SB

50

SENATE COMMITTEE REPORT

FURTHER

DATE TURNED INTO OFFICE 2/28/90

3/30/89

Mr. President:

FINANCE Committee considered SB 50

persons who are handicapped or mentally ill; efd

and recommended

[ ] replace with ___ CS ___) [] same title
[ ] or adopt ___ CS ___) [] new title
[] technical title change (HB only)

[ ] attached amendment(s) and

[ ] ___ letter of intent adopted

[✓] do pass

[ ] do not pass

[ ] no recommendation

[ ] individual recommendations

[ ] further referral to ___

FISCAL NOTE(S) [✓] zero SFC [ ] fiscal impact [ ] appropriation no FN
[✓] new [ ] updated [ ] previous
[ ] same as previous fiscal note(s) published ___

MEMBERS SIGNING DO PASS	OTHER RECOMMENDATIONS
[signature]	
[signature]	
[signature]	
[signature]	
Paul [signature]	
Co-Chair [signature] (DO PASS)	

___
Chairman signature and recommendation

[ ] Committee Backup attached

STATE OF ALASKA
1990 LEGISLATIVE SESSION

BILL VERSION: SB 50
PUBLISH DATE: _____

FISCAL NOTE

REQUEST: _____

Revision Date: _____
Title: Trust for persons who are handicapped or mentally ill
Sponsor: Senator Duncan
Requestor: Senate Finance

Agency Affected: Health & Social Services
BRU: Institutions & Administration
Components: Mental Health Administration

EXPENDITURES/REVENUES: (Thousands of Dollars)

OPERATING	FY 91	FY 92	FY 93	FY 94	FY 95	FY 96
PERSONAL SERVICES						
TRAVEL						
CONTRACTUAL						
SUPPLIES						
EQUIPMENT						
LAND & STRUCTURES						
GRANTS, CLAIMS						
MISCELLANEOUS						
TOTAL OPERATING	0	0	0	0	0	0
CAPITAL	0	0	0	0	0	0
REVENUE	0	0	0	0	0	0

FUNDING: (Thousands of Dollars)

GENERAL FUND	0	0	0	0	0	0
FEDERAL FUNDS	0	0	0	0	0	0
OTHER	0	0	0	0	0	0
TOTAL	0	0	0	0	0	0

POSITIONS:

FULL-TIME	0	0	0	0	0	0
PART-TIME	0	0	0	0	0	0
TEMPORARY	0	0	0	0	0	0

ANALYSIS: (Attach a separate page if necessary)

Prepared by: Senator Rick Uehling, Co-chairman
Division: Senate Finance Committee
Phone: 465-4821
Date: 2/28/90

Approved by Commissioner: _____ Date: _____
Agency: _____

Distribution (by preparer):
Legislative Finance
Legislative Sponsor
Requestor
Office of Management and Budget
Impacted Agency(ies)

page ____ of ____

Introduced: 1/9/89
Referred: Health, Education and
Social Services and Finance

6-0035E

IN THE SENATE BY DUNCAN

SENATE BILL NO. 50

IN THE LEGISLATURE OF THE STATE OF ALASKA

SIXTEENTH LEGISLATURE - FIRST SESSION

A BILL

For an Act entitled: "An Act relating to persons who are handicapped or mentally ill; and providing for an effective date."

BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF ALASKA:

* Section 1. AS 47.80 is amended by adding new sections to read:

ARTICLE 3A. SPECIAL FUNDS.

Sec. 47.80.200. SELF-SUFFICIENCY TRUST FUND. (a) There is established in the state treasury the self-sufficiency trust fund. It consists of money deposited in the trust fund by the commissioner of health and social services under AS 47.80.210.

(b) The commissioner of revenue is the custodian of the trust fund in the same manner as provided for the public school trust fund in AS 37.14.160 - 37.14.170, except where the provisions of AS 47.80.-200 - 47.80.290 conflict.

Sec. 47.80.210. CONTRIBUTIONS TO THE FUND. (a) The department shall deposit into the trust fund money accepted by the department from a self-sufficiency trust under an agreement with the trust. The agreement must name a beneficiary who is a resident person with a handicap or mental illness and specify the care or treatment to be provided for the beneficiary. The agreement may name more than one qualified beneficiary.

(b) The commissioner of revenue shall keep separate accounts in the trust fund for each beneficiary named under (a) of this section and allocate interest earned on the fund pro rata to the respective accounts.

Sec. 47.80.220. USE OF THE TRUST FUND. (a) Money in the accounts established under AS 47.80.210 may only be used by the department under its regulations to provide care and treatment to the named beneficiaries in accordance with the terms of the agreements by which the money was accepted and to pay the costs incurred by the Department of Revenue and the Department of Health and Social Services in administering AS 47.80.200 - 47.80.290. The commissioner of revenue shall direct payments from the trust fund upon vouchers properly certified by the Department of Health and Social Services.

(b) If the department determines that the money in an account cannot be used consistent with the agreement by which it was accepted or the regulations of the department, or upon request of the self-sufficiency trust that deposited the money, the balance of the account, together with any accumulated interest on it, shall be promptly returned to the self-sufficiency trust.

Sec. 47.80.230. EFFECT ON OTHER ASSISTANCE. The receipt by a beneficiary of money from the trust fund, or of care or treatment provided with that money, does not in any way affect the benefits to which the beneficiary is otherwise entitled by law.

Sec. 47.80.240. CHARITABLE ACCOUNT. (a) There is established in the trust fund a handicap and mental illness charitable account. The account consists of money from any source that is deposited with the commissioner of revenue for the account.

(b) Subject to appropriation, the department may use money in the account to provide care and treatment of low-income persons with handicaps or mental illnesses.

Sec. 47.80.290. DEFINITIONS. In AS 47.80.200 - 47.80.290

(1) "mental illness" has the meaning given in AS 47.30.915;

(2) "person with a handicap" has the meaning given in

AS 47.80.900, except that it does not include "gifted children" as defined in AS 14.30.350;

(3) "self-sufficiency trust" means a trust established by a nonprofit organization that

(A) has as its purpose the provision of care or treatment of persons with handicaps or mental illnesses;

(B) is incorporated under AS 10.20; and

(C) meets the requirements of 26 U.S.C. 501(c)(3);

(4) "trust fund" means the fund established under AS 47.-80.200.

* Sec. 2. This Act takes effect July 1, 1989.

SB 50
File

Alaska State Legislature

SENATOR JIM DUNCAN

P.O. BOX V JUNEAU, ALASKA 99811-3100

(907) 465-4766

COMMITTEES:
FINANCE
VICE CHAIR –
HEALTH EDUCATION
& SOCIAL SERVICES
BUDGET & AUDIT
BANKING &
ECONOMIC
DEVELOPMENT

MEMORANDUM

DATE: February 15, 1990

TO: Senator Rick Uehling, Co-Chair
Senate Finance Committee

FROM: Senator Jim Duncan

SUBJECT: Senate Bill 50, an act relating to persons who are handicapped or mentally ill - establishing the Self Sufficiency Trust

I again request that you schedule SB 50, Trust Fund for the Disabled for a hearing by the Finance Committee as soon as possible.

Senate Bill 50 will establish what is known as a "Self Sufficiency Trust" (SST) to be paid for by the parents of disabled dependents, minors or adults. Currently, parents of such dependents are not able to establish trust funds to provide for the current or future care of their children without jeopardizing that dependent's eligibility for government means-tested entitlement funds.

The State of Illinois was the first state to establish a Self Sufficiency Trust program for its residents in 1986. The program was designed and is maintained by a private sector board of trustees appointed by the National Foundation for the Handicapped. Their maintenance efforts include insuring that the program design continues to retain client eligibility for federal benefits.

The Self Sufficiency Trust is a private sector initiative administered by a Board of Trustees in cooperation with a nonprofit corporation which establishes life care plans to address the lifetime needs of each person with disabilities. The nonprofit agency would, working in conjunction with the parents, design services to augment those provided to the child by social services agencies and determine the cost of providing those services.

A life-care plan delineates the priorities for supplemental services to be funded by the individual private Self-Sufficiency Trust. The Trust can be funded either by testamentary provisions or as a living trust while the parents are still alive, or a combination of both methods.

The primary focus of the program is outside state government, but the Department of Health and Social Services, Division of Mental Health and Developmental Disabilities would be responsible for issuing vouchers to pay the claims certified by the non-profit for payment. The funds for that payment would be transferred from the private trust to the state treasury. The intent is that the State provide the administrative structure for bill payment without adding to the staffing level of the Department.

In addition to the individual Private Trusts established by the parents of disabled children, a Charitable Trust is also established which consists of assets left to the Charitable Trust by grantors of private trusts at the death of the disabled beneficiaries in addition to contributions from private donors, and bequests from corporations or foundations. These funds would be used to augment supplemental services provided to low-income and indigent persons with disabilities who are unable to participate in the private trust. The earnings from the Charitable Fund are to be used subject to appropriations to enhance and expand services to the disabled over and above what state and federal sources provide.

The Self Sufficiency Trust creates an additional non-State source of money to provide for the needs of people with disabilities and enables parents to plan for their disabled dependents' futures with certainty that their wishes will be carried out.

I would request that a teleconference be established with Mr. Paul Medlin from the National Foundation for the Handicapped who will be available to testify on SB 50. Roxanne Stewart of my staff will be happy to assist you in contacting Mr. Medlin.

I urge you to schedule the Self Sufficiency Trust Bill and lend it your support.

Attachments

Intergovernmental Health Policy Project

STATE HEALTH REPORTS

MENTAL HEALTH, ALCOHOLISM, & DRUG ABUSE

In This Issue: o System Integration o Self-Sufficiency Trusts *No. 46 March 1989*

States Look At System Integration

Spurred by reports documenting fragmentation of services, a shortage of community residential programs, an over-reliance on inpatient care, and gaps in community support services, state lawmakers have come to recognize major changes are needed in the way mental health services are organized and delivered.

At least three states (**Washington, Pennsylvania, Kansas**) are considering proposals that would significantly alter the delivery of mental health services. A forth state (**Montana**) is planning to develop a proposal to reorganize their mental health system. The common thread in all of these initiatives is "decentralization" -- transferring authority, accountability and responsibility for providing a range of community and inpatient treatment and rehabilitation services from the state to local agencies. It reflects a shift from state control to greater participation by local governments and usually involves a redistribution of funds directly to communities for community and inpatient services. Among several states that have already moved in this direction are **Wisconsin, Ohio** and **Virginia**.

Washington. After a year of study and evaluation, the state of **Washington** is considering a proposal to revamp its mental health system (SHB 1876). A recent report to the legislature documents a shortage of residences for mentally ill individuals and describes the current administration and delivery of mental health services as fragmented and overly focused on providing expensive inpatient acute care. It also reports on current national trends and models of integrated, community-based mental health systems, which have assisted in stabilizing state hospital populations and provided incentives for the development of community residential options.

Consistent with these national trends, testimony from several public hearings indicated that counties, mental health providers, consumers, and advocates wanted to design and participate in an integrated, decentralized, community-based delivery system that provides the entire continuum of care.

