ATRISSON
President
Stockton

BRENT GLAZIER
Executive Director

February 27, 1989

MARIE LEACH
Vice President
Wichita

MARY DONDLINGER
Secretary
Hutchinson

ED REMPE
Treasurer
Hays

CAROL A. DUCKWORTH
Past President
Lawrence

TO: Rep. Bill Bunten, Chairman
Members of House Appropriations Committee

FROM: Lila Paslay, Chairperson
Legislative Affairs

The ARC/Kansas is supportive of legislation which can provide services and programs which will enhance the quality of life for persons with mental retardation and their families.

H.B. 2333 appears to offer such a program but we would like to express some of our concerns.

- (1) If this legislation is developed on the Illinois model of Self-Sufficiency Trust, their staff indicated a start-up cost of \$100,000 to \$150,000 to develop the program and provide or contract with an agency to enroll families. This includes working with families on an individual basis.
- (2) The Illinois plan limits the use of trust funds to earned interest on the principal except in cases of emergency. If the trust program is designed for families without large amounts of money, the actual dollars available for purchasing services will not be great. It can, however, provide for enhancements, i.e. summer camps, clothes, medical care not covered by entitlements.
- (3) In my experience with the TARCARE Beneficiary Trust program, I can tell you that it takes families a long time to make a decision about such matters. I have some families I have worked with for two years. The director in Illinois expressed the same experience. I would anticipate a slow enrollment which would mean a subsidy for the program for several years. Illinois has \$100,000 in the trust fund after almost two years.

It would be an option that could assist parents in their future planning which would be wonderful. I would, however, hate to see the program funded if it were to be at the expense of current programs or other needed services for persons with mental retardation.

HA
2-27-89
Attachment 4



Kansas Association of Rehabilitation Facilities

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TO: House Appropriations Committee
Representative Bill Buntan, Chairman

FROM: Kansas Association of Rehabilitation Facilities

RE: HB 2333; establishing a self-sufficiency trust fund

DATE: Feb. 27, 1989

The Kansas Association of Rehabilitation Facilities represents thirty-eight not for profit agencies serving over 5000 children and adults and their families in Kansas. We are concerned that families have every available opportunity to plan and obtain long term services for their children.

House Bill 2333 would establish a self-sufficiency trust fund which would allow families to purchase services through the participation in a trust administered by the secretary of social and rehabilitation services.

After visiting with several parents of children with disabilities it is my understanding that in Kansas there are opportunities to establish trust funds. Those trusts are established to purchase, through a Trustee, primarily items to enhance the quality of life for their children. It may include medical care not covered by medicaid such as dental services, leisure and recreational activities or personal care items, etc. That trust, after their child no longer requires the support, can be designated to a beneficiary of their choice.

The Kansas Association of Rehabilitation Facilities would recommend that this concept be further explored. The questions we would have are similar to those asked of me by the parents when I reviewed this proposal with them. Has this made a significant impact in Illinois on the availability of services? If my child is on a waiting list for services will someone participating in this trust have a priority for services? Can I still have the choice of developing a trust separate from a state administered fund? How does this differ from the development of trusts already available in Kansas?

I am the first to admit that I do not have a strong background in trust development. The concept of this bill certainly appears to have merit. I would recommend that the families and advocacy groups that could benefit from such a trust mechanism have input as to how this would effect the life planning for their children. Many of our facilities have provided training in trust development for families through the Kansas-ARC. I would ask that this Committee review the current trust opportunities to determine how this proposal would enhance already existing trust mechanisms.

Thank you for your time and consideration.

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TESTIMONY
KANSAS DEPARTMENT OF SOCIAL AND REHABILITATION SERVICES
WINSTON BARTON - SECRETARY
HB 2333

The Department has reviewed the proposed legislation and some supporting materials developed by the National Foundation for the Handicapped. In addition, we have discussed the program with staff in Illinois.

The program has some noteworthy benefits. It allows families to supplement their relative's care without impacting their SSI or Medicaid eligibility. It allows the passthrough of funds without creating a Medicaid spenddown.

The Illinois program also has a provision that allows some usage of a charitable fund which is made up of portion of leftover proceeds from other trust at the death of trust recipient. This allows some funds to be used to support indigent care.

House Bill 2333 does not call for this proposal and as such will not benefit indigent clients.

SRS, while supportive of virtually any procedures that will enhance programs, has some basic concerns about this particular program:

- (1) The lack of the charitable trust provision, clearly makes this a two tier system. In fact, when families can enhance their relative's care without incurring any Medicaid spenddown, it effectively reduces the funds available.

- (2) The Kansas funding mechanism for local programs is not based upon individual funding, therefore, the passthrough from the state to the individual would be complicated and probably staff intensive.

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- (3) These programs are long range in nature and should not be seen as viable short term solutions to issues such as the mental retardation community waiting lists.
- (4) The agency has worked for several years to generate interest in the development of local ^{endowments} ~~endorsements~~ and would not like to see this program compete with these local efforts.

Ben Coates

Director of Policy

296-3765