Based on the testimony, the report recommends that the authority and responsibility for delivering mental health services be decentralized to the local communities, along with adequate funds to expand residential facilities and supports.

Early versions of the bill would have vested almost total authority at the local level for state hospital and community-based services. As it stands now, however, the bill has been modified somewhat, giving counties some but not all authority for public mental health services. As of this writing, it is proceeding through the legislative process with the possibility of more amendments.

HB 1876 attempts to pool the various mental health funds into block grants to counties and authorizes the formation of 10 or fewer regions of counties, called Regional Support Networks (RSNs). The bill calls for assumption of the block grant by regional networks according to

SPONSOR'S INFO. See page 3

HB 2016, drafted by the Special Committee, would transfer responsibility for both inpatient and outpatient mental health services to the counties. The committee emphasized in its report that it is responding to the federal mandate of PL 99-660, the State Comprehensive Mental Health Services Planning Act, which requires states to establish community-based systems of care, including case management services for chronically mentally ill individuals.

Under the proposal, effective February 1991, each county or group of counties would be mandated to establish a mental health authority responsible for providing an array of services to the chronically mentally ill. These services would be provided either directly or indirectly by the local authority. All court ordered commitments would be made to county mental health authorities rather than to state hospitals. The counties would make the determination as to where patients would be placed.

County authorities would act as "gate-keepers" by screening all admissions to state hospitals and assuring those denied admission would receive appropriate services in the community. In addition, the counties would assist in discharge planning by making sure patients receive necessary support services in the community.

HB 2016 would establish a pilot program in one state catchment area by February, 1990 to test the proposed system. The goal would be to reduce the size of one state hospital by one ward, or approximately 35 beds. Additional funds would be provided to the counties in the pilot area to finance the additional services required.

The bill also mandates that community support services be provided in all counties and specifies adult chronically mentally ill individuals as the priority population. As of this writing, no firm appropriation has been attached to the bill.

The measure has been assigned to the House Appropriations Committee, where a special subcommittee has been appointed to study it further. Because there has been negative reaction to the bill from various agencies and organizations in the state, the special subcommittee is now considering alternative proposals addressing different methods of financing and service provision.

Montana. Although there was talk among providers, advocates and some legislators to revise the organization and funding of the state mental health system this year, the issue is now being examined in the long-range planning process. Montana's new draft mental health plan for FY 1990-93 contains an objective stating that a proposal will be developed to restructure the mental health system through the mental health system planning process. The proposal which must be completed by October 1990, in time for consideration by the 1991 legislative session, will include increased incentives for serving people locally and mechanisms for local (CMHC) decision making on appropriate services for adults with severe mental illness.

Financing Issues: Self-Sufficiency Trusts

An innovative idea in estate planning, established first in the state of Illinois, removes the complications that have traditionally stymied effective estate planning efforts by parents with disabled children. The Self-Sufficiency Trust ("SST") is the first trust of its kind to provide a mechanism to facilitate the coordination and integration of private family financing for individuals with disabilities while maintaining their eligibility for government entitlement programs. As a truly private sector initiative, the SST makes possible the flow of private monies into the state's network of publicly-sponsored programs to supplement, enhance and expand services to all disabled residents.

Conceived in Illinois, the "SST" evolved from research by the National Foundation for the Handicapped under the direction of James H. DeOre. Funded in part by the Illinois Department of Mental Health, the "SST" was enacted into law (P.A. 84-1373) by a unanimous vote of the Illinois Legislature in September 1986. Maine is the only other state to enact such legislation but this year eight states (Alaska, Indiana, Kansas, Massachusetts, Michigan, Montana, New York, Oregon) have introduced model "SST" legislation, and twelve others have expressed interest and are in various stages of pre-legislative review. Legislation with similar goals, has also been introduced in Missouri,

though technicalities of the trust deviate from the Illinois model.

The SST is an irrevocable, "pooled-income trust" with spendthrift and discretionary trust language and clearly defined "charitable" and "private" trust provisions. Its structure and benefits are uniquely designed to facilitate active parental financing of supplemental care of the disabled without disruption of SSI and Medicaid.

Two wholly separate pooled-income trust funds make up the structure of the SST. The first, a Private Trust Fund, accepts, holds, and invests the "pooled" assets of each participating family. Although assets are commingled, all returns on investments are credited proportionately to the private trust. Interest earned on the private trust is transferred to the counterpart State Trust Fund, which immediately disburses the assets for supplemental goods or services that are to be provided. Because monies technically become State Trust Fund monies, they are not viewed as earned or unearned income to the disabled beneficiary, therefore do not affect entitlement eligibility.

Monies may also be disbursed to non-profit vendors such as advocacy groups or human service providers who will monitor the status and condition of the designated beneficiary. This service provision sets the SST apart from generic trusts devoid of life-care monitoring.

A second fund controlled by the Board of Trustees is the Charitable Fund. This fund is a repository to accept residual and donated assets earmarked for low-income and indigent persons with disabilities who are unable to participate in the Private Trust. Upon the death of the beneficiary, 50 percent of the residual principal of each private trust is donated to the Charitable Fund. The fund is also financed by donations.

A Volunteer Board of Trustees is appointed from the private sector to manage and control the Private and Charitable Trust Funds. Parents or family members serve as co-trustees and share in decisions concerning disbursements. A Life-Care Plan developed for each participant embodies the wishes of the parent and defines the intent and nature of supplemental services that will be provided to the beneficiary. Trained Self-Sufficiency Trust Advisors provide direction for parents to develop a realistic and need-specific plan. A Life-Care Planning Service Survey helps families target the services they want and reinforces areas that the SST is unable to finance.

SST fund monies may be spent for social services, recreational programs, rehabilitation services, educational services, rehabilitation and remedial services and training programs to assist in managing activities of daily living. The major restriction on the SST is that the dollars cannot be used to meet the same needs as those intended to be met through available public assistance programs.

The Self-Sufficiency Trust concept evolved from the realistic acknowledgement that a state's capacity to provide these 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 National Foundation for the Handicapped's goal is to see the SST available in all 50 states, allowing transferability and universal benefits for all disabled individuals. The potential benefit of a nationwide trust network is economy of scale, resulting in trust management savings, larger principal investment and return and, most importantly, a stronger private sector (parent and family) voice in services and financing of those services for the disabled.

For states, the advantages are: new sources of private funds to expand services; a computerized data collection system to identify type and scope of services; potentially reduced dependence on federal support; and a private-public partnership that actively involves each working toward improved and expanded services for disabled people. For the families, the trust fund gives them the peace-of-mind that their loved ones will be adequately cared for when they are not able to do so. [*This feature was prepared from excerpts of previous articles written by Paul L. Medlin, Senior Vice President for Corporate Development, National Foundation for the Handicapped, Elmhurst, Illinois (312) 832-9700.*]

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 in 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 life-care for mentally and physically handicapped relatives without affecting eligibility for Federal aid. A1

Chicago Sun-Times
Independent Newspaper

Robert C. Page, President & Publisher
Kenneth O. Towers, Executive Editor & Vice President
K. K. Gaur, Editor of the Editorial Pages
Raymond R. Coffey, Managing Editor
Mary L. Dedinsky, Online Manager

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 assistance and government can do wi one another to assist and bett our state," said Ann Kiley, direct of the Illinois Department of Me tal Health and Developmental Di abilities.

For John O'Connell, 25, the in mediate gain is that he can lea his parents' home and move into supervised apartment complex wi other disabled individuals. For h parents, "the long-term benefit h to do with the financial security t program provides for John aft we're gone," Dennis O'Conne said. "Without this program, h would become the responsibility 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 of income for the family."

By Grace Weinstein

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 parents' 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 individ can be kept on the policy as a d bled dependent.

- Take advantage of the Inter Revenue Code where you can. F example, medical expenses are longer deductible except to t extent that they exceed 7.5 perc of adjusted gross income. That pretty high figure for most fa lies. Grouping medical procedu within a calendar year, howev perhaps by scheduling necessa surgery for January a December, can make it possible claim some deductions. If you m make structural changes to yo house to accommodate a han capped person, such as by wide ing doorways for a wheelchair by adding a ramp, the cost is fu deductible. (Other improvemen such as a swimming pool pr

■ PARTIENTS, Page

Parents of handicapped must do financial planning

■ PARENTS
Continued from Page C1

scribed 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.

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—for 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

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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 this column will be answered.

FINANCIAL PLANNING WHEN YOUR CHILD IS DISABLED

THESE INSURANCE, TAX AND ESTATE PLANNING STRATEGIES WILL HELP ASSURE THE FUTURE FOR YOUR DISABLED CHILD.

Families with disabled children face special challenges when arranging their finances. Any financial plan must cover day-to-day living expenses for the family as well as the long-term needs of a child who may need to have individual care for a lifetime.

Thirteen-year-old Aaron Leaf of Minneapolis is such a child. He was born profoundly deaf and with numerous facial, spinal and internal problems that required extensive—and sometimes unexpected—medical and disability-related care. Aaron's needs for multiple operations strained the family income, so his parents took steps to set up a financial plan.

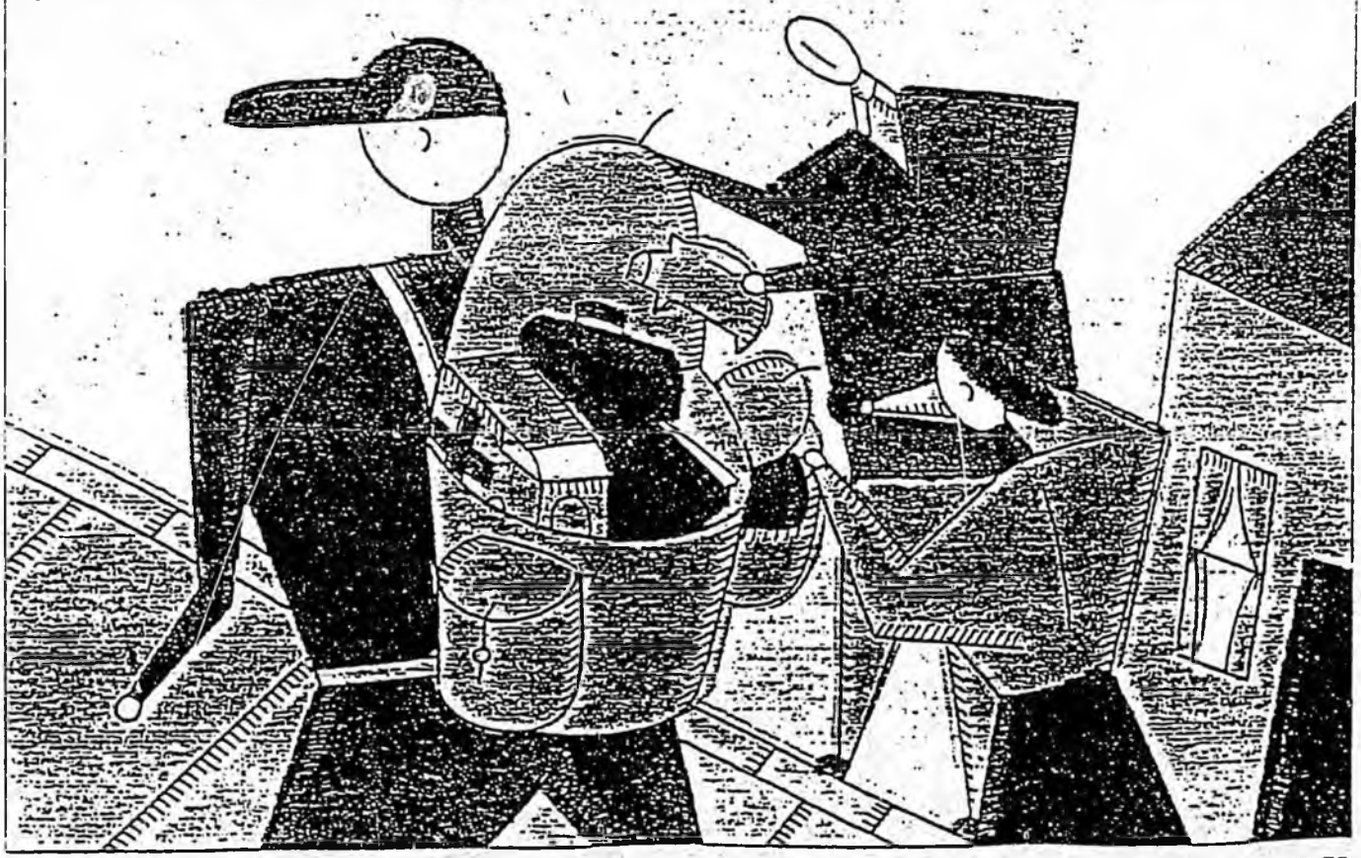
COVERING DAY-TO-DAY EXPENSES

Of course, no two family plans are exactly alike because each must take into account the severity of and prognosis for the child's disability as well as the family's financial resources. But a number of important issues are common to all families with disabled children.

REVIEW YOUR INSURANCE. Analyze what would happen to your income and cash flow under different scenarios. For example, if only one parent works outside the home, consider how you would manage if the breadwinner died or became disabled. When both parents work, what would happen if one income were cut off? Is your disability insurance or life insurance adequate to cover the loss?

Parents of a child with a handicap need more disability insurance than others. If you have a disability policy through your employer, it may only be tied to your base salary. Consider buying an additional policy to cover any overtime or bonuses.

Your life insurance needs will dif-



ILLUSTRATIONS BY PHILIPP WEISBECKER

fer, too, because you may need to keep up higher life insurance coverage longer than other parents. Term insurance is a cost-effective way to build an insurance estate while you are young and healthy. For example, $250,000 worth of term insurance for a 35-year-old man who does not smoke might cost around $230 for the first year and about $1,140 for the first five years' premiums. For a nonsmoking woman of the same age the premiums would be a bit less.

But term insurance premiums can get prohibitively expensive as you age. And unless your policy will be automatically renewed without checking your health, it may not be available when you need it most. A good rule of thumb, says Washington, D.C., insurance broker Andrew Gross, is to switch to a permanent type of insurance by age 50. Gross favors universal life insurance for each parent. Another possibility is a whole life policy with a last-to-die provision, which pays off when the surviving spouse dies. Insurance proceeds then go into a trust set up for the disabled child. With this type of insurance you may need an additional policy to cover the rest of the family if one parent dies.

Children who are born with disabilities are automatically covered under their parents' group health insurance policies. But coverage might not last indefinitely; typically it ends at age 19, or 22 for full-time students. Some group policies continue to cover permanently disabled children no matter how old they are, and some states require group carriers to extend such coverage beyond age 19. But you might lose coverage under some policies (and in some states) unless you notify the insurance company of the disability by that age.

A parent facing a job change should get assurances and a detailed explanation, in writing, of a child's coverage under the new employer's group health insurance policy. Often, if you join a new employer's medical plan within a certain number of days, all family members will be automatically covered. "Don't count on the disability being covered, though," says Rianne Leaf, Aaron's mother, whose search for information resulted in a career as a financial planner with IDS Financial Services in Minneapolis. "Some policies exclude preexisting conditions, which could mean your child would be covered for a broken leg but not his or her disability-related costs."

For those who cannot insure a child any other way, there are special-risk insurers. Whether it would be worth the considerably higher costs would depend on your child's disability. As a last resort, more than a third of the states have a statewide insurance pool through which you can buy health insurance for a disabled child. Call your state insurance commissioner to find out if such a pool is available.

DEDUCTIBLE MEDICAL EXPENSES CAN INCLUDE THE FULL COST OF SOME STRUCTURAL CHANGES TO YOUR HOME, SUCH AS A RAMP, AND PART OF THE COST OF OTHERS, SUCH AS AN ELEVATOR FOR A CHILD WHO CAN'T CLIMB THE STAIRS.

BUILD AN EMERGENCY FUND. A good health insurance policy is a must, but it won't cover all your health costs. One family with a severely mentally retarded and physically handicapped son had to absorb more than $4,000 of medical costs last year that their health insurance simply didn't cover.

You should create an emergency fund you can quickly convert to cash, recommend planning experts like CPA Bruce Shanker, a financial planner with the Wallace Financial Group in Bethesda, Md. Three months' expenses is adequate for most families, but those with a disabled child should strive for a six-month to a one-year nest egg.

Put the assets in safe, flexible or short-term investments, such as money-market and bond funds, certificates of deposit (divided among three-, six- and nine-month maturities) and Treasury bills with 30-, 60- and 90-day maturities. You could also consider a conservative stock fund from which you can withdraw your money without penalty.

DOUBLE-CHECK STATE RESOURCES. Review the social services available through state agencies to ensure that your child is receiving the financial and therapeutic help he or she is entitled to. Families faced with a move to a new state through a job transfer, for example, should find out well in advance whether a child can get similar special services at the new location. Check whether the state will pick up as much of the cost as your current state.

GETTING THE IRS TO HELP

You can deduct only those medical expenses that exceed 7.5% of your adjusted gross income, but many other related expenses qualify. For example:

- the cost of special schooling;
- health insurance premiums;
- most of your travel expenses to hospitals, including any lodging (up to $50 per day each for one parent and child), transportation and meals at medical facilities;
- and all mileage to and from doctors' offices and special-education facilities at 9 cents per mile (or the actual expenses of using your car), plus parking and tolls.

Schedule elective surgery, deductible equipment purchases and other tax-deductible expenditures in the same year whenever possible. Suggest to grandparents or others who want to help that they buy nondeductible items, such as a TV, so you can buy deductible items such as a TV caption decoder. And, of course, keep receipts and make meticulous records as you go along. The rules can change at any time. Leaf keeps receipts for everything that might be deductible and then sorts them out at tax time.

Your medical expenses can also include the full cost of certain structural changes to your home, such as widening doorways for wheelchairs, building ramps and installing bathroom grab bars. Others are generally deductible only to the extent that their costs exceed the increase in value of your home. For example, a $6,000 elevator for a child who cannot climb stairs might increase the value of the home by $3,500. You deduct $2,500. Get a written recommendation from the child's doctor and before-and-after ap-

A Helping Hand

A growing number of private organizations will watch out for the child when the parents can't. Some are guardianship programs that serve as surrogate families; others are trust programs. And some provide both services. Typically, the family works out a detailed future-care plan with the help of the organization. If it's primarily a guardianship-type program, the family will contract for such services as monitoring living arrangements, serving as an advocate for the child and working with attorneys, guardians and trustees. A trust program will provide for supplemental services that will not jeopardize eligibility for government benefits.

- ▶ *Foundation for the Handicapped* (1550 West Armory Way, Suite 205, Seattle, Wash. 98119). Washington: disabled orphans or abandoned people.
- ▶ *National Continuity Program* (The Anchorage, 253 Riverside Ave., Westport, Conn. 06880). Connecticut, New Hampshire and California: all disabilities.
- ▶ *PACT Inc.* (166 W. Washington St., Suite 300, Chicago, Ill. 60602). Cook County and surrounding counties: all disabilities.
- ▶ *Permanent Planning* (2530 University Ave., Waterloo, Iowa 50701). Black Hawk County and surrounding counties: mentally retarded.
- ▶ *Planned Lifetime Assistance Network (PLAN*—5001 W. Broad St., No. 28, Richmond, Va. 23230). Virginia: all disabilities. *Planned Lifetime Assistance Network of Maryland–D.C.* (912 Thayer Ave., Suite 108, Silver Spring, Md. 20910). Maryland and the District of Columbia: mentally ill.
- ▶ *The Self Sufficiency Trust, National Foundation for the Handicapped* (340 W. Butterfield Road, Suite 3C, Elmhurst, Ill. 60126). Illinois: all disabilities.
- ▶ *Star Systems Consultation and Training* (1011 70th Ave., Philadelphia, Pa. 19126). Pennsylvania, New Jersey and Delaware, plus national referrals: all disabilities and elderly disabled.
- ▶ *Virginia Beach Community Trust* (Pembroke Six, Suite 213, Virginia Beach, Va. 23462). Virginia Beach: for developmentally disabled.

An excellent source of information on all relevant issues is *Alternatives: A Family Guide to Legal and Financial Planning for the Disabled*, by L. Mark Russell (First Publications Inc., P.O. Box 5072—Dept. TC, Evanston, Ill. 60204; $18.95). Also available from First Publications is the Parent Planning Guide ($10), an extensive checklist that helps you assess how well prepared you are.

praisals to defend any IRS challenge.

The dependent-care credit, also used for child care, is applicable as well. This credit against your income tax offsets up to $2,400 in expenses for one dependent and $4,800 for two or more. It applies to the cost of caring for a child, spouse or other disabled dependent while you work.

PLANNING FOR THE FUTURE

Estate planning is a minefield for people with disabled children. Qualifying for state or federal programs, such as medicaid and supplemental security income, is a financial necessity for most. So a critical goal of estate planning is to protect eligibility.

You must also protect the financial resources you intend for your child. Many state programs expect the disabled person or whoever is responsible for that person to pay to the extent possible. If your child has assets of his or her own from gifts or inheritance, those become the source of the so-called cost-of-care funds, leaving little or nothing for extras. Possibly even worse, your child could also lose his or her government benefits completely. Re-establishing eligibility once disqualifying assets are gone can mean months with no benefits.

You may not have to disinherit your child to get around this problem, as many parents of disabled children fear. One of the most popular solutions is a trust that you set up during your life or in your will funded by some of your assets or by your life insurance proceeds. This "discretionary trust" names a trustee, who may be a relative, friend, lawyer, private guardianship program, a bank or trust company, or some combination. Most parents select at least one trustee who knows the

FAMILY DOCTOR

ALAN E. NOURSE, M.D.

Many of you have asked for details about the Illinois Self-Sufficiency Trust program mentioned in my August column. This project seeks to help families provide long-term care for disabled family members without reducing their eligibility for government aid. For more information write:
The Self-Sufficiency Trust of Illinois
340 West Butterfield Rd. Suite 3C
Elmhurst, Ill. 60126.
Or you may call:
(312) 941-3498 (for inquiries about the Illinois trust);
(312) 832-9700 (for inquiries about projects in other states).

HYSTERECTOMY UPDATE

For years there was concern that many unnecessary hysterectomies were being performed. Then things seemed to improve. It appeared that physicians were becoming more conservative in recommending this surgery. But that may be only partly true. According to recent studies, the hysterectomy rate has dropped in some areas of the country—particularly the Northeast—but has remained high in other areas. In the Northeast, for example, the rate is only 5 per 1,000 women (only 2.3 per 1,000 in New York City), compared to 8 per 1,000 women in the South. The American College of Obstetricians and Gynecologists is currently studying which reasons for hysterectomy are valid—uterine or cervical cancer, for example, or treatment of severe endometriosis. And which reasons—nonsymptomatic fibroid tumors or heavy menstrual bleeding—might better be treated by nonsurgical means. Meanwhile, it is wise (and sometimes necessary for insurance purposes) for a woman to obtain a second opinion before agreeing to the operation.

QUESTIONS FROM READERS

BIZARRE "DREAMS"

Recently, following gallbladder surgery, I hallucinated for four days. I have never had such an experience in my life. What could have caused it? Is there any way to prevent it if I need surgery in the future?

You were probably experiencing a reaction to the anesthetic or to some other pre-op or post-op medicine you were given. In any event, this is highly unusual; if you haven't done so already, you should report it directly to your surgeon, the anesthesiologist, and the hospital administration. In addition, you should obtain an accounting of all anesthesia and other medications you received, including precise doses. Then, if you need surgery in the future, you can present this information in advance, to avoid a recurrence.

EMBARRASSED SON

My 13-year-old son has a low-grade fever and needs his temperature taken twice a day. The doctor says rectal temps for accuracy. The boy says "no way." What can I do?

A 13-year-old boy might well object to his mother's taking his temperature rectally. But why can't he take and record it himself, in privacy? The major hurdle is to convince your son that accurate temps are really important—a job for you, the doctor, or both. (If he understands *why*, he won't cheat.) Then, the rest is just mechanics, which the doctor can explain.

AT RISK FOR POLIO

My mother is on chemotherapy for breast cancer. When my 18-month-old son had his oral polio vaccine, the doctor said that Mother shouldn't even visit our home for at least two months. Why?

The oral polio vaccine is made from live, though weakened, polio viruses. It works by giving the person inoculated a minor, controlled polio infection. Polio viruses are then shed from the nose, throat, bowel for about eight weeks, during which time other people can come in contact with them. Since your mother's immune system may not be working well due to the effects of her cancer and the chemotherapy for it, she may be at high risk of catching polio from the vaccine virus your son sheds. This doesn't happen often, but it *can*—and that's what your doctor is worried about.

SHAVING PROBLEM

Every time I shave my legs, I get a rash as well as infected hair follicles. Am I doing something wrong?

Possibly. Many women shave their legs in the shower or just afterward, without using any luoricant. You might try shaving with an antibacterial soap (to reduce skin bacterial, then use a foaming shaving cream, rinsing, and drying thoroughly when you're finished. If that doesn't solve your problem, try shaving *before* your shower with an electric shaver, using a pre-electric-shave powder first. This may not result in as close a shave, but may not do as much damage either.

You may address questions on medical problems or treatment 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.

Winter 1989

Mental Health ADVOCATE

NEWSLETTER OF THE MENTAL HEALTH ASSOCIATION IN ILLINOIS, INC.

New Trust Offers Secure Future to DD Children

Parents of an autistic, schizophrenic, or mentally retarded child all share a common concern: providing their developmentally disabled child with continuity of care, treatment and personal advocacy in the event of their deaths.

Efforts to help parents of disabled children attain their long-term estate planning goals have been greatly aided by the passage of an Illinois state law. This law establishes a self-sufficiency trust fund in the public sector that will receive moneys from private sources.

The term "self-sufficiency trust" is used to describe a trust established by a non-profit association for the purpose of providing for the care, support or treatment of a disabled individual who would be eligible for services by the Department of Mental Health and Developmental Disabilities.

When it established the nation's first self-sufficiency trust fund in 1986, Illinois became a leader in removing obstacles that families have traditionally faced when financially planning for the care of their disabled child. Chapter 91 1/2, Sections 5-118 and 5-119 of the Illinois Revised Statutes. Public-sector funding for programs and services has steadily decreased and governmental support has also failed to keep pace with the growing costs and demands for the care of the disabled. At present, it appears that state and federal funding allow for only basic maintenance of the system of care in place. Minimal annual increases would provide cost of living adjustments at best, but would not cover sufficiently the expansion of needs.

Implementation of the state law began early in 1988 with the federal HCFA approval of a specific document called the Self-Sufficiency Trust Model. According to James DeOre, Executive Director of the National Foundation for the Handicapped and creator of the Self-Sufficiency Trust concept, the SST Model is unique in its structure and specific in its intent. The SST has found a way to make private-sector funds available to supplement the limited and often insufficient public dollars available to expand the service delivery system for disabled children. Historically, the disabled have faced loss of public entitlement support if inherited assets were made directly available to them. In addition, if trusts were established, they were potentially subject to invasion by government creditors who had provided services in the past. In some cases, disinheriting a disabled dependent and leaving instructions for that dependent's care with other beneficiaries seemed the only estate planning option available to parents.

The SST has found a way to make private-sector funds available to supplement the limited and often insufficient public dollars available to expand the service delivery system for disabled children.

Now, the SST offers another alternative and makes it easier for parents to actively finance supplemental care of their disabled child without disrupting Supplementary Security Income (SSI) and Medicaid benefits. The intent of the Self-Sufficiency Trust is to augment these federal sources and not supplant them, thus making new funds available to enhance the service delivery system and meet the special needs of the child who is disabled.

As a result of this new estate planning option, parents can now assess their disabled child's needs and then decide what supplemental services they want provided in the future. The services provided could be recreational, educational, social or even training programs to assist in managing activities of daily living.

Parents who are considering the Self-Sufficiency Trust for their disabled child can discuss programs and services with specially-trained advisors. As SST applicants, they can input into the unique Disabled Population Profile System. This specialized database determines the dollar amount needed to provide the specific supplemental services that parents select for their disabled beneficiary. At this point, an attorney or financial planner could advise the family on ways to develop an estate or investment plan.

Thus, the self-sufficiency trust concept works by encouraging parents to determine the specific dollar amount that is necessary to generate a flow of income to pay for the supplemental services needed during the life of the disabled beneficiary. This is identified as the Life Care Plan. It allows parents to provide the quality of life that they have carefully determined is appropriate for their disabled child. DeOre points out that the SST's usefulness or benefits are individualized and based on the needs of the disabled beneficiary and the priorities of the family who is funding it.

Although the parents must have the principle necessary to fund their chosen priorities, the SST does not require a minimum dollar amount. The actual amount put in trust is proportional to the supplemental service priorities of the family involved.

In addition to supplying supplemental services to a disabled beneficiary, the SST is structured to act as an advocate for that beneficiary during his or her lifetime. DeOre states, "The SST incorporates fiduciary management and social service advocacy not traditionally found in trust structures

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SST, cont. page 4
within banking institutions." The SST model also gives its Board of Trustees and contractual agents the capacity to assess the on-going quality of service delivery and to adapt to the changing needs of the disabled beneficiary.

The unique qualities of the self-sufficiency trust make it an estate-planning option worthy of investigation by parents of disabled dependents. The National Foundation for the Handicapped, developers of the SST model, are active in the implementation of the SST model nation-wide. Locally, the Board of Trustees of the Self-Sufficiency Trust have contracted with PACT, Inc., to implement the SST in Illinois. Families making contact with one of four PACT offices in Illinois will deal with counselors who assist in the applicaton process and provide information about the SST.

Editor's Note: If you are interested in more information or wish to make an appointment to discuss the Self-Sufficiency Trust, please contact:

Self-Sufficiency Trust of Illinois
340 West Butterfield Road, Suite 3C
Elmhurst, IL 60126
(312) 941-3498

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 disabled 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 approach 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

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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 fundng. 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

a planning and contracting approval process. Implementation would be phased in over a period of time, with a target completion date of July 1995.

By 1993, counties would have to assume responsibility for a single block grant, which would include 15 percent of the state hospital funds as well as all funds currently provided for residential and community support services and services pursuant to the involuntary treatment act. At the same time, counties would assume responsibility for all short-term involuntary commitments.

Together with this new method of financing, there would be a significant change in approach to the delivery of community-based services. The current statute mandates day treatment and outpatient services, while residential and community support services are optional. HB 1876 would reverse these priorities. The measure also mandates resource management and gives explicit priority to those who are acutely or chronically mentally ill and those who are at risk of becoming so.

The bill would appropriate $17.3 million, with $9.6 million going toward residential services, crisis intervention services, and resource management. However, officials in the legislature have indicated that they are looking for up to $30 million during 1989-91, plus the possible use of bond money for residential treatment.

Pennsylvania. Going a bit further than Washington's proposal, HB 221 would make counties completely responsible for developing a full continuum of services for adults and children, including new mandated services such as residential care and case management. State hospital funds for all treatment services would be directed through county mental health programs. This responsibility would be phased-in over a five year period. The state would continue to run state hospitals and be financially responsible for administering and maintaining the facilities. They would essentially become another provider in the community from which counties may choose to purchase services.

Patient's rights are expanded under the bill to apply to all individuals receiving services. They include the right to: a treatment service appeal process; manage money or property unless adjudicated incompetent; independent evaluations; and representation by an advocate. The bill also would mandate that local mental health boards include consumers and family members in addition to advocates and professionals.

Extended care services for persons discharged from state-run facilities are more explicitly defined under the bill. It requires the county, in conjunction with the facility, to provide discharge planning and assistance to individuals released from the state hospital.

The bill is now in the House Health and Welfare Committee. Public hearings are scheduled for the last week in March. A coalition of consumers, advocacy groups and providers have drafted an alternative proposal that will be presented at the public hearings.

Although in basic agreement with the goals of the proposed initiative, the coalition is drafting a bill that they feel goes a bit further in terms of the financing mechanism and emphasizing community support services.

Kansas. Legislation under discussion in Kansas (HB 2016) is similar to Pennsylvania's bill in that responsibility for all inpatient and outpatient services would be transferred to the counties. Amendments to the proposed reorganization are likely, however, as the bill has received negative reaction from state and community officials.

Over the last 10 years, numerous interim committees, task forces, and groups have reviewed the mental health system. Many have recommended significant changes in the way the mental health system operates at both the state and local levels; yet many of these recommendations have not been adopted.

The renewed interest this year stems in part from problems the state mental health institutions have experienced recently with overcrowding and understaffing. Also, there are concerns that Kansas' mental health system does not operate as effectively or efficiently as it could.

Both the executive and legislative levels of government are committed to making a change now. On the legislative side, the main thrust comes out of recommendations proposed by the Special Committee on Ways and Means/Appropriations.

HB 2016, drafted by the Special Committee, would transfer responsibility for both inpatient and outpatient mental health services to the counties. The committee emphasized in its report that it is responding to the federal mandate of PL 99-660, the State Comprehensive Mental Health Services Planning Act, which requires states to establish community-based systems of care, including case management services for chronically mentally ill individuals.

Under the proposal, effective February 1991, each county or group of counties would be mandated to establish a mental health authority responsible for providing an array of services to the chronically mentally ill. These services would be provided either directly or indirectly by the local authority. All court ordered commitments would be made to county mental health authorities rather than to state hospitals. The counties would make the determination as to where patients would be placed.

County authorities would act as "gate-keepers" by screening all admissions to state hospitals and assuring those denied admission would receive appropriate services in the community. In addition, the counties would assist in discharge planning by making sure patients receive necessary support services in the community.

HB 2016 would establish a pilot program in one state catchment area by February, 1990 to test the proposed system. The goal would be to reduce the size of one state hospital by one ward, or approximately 35 beds. Additional funds would be provided to the counties in the pilot area to finance the additional services required.

The bill also mandates that community support services be provided in all counties and specifies adult chronically mentally ill individuals as the priority population. As of this writing, no firm appropriation has been attached to the bill.

The measure has been assigned to the House Appropriations Committee, where a special subcommittee has been appointed to study it further. Because there has been negative reaction to the bill from various agencies and organizations in the state, the special subcommittee is now considering alternative proposals addressing different methods of financing and service provision.

Montana. Although there was talk among providers, advocates and some legislators to revise the organization and funding of the state mental health system this year, the issue is now being examined in the long-range planning process. Montana's new draft mental health plan for FY 1990-93 contains an objective stating that a proposal will be developed to restructure the mental health system through the mental health system planning process. The proposal which must be completed by October 1990, in time for consideration by the 1991 legislative session, will include increased incentives for serving people locally and mechanisms for local (CMHC) decision making on appropriate services for adults with severe mental illness.

Financing Issues: Self-Sufficiency Trusts

An innovative idea in estate planning, established first in the state of Illinois, removes the complications that have traditionally stymied effective estate planning efforts by parents with disabled children. The Self-Sufficiency Trust ("SST") is the first trust of its kind to provide a mechanism to facilitate the coordination and integration of private family financing for individuals with disabilities while maintaining their eligibility for government entitlement programs. As a truly private sector initiative, the SST makes possible the flow of private monies into the state's network of publicly-sponsored programs to supplement, enhance and expand services to all disabled residents.

Conceived in Illinois, the "SST" evolved from research by the National Foundation for the Handicapped under the direction of James H. DeOre. Funded in part by the Illinois Department of Mental Health, the "SST" was enacted into law (P.A. 84-1373) by a unanimous vote of the Illinois Legislature in September 1986. Maine is the only other state to enact such legislation but this year eight states (Alaska, Indiana, Kansas, Massachusetts, Michigan, Montana, New York, Oregon) have introduced model "SST" legislation, and twelve others have expressed interest and are in various stages of pre-legislative review. Legislation with similar goals, has also been introduced in Missouri,

though technicalities of the trust deviate from the Illinois model.

The SST is an irrevocable, "pooled-income trust" with spendthrift and discretionary trust language and clearly defined "charitable" and "private" trust provisions. Its structure and benefits are uniquely designed to facilitate active parental financing of supplemental care of the disabled without disruption of SSI and Medicaid.

Two wholly separate pooled-income trust funds make up the structure of the SST. The first, a Private Trust Fund, accepts, holds, and invests the "pooled" assets of each participating family. Although assets are commingled, all returns on investments are credited proportionately to the private trust. Interest earned on the private trust is transferred to the counterpart State Trust Fund, which immediately disburses the assets for supplemental goods or services that are to be provided. Because monies technically become State Trust Fund monies, they are not viewed as earned or unearned income to the disabled beneficiary, therefore do not affect entitlement eligibility.

Monies may also be disbursed to non-profit vendors such as advocacy groups or human service providers who will monitor the status and condition of the designated beneficiary. This service provision sets the SST apart from generic trusts devoid of life-care monitoring.

A second fund controlled by the Board of Trustees is the Charitable Fund. This fund is a repository to accept residual and donated assets earmarked for low-income and indigent persons with disabilities who are unable to participate in the Private Trust. Upon the death of the beneficiary, 50 percent of the residual principal of each private trust is donated to the Charitable Fund. The fund is also financed by donations.

A Volunteer Board of Trustees is appointed from the private sector to manage and control the Private and Charitable Trust Funds. Parents or family members serve as co-trustees and share in decisions concerning disbursements. A Life-Care Plan developed for each participant embodies the wishes of the parent and defines the intent and nature of supplemental services that will be provided to the beneficiary. Trained Self-Sufficiency Trust Advisors provide direction for parents to develop a realistic and need-specific plan. A Life-Care Planning Service Survey helps families target the services they want and reinforces areas that the SST is unable to finance.

SST fund monies may be spent for social services, recreational programs, rehabilitation services, educational services, rehabilitation and remedial services and training programs to assist in managing activities of daily living. The major restriction on the SST is that the dollars cannot be used to meet the same needs as those intended to be met through available public assistance programs.

The Self-Sufficiency Trust concept evolved from the realistic acknowledgement that a state's capacity to provide these 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 National Foundation for the Handicapped's goal is to see the SST available in all 50 states, allowing transferability and universal benefits for all disabled individuals. The potential benefit of a nationwide trust network is economy of scale, resulting in trust management savings, larger principal investment and return and, most importantly, a stronger private sector (parent and family) voice in services and financing of those services for the disabled.

For states, the advantages are: new sources of private funds to expand services; a computerized data collection system to identify type and scope of services; potentially reduced dependence on federal support; and a private-public partnership that actively involves each working toward improved and expanded services for disabled people. For the families, the trust fund gives them the peace-of-mind that their loved ones will be adequately cared for when they are not able to do so. [*This feature was prepared from excerpts of previous articles written by Paul L. Medlin, Senior Vice President for Corporate Development, National Foundation for the Handicapped, Elmhurst, Illinois (312) 832-9700.*]

Substance Abuse Legislation Proposes New Treatment Programs

Legislation this year for new treatment programs is by and large focusing on specific target populations. The majority of these initiatives have an eye toward vulnerable groups such as adolescents, pregnant women and indigent persons. Furthermore, new initiatives have been proposed for the rehabilitation of individuals arrested for or convicted of drug-related offenses. Several states have also proposed more comprehensive efforts for prevention, education, and treatment.

Targeted Treatment Programs. A bill in New Jersey appropriates $2 million to establish residential drug treatment centers for individuals 14 years of age and older (SB 660). In a separate measure, an equivalent appropriation would be provided to establish residential alcohol and drug abuse treatment centers for adolescents between the ages of 12 and 18 (SB 1076). A third measure establishes a 15-member advisory task force to make recommendations on regulations to govern outpatient adolescent drug and alcohol abuse treatment programs (SB 2052).

A Rhode Island proposal (HB 5206) seeks to establish the "Adolescent Alcohol and Substance Abuse Treatment Fund," to be supported by increasing the charge for courtesy license plates from $10 to $15. The fund is for the development of treatment and rehabilitation programs designed specifically for adolescent substance abusers.

Legislation in Washington (HB 1793, SB 5832) targets assessment and treatment programs for low-income youth and pregnant women and new mothers. Within available funds, the Department of Social and Health Services is to provide expanded inpatient treatment slots for drug-addicted youth, incorporating appropriate aftercare and outpatient services. Intensive outpatient treatment services for children and youth are to be developed in cases where inpatient treatment is either unavailable or inappropriate.

A continuum of services would be specifically designed to serve pregnant women and new mothers and their infants, including inpatient care, transitional housing, intensive post-natal care for mothers with infants at high risk of chemical dependency, outpatient or follow-up, day care services and medical stabilization or detoxification services.

The bill calls for an appropriation of $6 million to expand services for youth, plus another $3 million for services to chemically-dependent pregnant women and new mothers.

Treating Drug Offenders. Several Assembly bills in California strengthen enforcement activities related to illegal drug use -- including mandatory drug treatment programs for defendants convicted of crimes committed while under the influence of alcohol or drugs (AB 78, AB 282, AB 436). A similar measure in Connecticut (HB 7053) requires mandatory enrollment in treatment programs for drug dependent defendants convicted of a drug offense. A separate measure (HB 6970) appropriates $750,000 to set up treatment programs for clients on probation who abuse drugs. Connecticut lawmakers are also considering establishing a pre-trial drug abuse diversion program (HB 6914).

Legislation in Florida (HB 312) establishes a voluntary program for mandatory sentencing of non-violent felony drug offenders to community-based drug treatment programs. Minimum eligibility criteria would be established for the program. Local county boards are required to establish a "drug sanctions advisory board" in order to quality for direct financial aid.

Funds may be used to develop a range of community-based treatment/detention options: 1) community corrections programs that do not provide for housing the offender in jail; 2) short-term and long-term residential treatment options involving closer supervision in a residential setting; 3) enrollment in residential inpatient or outpatient drug or alcohol treatment centers for detoxification and therapy; and 4) individualized services to evaluate and treat the special needs of prisoners.

A corrections-related drug abuse strategy is targeted in a measure in Kansas (SB 154). It allows courts to order convicted defendants in need of substance abuse or alcoholism treatment to be sent to state or county institutions providing these services prior to being sentenced. The term of confinement may not exceed the maximum prison term allowed for the crime committed. When the defendant returns to the court for sentencing, the court is authorized to credit the time the defendant

stayed in the treatment facility against the final sentence imposed.

Lawmakers in New York are debating a bill establishing an "alcohol intensive supervision demonstration program" (AB 395). The program, available only to those who have been convicted of at least two alcohol-related offenses within a two-year period, consists of the following three phases. First participants are screened and attend counseling programs. Second, participants are under house arrest for 90 days allowed to leave home for work and to meet with probation officers or community service workers. To monitor compliance, program participants may be followed by telephone calls and three home visits per week. Participants would be required to take their prescribed Antabuse in the presence of the probation officer or community service worker during these visits; Phase three continues for four years, during which time participants continue to take the required antabuse medication three times a week. Random visits would also continue.

The measure appropriates $50,000 initially for the program. In addition, clients would pay to participate, based on a fee schedule.

Texas lawmakers are looking into contracting with private agencies for distinct substance abuse treatment programs within state and county correctional facilities. Legislation under consideration in both houses (HB 833, SB 387) provides for the establishment of secure units to provide treatment services to inmates within the state correctional system -- low to medium risk inmates, probationers, parolees, state and county prisoners, juvenile offenders.

Involved state agencies are authorized to contract with one or more private vendors to develop these facilities and may further develop interagency contracts for inmates in different programs. Authorized facilities must: provide for the housing and treatment of up to 1,000 patients; be located within 55 miles of a county with a population of 230,000 or more; and be a secure facility capable of housing low- to medium-risk patients.

Highlights

o Legislation establishing criminal penalties for the manufacture, sale and possession of "Designer Drugs" -- chemical compounds that mimic substances such as cocaine and heroin-- was approved by the Senate in New York in early February. Under the proposal (S.934/A 1483), persons convicted either manufacturing or selling such drugs, the most serious charge under the bill, could face sentences of up to 7 years.

o Massachusetts legislators are considering a bill (H 2254) to establish a Mental Illness Research Board within the Department of Mental Health. The board would develop and oversee research programs relating to the causes and treatment of mental illness, including treatment within a comprehensive system of community services.

o Also in Massachusetts, S 665 would establish a task force and pilot project for the treatment of individuals diagnosed as suffering from both mental illness and substance abuse. The task force would determine the approximate number of people who are dually diagnosed, research the various aspects of it, and develop treatment procedures combining services currently provided by the Department of Mental Health and the Department of Public Health. The pilot would include a 10 bed detoxification unit, a 20 bed residential care unit, and training programs sufficient to enable clinicians to provide outpatient treatment services for such diagnoses.

o A bill that would give Missouri law enforcement officials broad authority to crack down on the drug trade has been approved by the Senate. The measure, known as the "Drug Control Act of 1989," would give enforcement officials the power to use wiretaps against drug dealers and organized narcotics rings.

o Florida's HB 21 would require the Mental Health Institute at the University of South Florida to establish a culturally-based mental health professional training program. The purpose would be to increase the number of minority group members in the mental health professions who work in minority communities in the state.

o HB 66 in Montana would add case management for chronically mentally ill individuals as a mandatory service under Medicaid. The bill is expected to be amended to provide funds for two demonstration centers, one urban and one

rural, in an effort to contain costs. Also on the legislative agenda is a bill (HB 304) to provide residential services to mentally ill children between the ages of 5 and 21.

o A new bill in the **District of Columbia** -- where current levels of drug-related crimes and murders make substance abuse the city's major public health problem -- provides for the establishment of a comprehensive drug abuse treatment facility to provide both residential and outpatient services to District residents, regardless of their ability to pay. The facility would initially have up to 250 slots, with adequate resources to provide follow-up outpatient treatment. The bill also requires the Mayor to establish and implement a public education campaign.

o In **Washington** state, HB 1619 requires direct care providers, institutions, and pharmacists to protect the confidentiality of individuals seeking treatment, counseling or rehabilitative services for alcoholism or substance abuse. If confidentiality is breached, the information is not admissible as evidence and may not be considered in any criminal proceedings. The provisions may be waived if the individual's identity is protected, and if the waiver is given voluntarily, with full understanding of the consequences of releasing the information.

o A measure in New Jersey (A 2154) requires both the Division of Rehabilitative Services in the Department of Labor and the Division of Mental Health and Hospitals in the Department of Human Services to develop a plan to provide vocational rehabilitation services to persons with mental illness. The plan must include provisions for those with chronic mental illness, who, until recently, were often considered too severely impaired to benefit from vocational services. The plan would be implemented jointly by both divisions. The bill includes an appropriation of $50,000 to the Department of Labor.

o A bill in the **Indiana** legislature (HB 1259) would require the Department of Public Welfare to develop or contract for three home-based treatment demonstration programs designed to provide time-limited services to families with a child who is in imminent danger of being removed from the home and placed in foster care, residential treatment, or a psychiatric hospital setting. The programs must be designed to prevent the unnecessary separation of a child from the family by providing intensive in-home services when an acute crisis threatens the family's ability to remain together. Services, to be provided for a maximum of 4 months, must include: intensive family and individual counseling; behavioral management training; parent training; client advocacy; access to caseworkers on a 24-hour basis; and arrangements for other services.

o A recent study of the Division of Mental Health and Mental Retardation in **Nevada** makes 28 recommendations to the legislature regarding the organization, management, and treatment of mentally ill clients. Some of the recommendations include establishing a legislative committee on mental health and mental retardation; improving training throughout the division with increased financial support; requiring certification of all mental health technicians; requiring inpatient facilities of the division to meet all licensing and accreditation standards by July 1992; eliminating all waiting lists in division facilities; lowering client-staff ratios in community training centers; establishing residential group homes; expanding services to the chronically mentally ill; providing case management; and constructing a 50 bed secure forensic facility.

o A new **Nebraska** law, LD 70, requires holders of liquor licenses to post signs on the dangers of alcohol consumption during pregnancy. The signs must be prepared by the Liquor Control Commission and are to read as follows: Drinking alcoholic beverages during pregnancy can cause birth defects.

o In **Washington**, HB 1599 (Chapter 3) appropriates $10.2 million in supplemental funds for services provided under the Alcoholism and Drug Addiction Treatment and Support Act (ADATSA) to indigent clients. Of this amount, $4.8 million will come from federal sources. Several restrictions apply to the appropriation, including placing caseload ceilings on outpatient and shelter services.

o The Robert Wood Johnson Foundation has announced the availability of $26.4 million in grants to support intensive, community-wide initiatives to reduce demand for illegal drugs to reduce demand for illegal drugs and alcohol. The purpose of these initiatives is to demonstrate that by consolidating resources and creating a single community-wide system of prevention, early identification, treatment and aftercare, communities can, over time, achieve

substantial reductions in the demand for -- and consequently the use of -- illegal drugs and alcohol.

o The Foundation program is intended for medium-sized communities -- those with populations of from 100,000 to 250,000 -- that are experiencing serious problems with drug and alcohol abuse and that have made these problems among their highest priorities. Also eligible are other geographic areas with similar-sized populations, such as multi-county regions or parts of larger cities. As many as 12 communities will be selected to receive one- or two-year planning grants of up to $100,000 per year. Once communities have completed planning and development, they will be eligible to compete for five-year implementation grants. Up to eight communities will receive implementation grants of as much as $3 million each.

For more information contact: W. Anderson Spickard, Jr., M.D., Program Director, Fighting Back, Room 2553, The Vanderbilt Clinic, 1301 22nd Avenue South, Nashville, TN 37232-5305; (615) 343-9603.

o Maryland's Governor Donald Shaefer has announced the establishment of a data base on drug abuse prevention and treatment. It will use a state-wide telephone service and computerized resource directory to assist the public and state agencies seeking to identify substance abuse treatment, prevention and aftercare programs available in the state.

STATE HEALTH REPORTS ON MENTAL HEALTH ALCOHOLISM AND DRUG ABUSE

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MODEL ACT

An Act to provide for a Self-Sufficiency Trust for the developmentally disabled, mentally ill and physically handicapped.

STATE OF _____

BE IT ENACTED by the People of the State of _____, as follows:

SECTION 1: Sections 1, 2 and 3 are added to the _____ _____(detail the State law section dealing with the disabled), the added sections to read as follows:

(A) CREATION. There is hereby created the Self-Sufficiency Trust Fund. The State Treasurer, ex officio, shall be custodian of the Trust Fund, and the Comptroller shall direct payments from the Trust Fund upon vouchers properly certified by the (Director or Commissioner) of (name appropriate state agency). The Treasurer shall credit interest on the Trust Fund to the Trust Fund, and the Director shall allocate such interest pro rata to the respective accounts of the named beneficiaries of the Trust Fund. For the purposes of this section, the term "self-sufficiency trust" means a trust created by a nonprofit corporation which is a 501-C-3 organization under the United States Internal Revenue Code of 1954 and which was organized under the Nonprofit Corporation Act, Chap.___ Section_____for the purpose of providing for the care, or treatment of one or more developmentally disabled, mentally ill or physically handicapped persons or persons otherwise eligible for department services.

(B) RULES. The department shall adopt such rules and procedures under the _____ Administrative Procedures Act, Title _____, chapter _____, as may be necessary or useful for the administration of the trust fund.

SECTION 3: ADMINISTRATION OF FUND

(A) NAMING BENEFICIARIES. The Department of (appropriate state agency) may accept money from a self-sufficiency trust for deposit in the trust fund pursuant to an agreement with the trust naming one or more beneficiaries who are developmentally disabled, mentally ill or physically handicapped persons or persons otherwise eligible for department services residing in this State and specifying the care, or treatment to be provided for them. The department shall maintain a separate account in the trust fund for each named beneficiary.

(B) CARE OF BENEFICIARIES. The money in these accounts shall be spent by the department, pursuant to its rules, only to provide care and treatment for the named beneficiaries in accordance with the terms of the agreement.

(C) RETURN OF MONEY. In the event that the director determines that the money in the account of a named beneficiary cannot be used for the care or treatment of the beneficiary in a manner consistent with the rules of the department and the agreement, or upon request of the self-sufficiency trust, the remaining money in that account, together with any accumulated interest on that account, shall be promptly returned to the self-sufficiency trust which deposited the money in the trust fund.

(D) OTHER BENEFITS NOT AFFECTED. The receipt by a beneficiary of money from the trust fund or of care or treatment pro-

vided with that money, shall not in any way reduce, impair or diminish the benefits to which the beneficiary is otherwise entitled by law.

SECTION 3: SPECIAL FUND

The fund for the disabled is created as a special fund from the State Treasury. The director may accept money from any source for deposit into the fund. The money in the fund shall be used by the department, subject to an appropriation, for the purpose of providing for the care, and treatment of low-income developmentally disabled, mentally ill and physically handicapped persons, or low-income persons otherwise eligible for department services, as defined by the department.

SELF-SUFFICIENCY TRUST OF ILLINOIS

DISABLED POPULATION PROFILE SYSTEM

DISABLED POPULATION PROFILE SYSTEM

OVERVIEW

There are two purposes for the Disabled Population Profile System:

1) It is the first step in forming a life-care plan for a disabled individual;

2) It is a planning tool which provides a system to collect information on the needs of the disabled population that are in need of services now and those needing services in the future. This information can be compiled state-wide and eventually nation-wide. Until now, there has been no successful system to accurately show these needs.

The service application will give the following information:

1) Parent demographic information;

2) Disabled person demographic information;

3) Functional disabilties of the disabled person - very basic "yes - no" function not an in-depth clinical review;

4) Scales for level determination - these scales will be used later to determine what level of residential care and day programming is needed by the disabled person. All costs associated with the level are also calculated (current year or future year costs). The system then takes these costs and produces an Income Earnings Projection which is the starting point for the financial planning for a parent for the needs of their son or daughter;

5) Current living arrangements and services;

6) Immediate needs of the disabled person;

7) Future needs - This is when the system takes the Life-Care needs, matches them to the level determination and costs for those needs, in any given year.

WHEN CAN I ENROLL IN THE SELF-SUFFICIENCY TRUST?

When it is time to deliver services under the Life Care Plan developed for your beneficiary who is disabled, you can enroll in and fund the Self-Sufficiency Trust (the "SST"). Depending upon your wishes, then, enrollment can occur currently, on a future set date, or at your death.

The Self-Sufficiency Trust has only two enrollment procedures. The first is for donors who desire services CURRENTLY; the second is for donors who desire services on a FUTURE SET DATE or AT THEIR DEATH.

CURRENT ENROLLMENT PROCEDURES

If the Life Care Plan for your beneficiary who is disabled has been completed and you have determined that services are to be purchased immediately, then your enrollment in the SST will be completed at once.

As you work with the SST Interviewers, your attorney and advisors, you will complete the Life Care Plan [which defines the services and the timing of their delivery to be provided to your disabled beneficiary], the Transfer Document [which is the agreement you sign with the SST], and the Appointment of Special Trustee [which gives you or your appointee a voice in the provision of services to your disabled beneficiary].

A summary of your file is then prepared for presentation to the Board of the Self-Sufficiency Trust. This file is identified only by the social security number of the disabled individual and contains a summary of the Life Care Plan, a verification of the financial projections, a verification that a Provider has been identified to provide services, and a verification that the Transfer Document and Appointment of Special Trustee have been executed by the donor.

If all these items are in order, the Board of Trustees will accept the enrollment pending funding. Immediately after that acceptance, the original Transfer Document and Appointment of Special Trustee are presented to the President of the Board for signature.

Now that enrollment has been approved, your file is returned to staff who will write to you giving instructions on how your funds are to be deposited into the SST. You will also be given copies of the fully signed Transfer Document and Appointment of Special Trustee.

When your funds are received and cleared, your enrollment is complete. Your disabled beneficiary becomes a Participant in the SST, and services will begin. Of course, we'll be interfacing with your Special Trustee as needed thereafter.

FUTURE/COMMITTED ENROLLMENT PROCEDURES

If you have completed the Life Care Plan for your beneficiary who disabled and determined that services are to be purchased at a Future Set Date or after your death, then your enrollment will be completed at that future time. However, it is important to both of us that your enrollment be COMMITTED. This allows you to depend upon and plan for your enrollment, and it allows us to plan for the future of the SST and your beneficiary.

Continued.....

Enrollment for future services is accomplished through testamentary devices, primarily through your Will and/or through life insurance.

As you work with the SST Interviewers, your attorney and advisors, you will complete the Life Care Plan. Then, if you intend to fund the Trust through your Will, you will prepare a new Will which includes the paragraphs necessary to enroll in and transfer funds to the SST and to appoint a Special Trustee.

If you intend to fund the Trust through life insurance, you will make the Self-Sufficiency Trust of Illinois the beneficary of your policy for the sum need to fund your Life Care Plan, and you will complete a Transfer Document and an Appointment of Special Trustee. As an alternative, you can flow the insurance proceeds through your estate and enroll in the SST through your Will, as discussed above.

We then ask that you give the SST a photocopy of your Will (just the pages that relate to the SST) and of your life insurance beneficiary designation with a letter stating that you intend to enroll your disabled beneficiary in the SST at a future time. This tells us that you are COMMITTED to enrollment in the SST.

Once we have all these documents, a summary of your file is prepared for presentation to the Board of the Self-Sufficiency Trust. This file is identified only by the social security number of the disabled individual and contains a summary of the Life Care Plan, a verification of the financial projections, and a verification that your financial/estate planning and documentation is in order so that future funding and enrollment can occur.

If all these items are in order, the Board of Trustees will recognize the enrollment pending future funding.

It is then necessary for us to meet annually to update your file and review the needs of your disabled beneficiary. This is very important; we need to know that you are still committed to the SST so that we can plan for the time when your disabled beneficiary will need us. We will gladly accomodate these reviews via the telephone or mail if that is easier for you. [Please see the SST handout entitled UPDATE PROCEDURES].

At your death, we will work with your Executor and Special Trustee to complete enrollment as described in the first part of this handout.

If you make arrangements for this kind of testamentary enrollment and decide in future years that you want services to begin even though you are still alive, just arrange to meet with an SST Interviewer. That change can be easily accomplished and services begun at that time.

Suppose for a moment that you know now that you want services to begin on a SET FUTURE DATE --for example, if you want services to start when you retire in 1999-- the SST requires that you go through the testamentary enrollment procedure. Then if you die before 1999, your beneficiary is protected through your Will or life insurance. If you survive until 1999, we will arrange for immediate enrollment at that time.

As you learn about the Self-Sufficiency Trust of Illinois (the "SST"), you will see that the goal of the SST is to fund services to meet identified needs of individuals with disabilities for defined periods of time.

It is important that you clearly understand each element of this goal as you evaluate your own participation in the SST.

When you meet with the SST Interviewers, the goal of the meetings is mutually to define service needs and when the needs are likely to occur. During the first interview, you will complete the computer-based Disabled Population Profile System ("DPPS") by answering a variety of questions. These will range from identification information (such as name, address, social security number) to level-of-functioning information. You will be asked about a variety of services (such as residential, day programming, advocacy, and guardianship) and whether or not your disabled beneficiary will need these services. You will also be asked when you think these services should begin.

After your first interview, our computer will process your answers in a number of different ways, and we will begin to develop a Life Care Plan for the individual with disabilities.

From your identification answers, the DPPS will apply a geographic descriptor as formulated by Illinois Department of Mental Health and Developmental Disabilities ("DMH-DD").

From your level-of-functioning and program needs answers, the DPPS will identify the residential and day program setting appropriate to your disabled beneficiary within the program parameters established by DMH-DD.

From your service timing answers, the DPPS will determine the number of years each service is to be provided. In doing this, DPPS examines the current age of your disabled beneficiary and the date you want services to begin, and it factors in an average life span of eighty-one years.

Service cost information from DMH-DD, the Department of Rehabilitation Services, advocacy groups, guardianship services, and others are also accessed by the DPPS program.

Under the Mental Health Code of Illinois, the SST must make appropriate placement determinations when identifying services for individuals participating in the SST. All of our efforts are to this end, and you play a large part in our success by supplying complete and objective information about your beneficiary who is disabled.

Continued.....

At your second SST interview, we will review the computer-projected costs of various programs for your beneficiary who is disabled. All of these projections will be based upon the level-of-functioning information and start-up date which you provided in the first interview. If the information you have given us is inaccurate, then the projections may be inaccurate.

That's why we call them "projections". These figures give us both an estimate of the cost of services and allows you to begin financial planning.

Actual enrollment in the SST will take place only when services are to be delivered to the individual with disabilities. In all cases, a Provider of those services will be identified prior to enrollment. If applicable to the services to be supplied, the Provider will be asked to do a complete evaluation of your disabled beneficiary. If the results of this evaluation differ from the information you have given us, then there is the potential that the actual cost of services will differ from the projections.

Some donors are not interested in securing services under the SST right away. They may have minor beneficiaries or they may want to keep their adult beneficiaries home a few more years. In these cases, the donors might want to work with the SST and other SST donors in developing new housing for future occupancy, or the donors might wish simply to contact the SST in the future when they are ready for services. [Please see the SST handout entitled SELF-SUFFICIENCY TRUST RESIDENTIAL INITIATIVES.]

In many instances, the donors will want to use the SST to make plans for after their own death. In this event, we ask that a qualified third party make a level-of-functioing assessment, and based upon that evaluation we will cost out service as if it were to begin today. These figures can then be used by the donors to make estate plans and life insurance decisions. Each anniversary thereafter, the donors should meet with the SST Interviewer to update their file. At that time, the cost figures will be verified to reflect any significant changes in the condition of the beneficiary. The donors can then adjust their estate plans or life insurance beneficiary designations. [Please see the SST handout entitled ANNUAL UPDATE PROCEDURES.]

As you can see, you and your input are a vital part of the SST effort <u>to fund services</u> <u>to meet the identified needs</u> of your beneficiary with a disability <u>for a defined period of time</u>.

COMMITMENT TO EQUAL ACCESS

It is the commitment of the Board of Trustees of the Self-Sufficiency Trust of Illinois to offer equal access to all citizens of the State of Illinois to meet with Trust Interviewers.

INTAKE PROCESS FEES

All donors with a beneficiary who is disabled are encouraged to come in for one interview and enroll their beneficiary in the Disabled Population Profile System computer database. This information will be shared with the State of Illinois for planning purposes. Of course, confidentiality is strictly preserved.

Fee for one interview to enroll in the
Disabled Population Profile System.....NO CHARGE

Families who wish to learn more about the Self-Sufficiency Trust may choose to come in for a second and third interview for this purpose. It is possible to complete all enrollment steps in these two interviews, however, remeber that you are not obligated in any way and that you may discontinue the process at any time.

Fee for second and third interviews to evaluate and
possibly enroll in the Self-Sufficiency Trust.....NO CHARGE
Additional interviews: Cook and collar counties $90.00 per hour
All other counties..... $60.00 per hour

TRUST MANAGEMENT FEE

After you have enrolled in the Self-Sufficiency Trust, the Trust charges a management fee of 1.4% (one and four-tenths percent) of annual principal and accrued interest to cover management costs.

Of this figure, 1% (one percent) is paid to the Self-Sufficiency Trust or its designated agent for account maintenance and administration. The remaining 0.4% (four-tenths percent) is paid to the bank for its management and investment of the Trust acccounts.

UPDATE FEES

Families are encouraged to update their Disabled Population Profile System file in the event that there is a dramatic change in the condition or needs of their beneficiary who is disabled. In most instances this update can be handled through the mail.

Fee to update the Disabled Population Profile System...NO CHARGE

UPDATE FEES (Continued

Families who are enrolled in and receiving services from the Self-Sufficiency Trust who wish to augment those services are invited to meet with us. Remember that you are not obligated in any way and that you may discontinue the process at any time.

Fee to augment current services, two interviews.....NO CHARGE
Additional interviews: Cook and collar counties $90.00 per hour
All other counties..... $60.00 per hour

Families who have neither completed current enrollment nor committed to future enrollment in the the Self-Sufficiency Trust and who wish to update their financial projections or to modify their Life Care Plans are invited to do so.

Update fee for donors who are neither currently enrolled nor committed to future enrollment in the SST, maximum of two interviews.....$100.00
Additional interviews: Cook and collar counties $90.00 per hour
All other counties..... $60.00 per hour

FUTURE/COMMITTED ENROLLMENT UPDATE FEES

Families who have committed to future enrollment in the Self-Sufficiency Trust are entitled to a one-year Annual Membership which includes the "SST Newsletter" free of charge. After the first year, the Annual Membership will cost $100.00 per year and, in addition to the newsletter, includes one one-hour conference to review accounts and keep records up to date. Additional conference time is billable as follows:
Cook and collar counties $90.00 per hour
All other counties..... $60.00 per hour

JOINT EMERGENCY SERVICES FUND

The Board of Trustees of the Self-Sufficiency Trust is empowered to levy a variable nominal fee against each particpant's account to fund a pooled Joint Emergency Services Fund. This Fund is available to all participants on an emergency first come, first served basis in the event that an unexpected change in the participant's condition results in a greater need than originally funded by the individual trust account

NOTICE: THE FEES HEREIN MAY BE CHANGED BY RESOLUTION OF THE BOARD OF TRUSTEES OF THE SELF-SUFFICIENCY TRUST WITHOUT NOTICE OR OBLIGATION.

WHAT DOES "UPDATE" MEAN?

During your first Self-Sufficiency Trust ("SST") interview, you will complete the Disabled Population Profile System ("DPPS") which is a computer-based file describing the status and needs of your beneficiary who is disabled. You may also have requested and at your second interview been given projections of the monies needed to fund services to meet the identified needs of your disabled beneficiary for a defined period of time.

Updating the DPPS file simply means reviewing your previous answers and supplying new answers that more accurately reflect your new situation.

If needed, new financial projections will also be prepared which reflect your new situation.

WHO NEEDS TO UPDATE THEIR FILE?

1. You should update your DPPS computer file anytime your disabled beneficiary experiences a dramatic and unexpected change in condition and/or needs. This information will then be shared with the Illinois Department of Mental Health and Developmental Disabilities to allow the state to plan for the needs of the disabled population. Of course, your privacy, and that of your disabled beneficiary will be fully protected; statistical information only will be given to the state.

   There is no charge for an update of your Disabled Population Profile System file.

2. If you are using financial projections provided at your SST interview for purposes of financial planning, you should update your DPPS computer file and your financial projections anytime your disabled beneficiary experiences a dramatic and unexpected change in condition and/or needs.

   You will be given new financial projections for cost of service based upon your beneficiary's new condition.

   There is a Fee for updating your financial projections. Please see the handout entitled FEE INFORMATION.

Continued.....

3. You should update your Disabled Population Profile System computer file and your financial projections annually if you are participating in the Self-Sufficiency Trust as a Future Commmitted Enrollment through your Will or Life Insurance.

You will be given new financial projections for cost of service based upon your beneficiary's age and condition, and upon your Life Care Plan at the time the projections are prepared. This information can then be used to update your Will and/or your Life Insurance Beneficiary designations.

There is an annual Membership Fee for donors participating in the Trust in this manner. Please see the handout entitled FEE INFORMATION.

HOW DO I UPDATE MY SST RECORDS?

It's simple. Just call your local office or agent for the Self-Sufficiency Trust of Illinois. If you want to update your DPPS file only, chances are we will be able to do it through the mail. If you want to update your DPPS file and review new financial projections, then we will schedule a mutually convenient time to meet and discuss the necessary revisions.

Self-Sufficiency Trust of Illinois
Elmhurst Headquarters Telephone: 312/941-3498
Springfield Office: 217/744-9208

Chicago Agent: PACT, Inc. 312/641-6363

Aurora Agent: Association for Individual Development
312/892-1199

WHO IS ELIGIBILE TO PARTICIPATE?

To be eligible to participate in the Self-Sufficiency Trust of Illinois, an individual must meet two criteria.

First, the individual must be developmentally disabled or otherwise entitled to receive services from the Illinois Department of Mental Health and Developmental Disabilities.

Second, the individual beneficiary of the Trust account must reside in the State of Illinois. There is no requirement that the Donor(s) live in Illinois.

[See: Illinois Revised Statutes Chapter 91 1/2, Section 5-118.]

ARE THERE OTHER LIMITATIONS ON WHO CAN PARTICIPATE?

There are no other legal restrictions. However there are some practical considerations.

One of the primary goals of the Self-Sufficiency Trust of Illinois is to preserve entitlements received by an individual who is handicapped.

The Health Care Financing Administration (H.C.F.A) has stated that the Self-Sufficiency Trust of Illinois will not jeopardize Medicaid benefits in all but the following instances. Medicaid benefits would be jeopardized if the Trust account is set up by the disabled individual or his/her spouse using the disabled person or the spouse's funds. Medicaid benefits would also be jeopardized if a guardian or legal representative set up a Trust account for a disabled individual using funds that are the property of the disabled person.

Although individuals falling in these categories are eligible under Illinois law to participate in the Self-Sufficiency Trust, it might not be a wise financial decision to do so.

[See: Letter of January 6, 1988, from the Health Care Financing Administration to the National Foundation for the Handicapped, reprinted in the Appendices of the Illinois Self-Sufficiency Trust ATTORNEY HANDBOOK.]

WHAT ABOUT BENEFITS PAID BY SOCIAL SECURITY?

The Regional Commissioner of the Social Security Administration has determined that, based on current regulations, Self-Sufficiency Trust Assets will not count as resources in determining eligibility under the Supplemental Security Income (SSI) program.

[See: Letter of June 29, 1987, from the Office of the Regional Commissioner, Social Security Administration to Daniels and Sheen, counsel for the National Foundation for the Handicapped, reprinted in the Appendices of the Illinois Self-Sufficiency Trust ATTORNEY HANDBOOK.]

SFC - 2/28/90

SELF-SUFFICIENCY TRUST

PRIVATE 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).

PUBLIC SECTOR

* 1986 passaged into law of Public Act 84-1373 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.

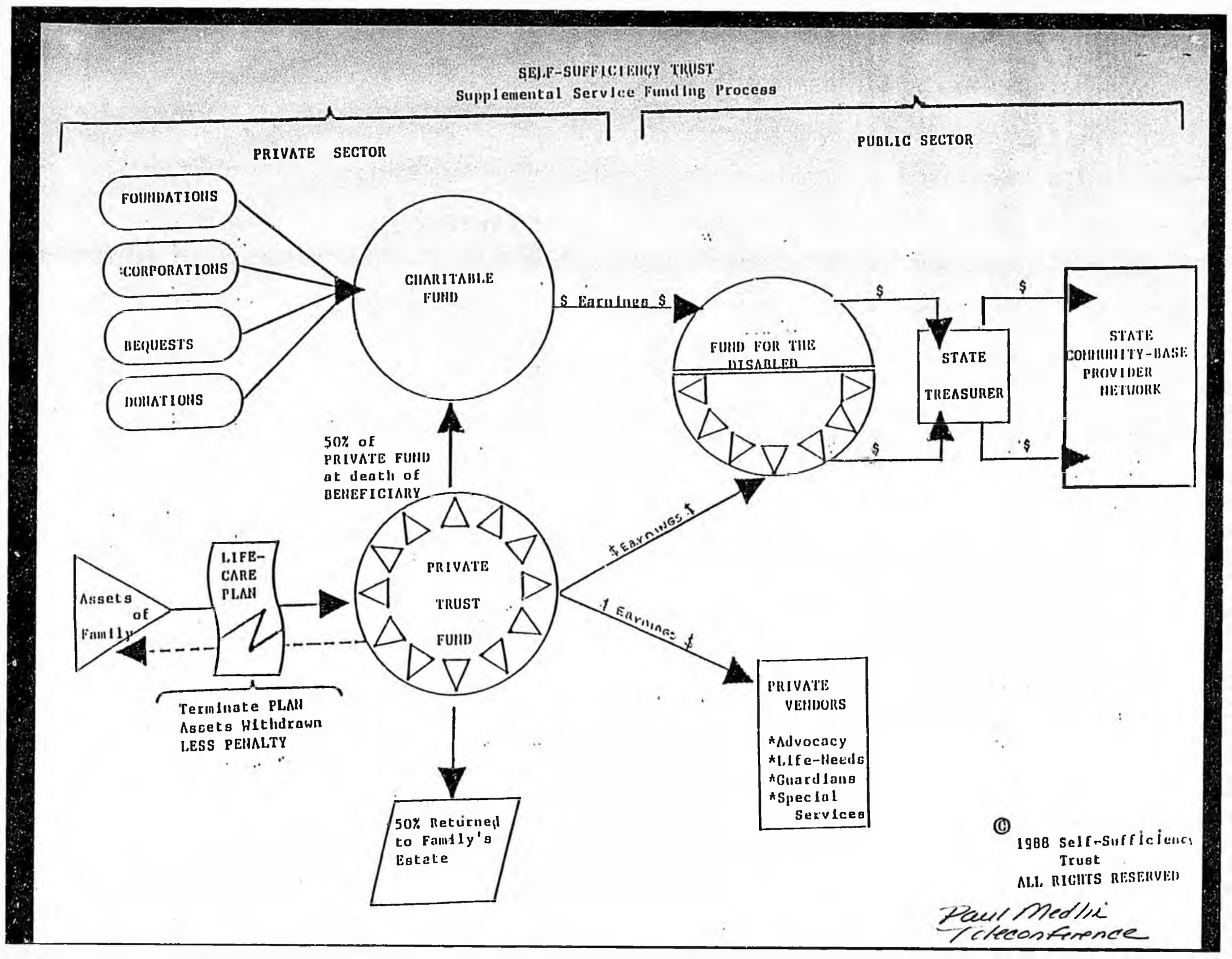
- Requires DMH DD to adopt rules and regulations for the administration of the public sector "fund"

- 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.


SELF-SUFFICIENCY TRUST
Supplemental Service Funding Process
PRIVATE SECTOR
PUBLIC SECTOR
FOUNDATIONS
CORPORATIONS
BEQUESTS
DONATIONS
CHARITABLE FUND
$ Earnings $
FUND FOR THE DISABLED
STATE TREASURER
STATE COMMUNITY-BASE PROVIDER NETWORK
50% of PRIVATE FUND at death of BENEFICIARY
PRIVATE TRUST FUND
$ EARNINGS $
$ EARNINGS $
Assets of Family
LIFE-CARE PLAN
Terminate PLAN Assets Withdrawn LESS PENALTY
50% Returned to Family's Estate
PRIVATE VENDORS
*Advocacy
*Life-Needs
*Guardians
*Special Services
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Paul Medlik
Teleconference

STATE OF ALASKA
1989 LEGISLATIVE SESSION

BILL VERSION: SB 50
PUBLISH DATE: 3/30/89

FISCAL NOTE

REQUEST:

Revision Date:
Title: An Act relating to persons who are handicapped or mentally ill...
Sponsor: Duncan
Requestor:

Agency Affected: Health & Social Services
BRU: Institutions & Administration
Components: Mental Health Administration

EXPENDITURES/REVENUES: (Thousands of Dollars)

OPERATING	FY 89	FY 90	FY 91	FY 92	FY 93	FY 94
PERSONAL SERVICES			46.9	46.9	46.9	46.9
TRAVEL			2.0	2.0	2.0	2.0
CONTRACTUAL			3.0	3.0	3.0	3.0
SUPPLIES			.5	.5	.5	.5
EQUIPMENT			1.0	-0-	-0-	-0-
LAND & STRUCTURES						
GRANTS, CLAIMS						
MISCELLANEOUS						
TOTAL OPERATING	-0-	-0-	53.4	52.4	52.4	52.4
CAPITAL	-0-	-0-	-0-	-0-	-0-	-0-
REVENUE	-0-	-0-	-0-	-0-	-0-	-0-

FUNDING: (Thousands of Dollars)

GENERAL FUND			53.4	52.4	52.4	52.4
FEDERAL FUNDS						
OTHER						
TOTAL	-0-	-0-	-0-	-0-	-0-	-0-

POSITIONS:

FULL-TIME			1	1	1	1
PART-TIME						
TEMPORARY						

ANALYSIS: (Attach a separate page if necessary)

See attached.

Prepared by: Todd Risley, Director TRisley 3-29-89 Phone: 465-3370
Division: Mental Health & Developmental Disabilities Date:

Approved by Commissioner: Myra M. Munson Myra M Munson Date: 3-29-89
Agency: Department of Health & Social Services

Distribution (by preparer):
Legislative Finance
Legislative Sponsor
Requestor
Office of Management and Budget
Impacted Agency(ies)

Senate Bill 50

This fiscal note assumes that one position (Range 16) and support costs would be needed by the Division of Mental Health and Developmental Disabilities, beginning in FY 91, to verify and monitor services offered by the Department of Health and Social Services through agreements with the Private Trust. The need for the fiscal note can be eliminated to the extent that this verification and monitoring function is not performed by Department personnel.

Range 16:	46.9	Personnel
	2.0	Travel
	3.0	Contractual
	.5	Supplies
	1.0	Equipment